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The mental health and experiences of fathers with a son/daughter with intellectual disabilities: A mixed methods approach

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Abstract

While caring can be a very rewarding experience, it has also been reported that some parents who care for a son/daughter with intellectual disabilities experience poor mental health at various points throughout their caring journey. In recent decades, the increasing lifespan of people with intellectual disabilities has led to parents caring for their son/daughter longer than in previous generations. Given that parents are now caring into older age it is particularly important to gain an understanding of the impact of caring on parents who care for a son/daughter with intellectual disabilities, and which factors are associated with poor mental health. Existing research in this area has traditionally focussed on mothers, due to the assumption that they are the main caregivers within the household. However, following a gradual change in societal attitudes towards the role of the father within the family unit and their potential impact on the child's development, governmental policies within the UK have begun to acknowledge the importance of fathers. Thus far, only limited research has been conducted which focuses on the experiences of fathers of a son/daughter with intellectual disabilities. Using a mixed-methods approach, this study sought to gain further understanding of the well-being and experiences of fathers of a son/daughter with intellectual disabilities. A systematic review and meta-analysis found that fathers reported poorer mental health than fathers in the general population, but better mental health than mothers of a son/daughter with intellectual disabilities. Evidence for factors associated with poor father mental health was mixed, although marital support was significantly associated with better mental health in all included studies. The review identified a gap in our understanding of the experiences of older fathers in the literature, and interviews were conducted with seven older fathers (age 60+) to address this. The results corroborate previous claims that parents experience both positive and negative effects of caring for their son/daughter with intellectual disabilities. The findings also highlight the stress that fathers experienced in their 'battle' to obtain necessary supports and services. Further, the interviews demonstrated that this group of fathers continue to follow traditional gender roles within the family unit, despite recent claims that fathers are now more involved in caregiving. Fathers emphasised the importance of the family unit and their relationship with their son/daughter. This was further explored with analysis of father-child closeness in a longitudinal nationally representative data set. Findings revealed that higher marital satisfaction is associated with greater father-child closeness. Implications for theory, policy and practice are outlined, and directions for future research explored.

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Dunn, K., Kinnear, D., Jahoda, A., McConnachie, A. 2019 Mental health and well-being of fathers with a son or daughter who has intellectual disabilities: a systematic review and meta-analysis. *British Journal of Psychiatry Open*, Accepted for publication.

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Author declaration

“I hereby declare that I am the sole author of this thesis, except where the assistance of others has been acknowledged. It has not been submitted in any form for another degree or professional qualification.”

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Chapter 1: Introduction

This preliminary chapter introduces the topic of people with intellectual disabilities and their family carers, particularly fathers of a son/daughter with intellectual disabilities, and the impact that caring can have on fathers' mental health and well-being. It demonstrates the need for further study of the experience of fathers who care for a son/daughter with intellectual disabilities, particularly as both fathers and children age.

1.1 Intellectual disabilities

1.1.1 Definition

The World Health Organisation classifies intellectual disability as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development' (World Health Organisation, 2010). This is a lifelong condition and while definitions vary slightly between institutions and organisations around the world, a 'significant impairment in general cognitive functioning, social skills and adaptive behaviour' are included in definitions by the World Health Organisation, American Association for Intellectual and Developmental Disabilities, and the Diagnostic and Statistical Manual of Mental Disorders. In this context, significant impairment is defined as two or more standard deviations below the mean on normed measures of cognitive and adaptive functioning (McKenzie et al, 2016).

While people with intellectual disabilities all have impaired cognitive abilities and adaptive functioning, they are a very heterogeneous group. There are differences in terms of their socioeconomic background, family circumstances, skills and support needs, as well as the cause and degree of their intellectual disabilities. Due to reduced intellectual and social functioning, people with intellectual disabilities may need support or supervision to complete everyday tasks. Planning and provision of local support services to meet these support needs requires an understanding of the prevalence of intellectual disabilities within the community. However, prevalence rates have differed between studies, and issues with measures of cognitive and adaptive functioning have contributed to varied prevalence rates being reported around the world and over time.

1.1.2 Prevalence

In the 1970s, when diagnosis focussed on IQ test cut off scores (with a score of 70 or below being categorised as impaired intelligence), it was estimated that around 3% of the population would meet the criteria for intellectual disabilities at some point during their lives (Tarjan et al, 1973). However, it is no longer considered sufficient to rely solely on IQ scores as this provides an inaccurate picture of an individual’s abilities. Certain adaptations to the test may be required for those with certain physical disabilities, as there are particular sections of IQ tests where additional points are granted for answering quickly. This may put individuals with additional physical disabilities or communication issues at a disadvantage when responding to questions posed by an assessor (Kaufman, 2018). Individuals from certain cultures may also be more familiar with tasks included in the IQ test as these tests were predominantly designed in and for individuals from North America and Europe, putting those who are less familiar or with less access to formal schooling at a disadvantage (Nell, 2000; Wicherts et al, 2010). Another issue with using intelligence tests as a measure of cognitive functioning is that these tests do not consider an individual’s ability to learn the necessary skills required to function in everyday life and to deal with (adapt to) everyday demands and circumstances. In order to take this into account, adaptive functioning is also used to assess an individual’s ability to live independently within the community. Adaptive functioning is generally measured using the Vineland Adaptive Behaviour Scales (Sparrow et al, 2005).

Current prevalence rates are generally believed to be lower than the 3% prevalence estimate of the 1970s. In a review of studies published between 1980 and 2009, the prevalence of intellectual disabilities was estimated to be 1.04%, globally (Maulik et al, 2011). Prevalence rates varied between studies, with a higher incidence of intellectual disabilities reported in studies from low- and middle-income countries, child or adolescent populations, and when different psychological assessments were used to identify intellectual disabilities. Prevalence rates were almost twice as high in low- and middle-income countries compared to high-income countries. This difference in prevalence rates may be partly attributed to lower rates of antenatal screening, leading to more births of children with intellectual disabilities (Dave et al, 2005). However, of the studies from low- and middle-income countries included in the meta-analysis, the assessments of intellectual disabilities used in these studies often did not take an individual’s adaptive functioning into account. The included studies from higher income countries, on the other hand, used standard diagnostic assessments of intellectual disabilities. This could lead to individuals with IQ scores at or just below 70, but sufficient life skills to live independently, being classified as having intellectual disabilities in low and middle- but not high-income countries. Different levels of support and familiarity with IQ tests across cultures could also contribute to these differences in prevalence rates (Kaufman, 2018). The meta-analysis found that studies which used administrative datasets had lower prevalence rates than those which used household sampling. Household sampling strategies were used in the majority of included studies from low- and middle-income countries, while administrative data was used in most studies from high income countries. Administrative data sets, particularly education-based data sets, are more likely to classify individuals with mild intellectual disabilities and good levels of adaptive functioning as having ‘learning disorders’, which may also contribute to lower rates in high income countries which tend to rely on this method of data collection for research (Harris, 2006).

More recently, Scotland’s 2011 Census recorded prevalence of intellectual disabilities at a national level. The census reported 26,349 people to have intellectual disabilities (15,149 males and 11,200 females), which is 0.5% of Scotland's population (Scottish Government, 2011b). However, there continues to be variation in reported prevalence rates around the world. Prevalence rates of 0.05 to 1.55% were reported by a more recent systematic review of prevalence papers published between 2010 and 2015 (McKenzie et al., 2016). The results suggest that the global prevalence of intellectual disabilities may be less than 1%. However, due to the heterogeneity of included studies, a definitive prevalence rate could not be reached. One consistent finding within this review was that intellectual disabilities continues to be reported more often in males than females.

1.1.3 Causes

For many people with intellectual disabilities, no known cause of the condition is identified. However, a variety of causes of intellectual disabilities have been identified by medical professionals. Certain genetic conditions are associated with intellectual disabilities, with Down Syndrome and Fragile X Syndrome being among the most common. Down syndrome has an estimated incidence of one in 750-1,000 live births worldwide (Weijerman et al., 2008). People with Down syndrome have a full, or partial, extra copy of chromosome 21 in their DNA, and the occurrence of the disorder increases with maternal age. Fragile X Syndrome is the most commonly known cause of inherited intellectual disability, with an incidence of approximately 1/4,000 males and 1/8,000 females (Coffee et al., 2009; Crawford et al, 2001), and is caused by a mutation on the X chromosome. Females with Fragile X Syndrome are usually less affected by the condition, as it is an X chromosome linked disorder and so their other X chromosome can dilute the effects (Eliez et al, 2001).

Various environmental factors have also been associated with increased risk of intellectual disabilities, such as the use of alcohol or drugs during pregnancy (O'leary et al., 2013). Exposure of the mother to environmental toxins such as lead, manganese, methylmercury and many others, can increase the risk of the child developing intellectual disabilities (Khan et al., 2011; Oken et al., 2008; Rzhetsky et al., 2014). Issues during birth, which cause a deprivation of oxygen for the child can also lead to subsequent intellectual disabilities (Bilder et al., 2013).

1.1.4 Degree of intellectual disabilities

Intellectual disabilities are often categorised as mild, moderate, severe and profound to reflect the nature and extent of the condition. This classification system is used by the World Health Organisation and defines the extent to which an individual differs from the normal distribution of IQ in the general population.

Mild intellectual disabilities have the highest prevalence within the population, with an estimated 85% of people with intellectual disabilities being categorised as having mild intellectual disabilities (IQ 50-70) (Barr & Gates, 2018). Mild intellectual disabilities lead to the individual's development being slower than typical in all developmental areas, and a limited level of literacy and numeracy. However, these individuals are able to learn practical life skills and function within society with some additional support. Those with moderate intellectual disabilities make up around 10% of the intellectual disabilities population and have an IQ of 35-49. They can communicate in simple but not usually complex ways, and are able to learn basic health, safety, and self-care skills. This group will need lifelong guidance and support, preferably in a semi-independent living arrangement (D'Arrigo et al, 2015). As the degree of intellectual disabilities increases, the amount of support required also increases. Those with severe intellectual disabilities have an IQ of 20-34 and represent 3-4% of the population. Basic communication skills, a need for direct supervision in social situations and assistance with self-care are required to support those with severe intellectual disabilities. Only around 1-2% of people with intellectual disabilities are classified as having profound intellectual disabilities, with an IQ of less than 20. They have severe limitations in language comprehension and expression, often experience restricted mobility, and require constant support and supervision (D'Arrigo et al., 2015).

However, the severity of intellectual disability may also vary over time as more adaptive skills are acquired throughout the life course. As a result, professionals may choose to diagnose intellectual disabilities without specifying the degree of disability (Rubin et al, 2016). The impact of an individual's level of intellectual disabilities on their life also depends upon the degree and quality of support that they receive, as well as the extent that society makes reasonable adjustments for them (Beadle-Brown et al, 2016). Moreover, for those with mild or borderline intellectual disabilities, their diagnoses may not be fixed. Continuing to receive a diagnosis of intellectual disabilities may depend upon the individual's continuing need for services and so their need to continue to be labelled as having intellectual disabilities. Many people who no longer require such supports and services may disappear from service records when they leave school (Harris, 2006).

Due to the nature of their condition, people with intellectual disabilities often require some level of care and support, with more care usually required for those with more severe intellectual disabilities, as outlined above. While individuals with intellectual disabilities can be categorised as mild to profound, each individual is unique and has their own specific support needs. As the majority of people with intellectual disabilities in the UK remain in the family home after reaching adulthood, this support is often received from their parents and other family members (NICE guidelines, 2018).

1.2 Carers

1.2.1 The role of a carer

Despite the prevalence of its use, the term ‘caring’ remains poorly defined (Nolan et al, 1996). While the meaning of the term ‘caring’ seems intuitively obvious, what it actually covers is often unclear. For some, this could involve caring for a family member who had previously been fit and healthy but now requires additional support in later life. For others, it refers to a long-term role to support a child with complex conditions or a spouse with a long-term illness. Caring and caregivers encompass such a wide variety of types of care and caregivers that it is challenging to find a definition that is relevant for every situation. This led Arber and Ginn to conclude that the search for a single definition that separates a carer from a non-carer is ‘overly ambitious and probably futile’ (Arber & Ginn, 1990).

However, various definitions have been put forward to capture the role of a carer. According to Carers UK, a carer is ‘someone who provides unpaid care by looking after an ill, older or disabled family member, friend or partner’ (Carers UK, 2014: 1). The World Health Organisation defines a caregiver as ‘a person who provides support and assistance, formal or informal, with various activities to persons with disabilities or long-term conditions, or persons who are elderly. This person may provide emotional or financial support, as well as hands-on help with different tasks. Caregiving may also be done from long distance' (World Health Organisation, 2004). A more encompassing definition describes carers as 'anybody who provides unpaid or arranges for paid or unpaid help to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves or because they are getting older. This kind of help could be with household chores or finances or with personal or medical needs. The person who needs help may live with you in your home, in their own home or in another place such as a nursing home' (Gould 2004: 18).

The tasks that carers undertake as part of their caregiver role varies greatly depending on their availability and health, as well as the care and support needs of the person for whom they are caring. In an attempt to define what carers actually do, a qualitative study of 80 carers in the UK was conducted by Arskey and colleagues (2005) to produce a list of generic care-giving tasks based on the regular caring duties which these carers performed. The list included: help with personal care, help with mobility, undertaking nursing tasks such as administering medication, escorting the recipient to appointments, supervising and monitoring the recipient, providing emotional support, being a companion, undertaking practical household tasks such as cooking and cleaning, help with financial matters and paper work. In addition to these tasks, parent carers were found to: manage behaviour, provide social stimulation, choose appropriate clothing for the day, ensure personal hygiene, provide constant supervision, arrange entertainment and daily timetables, supervise homework and handle money for their offspring (Arskey et al, 2005). While these tasks would usually be undertaken by parents, those caring for a son/daughter with intellectual disabilities may need to provide help in these areas into their offspring's adulthood.

The amount of time spent engaging in caregiving tasks varies dramatically between carers. The Scottish Census 2011 documented the number of hours of care per week that individuals reported providing unpaid care. The census found that of those who reported providing care, almost 266,000 (6.1% of the population) provided 1-19 hours of care per week, over 45,000 (1.0%) provided

20-34 hours of care a week, and over 171,000 (3.9%) provided 35 hours of care or more each week (Scottish Government, 2011b). Research which has sought to increase understanding of what carers do and who they are has identified carers as a highly heterogeneous group. Various types of individuals perform a caring role and their experiences vary between groups of carers, as well as between individuals.

1.2.2 Types of carers

It is estimated that 59% of carers in Scotland are female. However, following retirement, the proportion of males and females providing care is more even (Scottish Government, 2015). The number of hours of care provided also increases in old age, with just over half of carers aged 65 and over providing 35 hours of care per week compared to just over a fifth of carers aged 24 years and younger (Scottish Government, 2011b). Currently there are approximately 1.3 million older carers and whilst total carer numbers have risen by 11% since 2001, numbers of older carers rose by 35% over the same period (Carers UK, 2015).

Most research on carers is based on individuals who are known to charitable organisations or services, since these organisations are commonly approached during recruitment for a research study. However, some carers only come to the attention of services during a crisis and so these carers' experiences may not be well represented in the current literature. A further challenge of identifying carers within the population is that individuals providing care may not identify themselves as carers. Often people providing unpaid care for a family member do not self-identify as a carer because they consider their role to be that of a relative, and that caring duties are a normal and expected aspect of this role (Carduff et al., 2014; Smyth et al, 2011). This may be particularly true for parents of a son/daughter with intellectual disabilities, as the parent may be expected to perform caregiving tasks for their offspring, regardless of whether they have disabilities. The hesitancy to identify as a carer is particularly true of female carers, who are more likely than males to consider caring duties as belong to their existing role of 'mother', 'daughter', 'sister' (Jarvis & Worth, 2004). Identifying as a carer also requires an acknowledgment that the cared-for person requires care, both on behalf of the carer and the cared-for person, which can prove difficult for some families (Carduff et al., 2014). As a result, official statistics on the numbers of carers and the hours of caregiving may be incomplete.

1.2.3 Carers in the UK

Carer numbers have grown faster than the rise in population in the UK, and this increase is most evident among those caring for 20 or more hours per week (Yeandle, 2016). The first attempt to document the extent of informal care in the UK was provided by Green's (1998) analysis of the General Household Survey 1985 (Green, 1988). This survey reported that one in seven adults was providing informal care. However, the survey used an inclusive definition of informal care which may have led to an overestimation of the number of carers in the UK (Nolan et al., 1996). By current estimates there are now around seven million carers in the UK, which is one in ten people, and this figure is expected to rise (The Carers Trust, 2018). According to a recent report by Carers UK, there was a 16.5% increase in the numbers of people providing care between 2001 and 2015 (Buckner & Yeandle, 2015).

The Scottish Government estimated that, as of June 2017, there are 788,000 people in Scotland who are caring for a relative, friend or neighbour (Scottish Government, 2019). Around 17% of those aged 16 years and older in the Scottish population currently provide unpaid care (Scottish Household Survey Project Team, 2016), and three out of five are expected to become a carer at some point in their lives (The Carers Trust, 2018). Given these figures, it is important to consider the impact of caring, both on the carer and on the wider society.

1.2.4 Importance of Carers

In addition to providing essential support for the people that they care for, family carers also reduce government spending on social care services. Carers save the Scottish economy £10.3 billion annually, which is close to the cost of providing National Healthcare System (NHS) services in Scotland (Carers UK, 2018). A report by Carers UK calculated the value of care provided by carers in Scotland as £10,816,000,000 a year in 2015. This is a £4,780,000,000 increase since 2001.

The value of care is attributable to two main factors: increases in the cost of care and increases in the additional hours of care provided (Buckner & Yeandle, 2015). The report highlights that the amount of home care provided by local authorities in the UK has fallen by 4.3% from 2011-2014, and recent estimates put the total funding gap between those needing care and shrinking local authority budgets at £700million a year. As a result, families are increasingly stepping in to fill the gap.

Social care services have been drastically cut in recent years due to the UK government's austerity policies in response to the 2007-08 financial crisis. In 2010, local authorities funded social care for 700,000 frail older people. Now only 400,000 are cared for in this way (Innes & Tetlow, 2015). Local authorities with the most need have been found to provide the least amount of social care (Franklin, 2015). Such reductions in formal carer services have resulted in further pressure being placed on informal carers. These carers receive very little support for their role, currently earning only £64.60 per week for a minimum of 35 hours of care. This means that carers are required to spend a significant portion of their week caring in order to be recognised as a carer and to receive help from the government to support them in this role. Given the essential function that carers perform, their role appears to be greatly undervalued within British society.

In addition to saving social and care services billions of pounds each year, carers provide essential practical, physical and emotional support for the cared-for person. In the case of people with intellectual disabilities, this support is often required across their entire life course. While people with intellectual disabilities are more likely to experience poor physical health than the general population, changing trends in mortality have led to an increase in their lifespan, which in turn has impacted family members who care for them.

1.3 Carers for People with Intellectual Disabilities

1.3.1 Increased lifespan of people with intellectual disabilities

In 2014 The Confidential Inquiry was commissioned to investigate premature deaths of people with intellectual disabilities in England. The results of this inquiry provided evidence of the disparities in health care and life expectancy for people with intellectual disabilities compared to the general population. Just under a quarter of people with intellectual disabilities were less than 50 years old when they died, and the median age of death was 64 years of age (Heslop et al., 2014). This disparity may be attributed to a number of factors. People with intellectual disabilities are prone to a range of additional physical and mental health conditions. A population-based cross-sectional analysis of comorbid health conditions among people with intellectual disabilities in Scotland demonstrated the high rates of comorbidity in this population (Cooper et al., 2015). Certain symptomologies are associated with particular comorbid conditions or patterns of ageing. For example, people with Down Syndrome are more likely to develop dementia (Coppus et al., 2006) and early menopause (Coppus et al., 2010; Seltzer et al, 2001). Additional health conditions and inequalities in health care contribute to a reduced life expectancy for people with intellectual disabilities compared to the general population (Evenhuis et al., 2000; Heslop et al., 2014; O'leary et al, 2018). This population also commonly receives lower levels of health screening than the general population (Reichard et al, 2011). Health issues are often masked due to challenging behaviour, mental health conditions, and polypharmacy (McCarron et al, 2011). A further contributor to poorer health within this population is lifestyle. A Health Interview Survey, which involved 18 key health indicators, was conducted with people with intellectual disabilities from 14 European countries and found that over half of the sample led a sedentary lifestyle (Haveman et al., 2011).

While people with intellectual disabilities continue to have shorter lifespans than the general population, this group is now living longer than ever before. Early studies predicted extremely low life expectancy for people with intellectual disabilities. In the 1930s, people with intellectual disabilities were not expected to live beyond their mid-20s, but by the 2000s their life expectancy had significantly increased (Foundation for People with Learning Disabilities, 2003; O'leary et al., 2018; Penrose, 1949). A study of trends in survival profiles in Western Australia found that the 50% survival probability for the whole intellectual disability population in the study was 68.6 years (Bittles et al., 2002). Comparable 50%

survival probabilities in the general Australian population were 75.6 years for men and 81.2 years for women (Australian Bureau of Statistics, 2000). In the U.S.A. a slightly lower average age of death was reported for this population. The mean age of death among people with intellectual disabilities, based on deaths between 2009 and 2011, was 61.8 years for women and 59.2 years for men (Lauer & McCallion, 2015). A recent study on the Finnish population also found that the age of death of both the intellectual disability population and the general population had increased over time, and the difference in age of death between these populations had decreased (Arvio et al, 2017).

Changes in lifestyle, improvements in and better access to health care have been cited as contributing towards this increase in lifespan (Evenhuis et al., 2000; Haveman et al., 2011). However, this does vary between individuals and is partly dependent on the level of intellectual disabilities, nature of comorbid conditions and mobility limitations which may make it harder to lead an active lifestyle (Coppus, 2013). For example, lower life expectancy correlates with higher morbidity rates for people with intellectual disabilities who have comorbid respiratory and neurological conditions (Leeder & Dominello, 2005) and who are at a higher risk for developing cardiac disease (Van den Akker et al, 2006).

1.3.2 Ageing carers

As the life expectancy of people with intellectual disabilities increases, many family carers are continuing their caring role into old age. In some instances, family carers make the difficult decision to end their caring role. This decision may be reached for a number of reasons including the level of their offspring's disability and associated support needs, challenging behaviour, physical and mental health and well-being (Grey et al, 2018). Other reasons include exhaustion and/or the recognition of natural mile-stones suggesting that young adults should move out of home (Nankervis et al, 2011). Alternatively, individuals with intellectual disabilities may themselves express a desire to move out of the family home to experience more independence (Grey et al, 2015; McConkey et al, 2004).

However, many parents wish to continue caring for their son/daughter for as long as possible. In some cases, this role is continued right up until the parent's own death (Cairns et al, 2013). When undertaking a study on carers of people with intellectual disabilities in Northern Ireland and the Republic of Ireland, it was found that 32.7% of family carers were 65 years and over (McConkey, 2006). More recently, a study of 36 carers aged 50 years and over in Northern Ireland found that the mean age was 70 years, with ages in the sample ranging from 52–87 years (Black & McKendrick, 2010). Within the literature, parents often describe it to be their duty to continue caring for as long as possible (Bibby, 2013; Chou et al, 2009; Taggart et al, 2012). Torbin describes parents of people with intellectual disabilities as 'perpetual parents' as their offspring may never complete the transition into independent adulthood (Tobin, 1996).

While parents often wish to support their offspring for as long as possible, the literature has also documented that parents are eager to see their son/daughter settled in alternative residential arrangements before they themselves become too old to care for or help them (Bibby, 2013; Cairns et al, 2013; Cairns et al., 2014; Grey et al., 2015).

1.3.3 Impact of caring

The majority of carers experience some degree of social, psychological, and physical effect from their caring role (Samuel et al, 2012). Carers have been described as facing a 'triple penalty': negative impact on their own health, financial strain, and risk of isolation or loneliness (Yeandle, 2016). However, the impact of caring on parents can be wide ranging, and varies from family to family, as well as across the caring journey. Certain time points in the caring journey have been identified as potentially more stressful than others e.g. diagnosis, transition between child and adult services, and as carers enter old age. The time of diagnosis has been reported as the most stressful event in the life of family carers of a child with intellectual disabilities (Thomson et al, 2017).

Within the research literature there has been a tendency to focus on the potentially negative impact of caring on parental well-being, without considering the ways in which caring could positively affect parents. However, the last few decades have heralded an interest in the potentially positive impacts of caring on family carers. Hastings and Taunt (2002) were among the first to draw together existing research which investigated positive effects of caring for people with intellectual disabilities. Their review identified 14 themes or ‘positive perceptions’ which carers of people with intellectual disabilities experienced. These themes include: pleasure in providing care, child as a source of joy or happiness, sense of accomplishment in having done one’s best for one’s son/daughter, sharing love with child, child providing a challenge or opportunity to learn, strengthened family and/or marriage, new or increased sense of purpose in life, development of new skills, abilities or new career opportunities, becoming a better person, increased personal strength or confidence, expansion of social and community networks, increased spirituality, changed perspective on life and making the most of each day, and living life at a slower pace (Hastings & Taunt, 2002).

The experience of caring for a son/daughter with intellectual disabilities is unique to the individual and appears to impact parents in different ways. This is partly dependent on a number of factors which have been identified in previous research. These factors are discussed below.

1.4 Factors mediating the impact of caring

The existing literature has identified a number of factors on which the impact of caring on parent mental health and well-being is dependent. These factors relate to characteristics of their son/daughter and characteristics of the parent and environment or family unit.

1.4.1 Characteristics of the offspring

Previous research has examined characteristics relating to the offspring with intellectual disabilities, and the impact that this has upon family carers. These characteristics include the presence of challenging behaviour, other comorbidities, severity of intellectual disabilities, and specific syndromes.

Challenging behaviour, or behaviours that challenge, is the term commonly used to describe a range of behaviours shown by some people with intellectual disabilities which are generally considered harmful to the individual performing them (e.g. consuming inedible items, self-injury etc.), breaks social norms (e.g. regurgitating food, faecal smearing etc.), or is difficult for carers to manage (e.g. aggression, disturbed sleep patterns etc.). While such behaviours may prove challenging for carers in certain situations, they may be functional for the individual performing them. For example, such behaviours may be used by individuals with intellectual disabilities to create sensory stimulation or gain assistance with a task. These behaviours may result in a reduced quality of life for both the individual with intellectual disabilities, and their carers. Individuals who perform the challenging behaviours may experience physical restrictions to their movement or freedom, such as restraints or seclusion, and may be removed from familiar environments, such as through out of area placements. Challenging behaviours can be particularly stressful for parents as they may experience stigma and feel judged by society for having a child who publicly exhibits behaviours which do not conform to social norms. A meta-synthesis on the experiences of family carers of individuals with intellectual disabilities and challenging behaviour found that carers often report challenging behaviour to be the most difficult aspect of their caring role to deal with (Griffith & Hastings, 2014). Challenging behaviour has been consistently linked to poor parental mental health and well-being (Blacher & Baker, 2007; Ekas & Whitman, 2010; Griffith et al., 2011). Studies on mothers of adults who exhibit challenging and violent behaviours report greater care-giving burden than mothers whose offspring does not show such behaviours (Kim et al, 2003; Miltiades & Pruchno, 2001; Pruchno & McMullen, 2004; Pruchno & Meeks, 2004).

A study by Rowbotham and colleagues (2011) reported higher levels of stress for mothers when their offspring displayed challenging behaviour, but not among fathers. Mothers in this study reported spending 12.5 hours per day completing caregiving tasks, while fathers only spent 7.3 hours per day on these activities. This disparity in time spent caring for their offspring between mothers and fathers may partly account for this difference in impact of challenging behaviour.

Other studies have found a similar pattern for fathers of a son/daughter with intellectual disabilities (Baker et al., 2003). As no record was made of time spent on caregiving activities in this study, it is possible that fathers contributed more equally to caregiving tasks than in the Rowbotham and colleagues (2011) study. The significant effect of challenging behaviour is evidenced by studies where, in the absence of challenging behaviour, parent carer stress was not significantly different from parents of typically developing offspring (Baker et al, 2002; Morse et al, 2014).

More challenging behaviour has been reported in individuals with autism than with other difficulties (Ekas & Whitman, 2010; Griffith et al., 2011). In addition, autism is also associated with higher levels of anger, anxiety, psychosis, depression, and withdrawn behaviours (Griffith 2010). These additional problems may contribute towards the lower levels of mental health and well-being of parents with offspring who have intellectual disabilities and autism, due to the additional stressors of caring for such individuals (Mak & Ho, 2007). Previous studies have reported that the presence of autism, but not intellectual disabilities significantly increased the likelihood of emotional disorders in mother carers (Totsika et al, 2011). However, as autism is a term used to describe a spectrum of behaviour, these results may only apply to individuals who were at the lower functioning end of the autism spectrum. The majority of studies which have compared challenging behaviour between individuals with intellectual disabilities and autism have not reported where individuals included in their samples would be placed on the autism spectrum. In such studies, mothers are often asked to rate their son/daughter's level of autism symptoms, which may give an inaccurate picture of the individuals in the sample. Some studies have also purposively recruited individuals who are known to have higher rates of challenging behaviour. For example, the Griffith and colleagues (2011) study required children with autism to display either aggressive or self-injurious behaviour at least once per day in order to be included in their study. Therefore, the results of such studies may not be representative of children with autism who do not meet these criteria.

Studies in the existing literature are inconsistent as to whether severity of intellectual disabilities affects parental impact. Mak and Ho (2007) conducted analysis with 212 Chinese mothers living in Hong Kong whose child with intellectual disabilities was an average age of 12.7 years old. While more severe intellectual disabilities were associated with higher impact of caring on mothers, regression analysis found this influence to reduce as other factors were added to the model, such as coping strategies. An Australian study by Povee and colleagues (2012) investigated the impact of child functional ability on family functioning in interviews with 224 primary carers of individuals with Down syndrome with an average age of 13.7 years. In the qualitative phase of the study, low functional ability of their child was commonly identified as having a negative impact on family functioning. The additional caregiving needs that these children required were described as stressful and exhausting, and as limiting the time that the carer could spend with other family members. However, in the quantitative phase of this study functional ability was not significantly related to family functioning or marital adjustment, while child challenging behaviour and autism spectrum behaviours were significantly associated with these outcomes. These studies suggest that severity of intellectual disabilities does not have a significant impact on parent carers, when other factors are taken into account.

Some researchers have compared the impact on parents caring for individuals with different syndromes. For example, some evidence suggests that parents of offspring with Down syndrome have lower stress levels and better mental health and well-being than parents of offspring with other types of intellectual disabilities (Abbeduto et al., 2004; Fidler et al, 2000; Hatton & Emerson, 2009; Stoneman, 2007; Tsai & Wang, 2009). Various explanations have been proposed to explain these results. These include increased sociability and social awareness of individuals with Down syndrome (Bostrom et al, 2011; Griffith et al., 2011), less emotionality (Bostrom et al., 2011) and fewer behavioural problems (Griffith et al., 2011). However, the small sample sizes involved in studies which have found a difference in parent outcomes of offspring with Down syndrome compared to other types of intellectual disabilities, as well as differences between groups in the sample call into question the generalisability of such results. For example, in Abbeduto and colleagues' study (2004), parents of children with Down syndrome were from larger families than those with Fragile X Syndrome, and this may have provided them with more social support. In the Fragile X Syndrome group, there were also more additional children with disabilities in the family which may be partly responsible for increased stress levels experienced by parents. Most research in this area has compared families of individuals with Down syndrome to families whose offspring has a range of other types of intellectual disabilities. Further research is required to compare the impact of caring on parents whose offspring have other specific types of intellectual disabilities in order to understand the role that individual syndromes play.

1.4.2 Characteristics of the carer

The relationship between impact of caring and characteristics relating to carers themselves has also been investigated in previous studies. These include factors such as socioeconomic status, formal and informal support, coping strategies adopted by carers, carer gender, and carer age.

Family socioeconomic status and household income have been associated with poorer mental health in carers of individuals with intellectual disabilities. Many family carers experience difficulties remaining in the workforce while also balancing their caring duties, which can lead to a reduced household income and socioeconomic position. A representative household survey of mothers of offspring with disabilities found that while mothers expressed no less desire to work, their level of workforce participation was impacted by having a son/daughter with disabilities. Being a single parent, and having a son/daughter with more severe or profound caregiving needs significantly impacted a mother's ability to obtain and remain in employment (Gordon et al, 2007). As individuals with severe or profound intellectual disabilities are more likely to require higher levels of carer assistance and support, the impact of low socioeconomic status may be especially noticeable for these families. While this survey did not only include mothers of offspring with intellectual disabilities, the large sample size, variety of disabilities and inclusion of individuals with more severe caregiving needs makes it broadly applicable to parents of offspring with intellectual disabilities.

Studies which have specifically investigated the effect of socioeconomic factors of families of individuals with intellectual disabilities have also found an association between low socioeconomic status and poor mental health. Emerson and colleagues (2010) conducted a secondary analysis of a large cohort study in the UK and found that after matching on socioeconomic variables, fathers of children with early cognitive delay were no more likely to have a psychiatric disorder, and that the strength of this association for mothers was substantially diminished. As this study only included fathers of very young children, this may not be representative of the impact of socioeconomic factors on fathers of older children. However, earlier studies conducted on parents of older children by the same author have found similar results (Emerson, 2003; Emerson & Hatton, 2007; Emerson et al, 2006). This is of particular concern as a recent study in the UK, which was based on a population representative sample, reported that carers of people with intellectual disabilities were more likely to be experiencing poverty than all other types of carers (Totsika et al, 2017).

Social support also appears to play an important role in the impact of caring on parents. A survey study of 100 parent carers aged 65 and above found that 66% of the sample described caring to be rewarding (Cairns et al., 2014). Yet 79% of parents also described their role as demanding, and 73% described it as stressful. Those who reported more positive experiences also reported that they received some form of support from a family member or friend, suggesting that their positive perception of the caregiving role may be due to receiving adequate support to perform this role. When interviewing 12 mother and father couples aged 45-65 years old about the impact of caring, Rowbotham and colleagues also reported that both mothers and fathers experienced more satisfaction than difficulties as a carer (Rowbotham et al, 2011). Similar to the Cairns and colleagues' study, poor mental health was reported by both parents in the Rowbotham and colleagues (2011) study, in addition to their positive experiences of caring. The majority of parents in this study also reported being satisfied with the support provided by their partner, which may have contributed to their positive experiences of caring, despite the negative impact on their mental health. While the sample in this study was very small, it provides a rich picture of parents' experiences and the results are supported by other research in this area. As evidenced by the studies described above, both negative and positive effects of caring can be experienced by parents simultaneously.

Carer appraisals of their situation have been identified as an important factor which mediates stress and poor mental health. A study which investigated mediators of well-being in 80 parents of individuals with intellectual disabilities aged 50 years and older identified carer perceptions of ageing and stress as significant mediators of the relationship between health and depression. Perceived carer stress was also a significant mediator of the relationship between maladaptive behaviour and carer depression. However, perceived carer stress was not a significant mediator between overall health and quality of life (Minnes et al, 2007). As quality of life in this study was reported using a single item measure, a more detailed assessment of this outcome may have had different results. However, other studies have also found a link between parental perceptions and mental health or well-being. Minnes and colleagues (2007) reported that stronger negative perceptions about their caring role were associated with higher stress levels among 212 middle aged mothers of a son/daughter with intellectual disabilities (Minnes et al., 2007). In an earlier study, family perception of having a son/daughter with intellectual disabilities in the family unit accounted for 37% of stress experienced by 120 middle aged fathers of an individual with intellectual disabilities (Saloviita et al, 2003). The cross-sectional nature of these studies makes it impossible to determine whether higher stress preceded or followed the development of negative perceptions.

Age of the carer is another factor which has been associated with the impact of caring. This is a particularly important characteristic to consider given the ageing population of carers in the UK. The World Health Organization (2000) identified older people with intellectual disabilities and their ageing family carers as two vulnerable groups since they are both affected by the ageing process while also fulfilling a mutual caregiving role. Ageing carers of a son/daughter with intellectual disabilities face a number of unique challenges. For example, they are more likely to experience social isolation and financial strain than other types of carers (Argyle, 2001; Black & McKendrick, 2010; McConkey, 2005). As carers enter retirement age they are likely to have fewer financial resources available to them as they leave work and receive their pension. As previously discussed, providing unpaid care can lead to a reduction in working hours, working in less well-paid roles, or leaving employment altogether (Colombo et al, 2011). Due to these issues, if a carer is to remain in employment while continuing their caring role, they often require assistance from public services (Pickard et al, 2015).

Older carers may also be balancing multiple caring roles, where they are caring for both their offspring with intellectual disabilities and an ageing parent. A study of 91 older parent carers of an individual with intellectual disabilities, with a mean age of 60, found that 37% of these parents were caring for at least one additional relative such as a parent or spouse. While parents with additional caring responsibilities in this study also reported little personal time and inadequate levels of help from others, life satisfaction, depression, physical and mental health did not differ between parent carers who did and did not have additional caring responsibilities (Perkins & Haley, 2010). These results may have been biased by the parent-to-parent referral system that was used to recruit some of the participants, as parents identified in this manner are more likely to belong to support networks which may protect against poor outcomes of caring. The majority of studies which exist in the literature have recruited participants through support groups or services, making it difficult to determine the extent to which findings relate to carers who do not seek out such services or supports.

Family carers have been documented to experience a physical and mental toll of caring into old age. A study of 29 parents and carers in the United States with an average age of 65.2 years, found that carers’ stress levels had increased with age as caregiving tasks became too demanding for them, particularly tasks which required physical strength such as lifting and carrying their offspring. This occurred partly because of a decrease in their own physical health and a reduction in strength, as well as an increase in their son/daughter's care and/or social needs (Dillenburger & McKerr, 2009). Carers UK reported that 75% of carers in Scotland had experienced mental ill-health, and 63% had experienced poor physical health as a result of caring. Taggart and colleagues (2012) conducted a two-stage study of older parent carers and their changing support needs as they aged. Stage one gathered data through a questionnaire from 112 family carers (aged 60 years or above). A high percentage of carers reported experiencing anxiety (40%) and depression (31%). In addition, a significant proportion indicated that their anxiety (71%) and depression (46%) was related to their caregiving. These carers also linked sleep problems (46%), back problems (33%) and weight issues (18%) to caring for their family member. In stage two of the study, 19 family carers (aged 60 years or above) of individuals with intellectual disabilities were interviewed. All carers reported experiencing various physical conditions such as arthritis, cardiac problems and diabetes in addition to mental ill-health. Carers stated that many of these mental health issues such as stress, depression and anxiety were directly related to the demanding and prolonged nature of their caregiving role. Parents often had to continue caring despite their poor health. Yet, parents interviewed displayed a strong level of resilience and determination to continue their caregiving role (Taggart et al., 2012). However, the relatively small and self-selected nature of the samples in these studies may have reduced the generalisability of these results.

Not all older carers report their health to have been negatively impacted by caring. A recent systematic review of both quantitative and qualitative literature relating to the experiences of carers aged 75 years and over reported that quantitative studies generally emphasised the difficulties of caring whilst the qualitative studies emphasised the rewards of caring. This can produce an unbalanced picture of carers' experiences within the literature. Some studies identified in this review suggested caring might be less challenging for older carers as they adapt to their role, and highlighted the normality of caring as part of family relationships (Greenwood & Smith, 2016). However, given the limited number of studies identified in the review which directly compare the experiences of older and younger carers, it is difficult to draw firm conclusions about the impact of ageing on caring experience. Another study of 206 middle aged and older female carers of an individual with intellectual disabilities found that self-reported health related quality of life was similar to or better than women in the general population. Yet this pattern differed for older carers' mental health, which was reported to be poorer than those in the general population (Yamaki et al, 2009). As the sample of carers reported a higher socioeconomic and educational status than the comparison group, it is possible that their socioeconomic status is also higher than carers of individuals with intellectual disabilities in the general population. Therefore, the quality of life reported in this study may not accurately reflect the average experience of this population.

While ageing parents continue to care for their offspring in the face of challenges related to old age, there is often a failure to appreciate that many parents benefit from help and assistance provided by their son/daughter with intellectual disabilities. Gant (2010) conducted interviews with 24 parents over the age of 60, who spoke of the physical support and assistance that their offspring provided to complete everyday tasks, such as emptying the bins, cleaning, and assisting with personal care. Parents who continued caring into old age in this study also benefited from the companionship of their son/daughter. The relationship was one of interdependence, rather than dependence of the cared-for offspring on their parent, although this was partly dependent on the abilities of the individual with intellectual disabilities.

A larger qualitative study of 51 families recorded the experiences of both carers and the cared-for individuals with intellectual disabilities. In this study parent carers also related how they needed and appreciated the support that their offspring provided, and the individuals with intellectual disabilities who participated in the study focus group spoke with pride of how they were able to help their parents (Williams & Robinson, 2001). In some instances, individuals with intellectual disabilities actually took on the role of carer for their ageing parents. Where physical or practical caregiving activities were carried out by an individual with intellectual disabilities, this was more likely to be undertaken by a man. On the other hand, emotional support was more likely to be provided by a woman. As with the previous study, the degree to which these tasks were undertaken varied by the abilities of the individual with intellectual disabilities. Therefore, many aspects of these reciprocal relationships, such as practical or physical assistance, are more likely to take place when an individual has milder rather than severe or profound intellectual disabilities.

The importance of this reciprocal relationship is often overlooked by service providers and policy makers, who continue to dichotomize families into the caring and the cared-for (Williams & Robinson, 2001). This relationship may also not be recognised within families themselves, as a family carers may not recognise the tasks that their offspring performs for them as evidence of a reciprocal caring relationship (Williams & Robinson, 2001). The majority of work in this area has involved cross-sectional studies, preventing the examination of the changing relationship between parents and their offspring over-time. Longitudinal studies would enable the investigation of potentially long-lasting effects of the reciprocal relationship.

While the majority of existing research has focussed on mothers, some studies have compared the impact of caring on mothers and fathers. Mothers have reported experiencing significantly more caregiving challenges and rewards than fathers (Norlin & Broberg, 2013; Rowbotham et al., 2011). Given that mothers have traditionally served as the main caregiver, it is possible that this discrepancy in impact is due to amount of time spent caring or time spent outside the home. While amount of time spent in employment or caring for their offspring was not reported in the Norlin and Broberg (2013) study, the vast majority of fathers and only a small minority of mothers in Rowbotham and colleagues (2011) study were in full-time employment. Olsson and Hwang (2006) reported that fathers of an individual with an intellectual disability were somewhat protected from depression by participating in paid employment. However, due to the cross-sectional nature of the study, there was no means of determining whether fathers with poorer well-being were less likely to obtain full-time employment or if being in full-time paid employment positively impacted father well-being (Olsson & Hwang, 2006).

Given the reliance on mother carer reports within the literature, it is important to consider the impact of caring on fathers, and how gender roles within the family unit may influence their experiences of caring.

1.5 Gender role shift of carers

1.5.2 Changing division of household chores

Although women, mothers, and daughters are most widely recognized as primary caregivers, especially in homes where there is a person with a disability, recent research indicates that male caregivers and father participation in household tasks has been increasing over time (Essex & Hong, 2005). A large scale nationally representative data-set of caregiving from the 1960s to 2000 reported on the division of household tasks in six countries in Europe and North America. The study reported that time per day spent on household tasks had decreased slightly for women and increased by 20 minutes a day for men. These survey results controlled for changes over time in employment status and individual country effects (Gershuny, 2000; Sullivan & Gershuny, 2001). Mothers and fathers are now taking a more flexible approach to providing childcare and how caregiving tasks are divided varies between couples (Johansson & Andreasson, 2017). The number of fathers taking on a caregiving role with their child has increased by 15-20 minutes each day every decade since the 1970s (Altintas, 2016). Data from a longitudinal cohort study, demonstrates that childcare provision in Scotland is also changing. Analysis of this dataset revealed that more Scottish fathers than fathers in other UK countries read to their children and get them ready for bed ‘several times a week’. The findings also revealed that more Scottish fathers than fathers in other UK countries play outdoors and indoors with their children and look after their children on their own (Jones & Smith, 2008).

Despite the research evidence reporting an increase in males participating in care, it appears that in most instances, mothers continue to fulfil the role of main carer. A study of self-reported caring tasks of middle-aged mother and father couples found that mothers continue to complete more tasks than fathers, but that the range of tasks that each parent completed was similar (Rowbotham et al., 2011). Mothers of offspring with intellectual disabilities reported spending an average of 12.5 hours per day on caregiving tasks, while fathers reported spending 7.25 hours per day (Rowbotham et al., 2011). Such figures challenge the idea that fathers are taking an equal share of caregiving responsibilities within the family. It has been suggested that there is a double standard applied to transgressing traditional gender norms, and that more stigma is placed on men who transgress than on women (Coleman & Franiuk, 2011; Gaunt, 2013; Goldscheider et al, 2015). These attitudes affect the ability of fathers to serve as main caregivers in their household. For example, fathers who seek work leave to care for a relative are less likely to be granted leave than a mother who seeks time off for the same reason (Coleman & Franiuk, 2011). This lack of flexibility within gender roles is especially difficult for aging fathers who take on the primary caregiving role when the death or declining health of the mother makes this alteration necessary (Essex & Hong, 2005).

Several gender role differences have also been noted among mother and father caregivers of individuals with intellectual disabilities. These include differences in the type of care provided, perception of care burden, and the stigma associated with caregiving. Most often mothers provide primary care that includes nurturing while fathers provide supplemental care (Essex & Hong, 2005). Fathers were found to be more likely to contribute financial help than mothers (Ha et al, 2008; Hodapp, 2007). Additionally, fathers were found to reduce care burden of mothers by providing respite care and some assistance with household tasks (Essex & Hong, 2005; Hodapp, 2007). It is evident that some fathers are more involved in housework and childcare than others, and some researchers have begun to investigate which factors are associated with an increase in caregiving. Sullivan reported that changes in male contributions to household and childcare tasks were mostly happening among middle-class fathers. However, there is some evidence that this is changing, and that fathers from lower-class backgrounds are beginning to participate more (Sullivan, 2004). Yet, an in-depth study of the division of household tasks between mothers and fathers found no differences in caregiving tasks by class (Gerson, 2001). Higher educational attainment has also been linked to an increase in household and caring tasks undertaken by fathers. For example, an increased contribution to housework and childcare was documented in 13 European countries among younger higher educated fathers (Sullivan et al, 2014). As some fathers begin to participate more in childcare tasks, the question of whether this involvement actually impacts the offspring being cared-for has been investigated.

1.5.3 Importance of father involvement

There is now a cultural expectation within the UK for father involvement (Towers, 2007) and an acknowledgement of the importance of this involvement for child development (Ferreira et al., 2016; Lamb, 2004, 2010; Meuwissen & Carlson, 2015, 2018). According to Family Systems Theory (Minuchin, 2002), the well-being of different members within the family unit is likely to be related. Bidirectional rather than linear relationships exist between individuals in the family, with each member being influenced by and influencing the other members of the family unit. The family unit is a complex and interactive system. Therefore, well-being outcomes for any family member are not dependent on any one individual, but are influenced by all other family members. In the context of the current project, this theory acknowledges the impact that raising a child with intellectual disabilities has on the father, as well as the impact that fathers have on their child’s well-being and development.

Twamley and colleagues produced a report on fathers' involvement and the impact on family mental health, using evidence from published studies on the UK Millennium Cohort Study, which is a large nationally representative data set (Twamley et al, 2013). Ten studies were identified that investigated father engagement (time spent one-on-one with their child), accessibility (being physically available for the child), and responsibility (taking responsibility for the child’s care and well-being). Overall, the included studies found a positive impact of father involvement on the child’s mental health and well-being.

The majority of identified studies in the report explored the impact of father accessibility on mental health (Dex & Ward, 2007; Emerson et al., 2010; Essex & Pickett, 2008; George et al, 2007; Kiernan & Mensah, 2009; Kiernan & Pickett, 2006; Mensah & Kiernan, 2009, 2010; Sullivan et al, 2010). The seven studies, which measured accessibility and child mental health, found mixed evidence of a positive impact. Accessibility in these studies was generally measured by family structure, such as whether the father was living at home, which does not give a complete picture of how often the father was available for their child. However, other studies looked at type of leave taken from work. For example, Dex and Ward (2007) found that taking paternal leave or using flexible working hours was associated with a benefit in child cognitive and behavioural domains. This lends support for the importance of encouraging fathers to take advantage of parental leave and flexible working policies during their child's early years. The majority of studies, which measured responsibility of the father, did so through employment. The five studies, which investigated the impact of this variable, found a positive effect on child mental health of fathers in employment. Only three studies reported the impact of father engagement on child mental health, all of which found a positive relationship.

The use of a nationally representative data set makes the results relatively robust. Yet it must be taken into consideration that some data from these studies were based on self-report measures, such as mental health, and mothers completed measures for fathers not living in the household. Additionally, the measures which were used to investigate the three different types of involvement (engagement, accessibility, and responsibility) differed by studies. As the majority of included studies focussed on the accessibility of the father to their child, this does not take quality of interactions or closeness of the father-child relationship into account when considering father impact on child well-being and development.

The impact of father-child relationship quality on child outcomes was investigated with the Growing up in Scotland study, which consisted of a nationally representative sample of 2,500 couple families in Scotland. The study found that compared to children with good or excellent father-child relationships, those with poor relationships are most likely to have high levels of behavioural and emotional problems, and most likely to have poor school adjustment. While the sample did not separately report the results for fathers of a child with intellectual disabilities, the models show that father-child relationships are associated with well-being within the general population, even after taking account of the mother-child relationship (Parkes et al, 2017).

Given the link between father involvement or closeness and child outcomes in the general population, it is essential to recognise the importance of fathers within the family unit and to investigate factors associated with positive father-child relationships. In the existing literature, a number of researchers have begun to examine the impact of positive parent-child relationships for parents of a child with intellectual disabilities, as well as the factors associated with such relationships. Totsika and colleagues (2014) examined the impact of mother-child relationships on child behaviour using data from the UK Millennium Cohort Study. Closer mother-child relationships were associated with fewer child behavioural problems at age 3 and 5 years of age. The quality of this relationship was also found to be more important for long-term behavioural outcomes than practical elements of parenting such as discipline. Taken together with research on the importance of father-child closeness in the general population, this suggests that degree of closeness may also impact child outcomes in fathers of a child with intellectual disabilities.

Studies which have investigated father-child closeness in individuals with intellectual disabilities have identified a number of factors associated with closer relationships. Essex (2002) conducted a longitudinal study of father-child closeness among families with an adult son/daughter with intellectual disabilities. Functional skills and number of behaviour problems of the son/daughter, as well as marital satisfaction, were all significantly associated with degree of father child closeness. A later longitudinal study of parent-child relationships of 15-year olds with developmental disabilities reported an association between father–child relationship and early behaviour problems (Mitchell & Hauser-Cram, 2010).

1.5.4 Previous research

Due to the assumption that fathers were not involved in caring, previous research into the experience of family caregivers for people with intellectual disabilities has tended to centre around mothers. This gap in existing research is significant given the changing expectations around a man's role in the family and evidence that their involvement positively impacts child development. Studies which have referred to fathers have a number of limitations. For example, some studies which have included both mothers and fathers have a very small proportion of fathers in their sample (Cairns et al., 2014; Foster et al, 2010; Rowbotham et al., 2011) or have removed fathers from their analysis due to the low numbers that participated (Thomson et al, 2017). A meta-synthesis conducted on the experience of care givers also noted that the majority of studies did not separately report the experiences of father and mother carers (Griffith & Hastings, 2014).

Within the literature, there are some reports that men experience caregiving differently to women. A survey of 609 male carers, which included 119 fathers, was conducted by the Carers Trust and the Men's Health Forum in 2014. Of the men who took part in the survey, 53% felt that the needs of male carers are different to the needs of female carers (The Carers Trust, 2014). A number of issues were identified in this survey which participants considered to be unique or different for male carers. These included a lack of recognition of their role by society, professionals and services. They also reported that it is particularly challenging to provide intimate care for women that they care for. The balance between work and care was further identified as a challenge that was different for male carers. These results suggest that the experience and impact of caring is not the same for mothers and fathers. Therefore, studies which report the impact of caring on parents, based only on data from mothers, are incomplete.

A recent review on research around fathers of offspring with intellectual disabilities from birth up to the age of 22 discussed key themes from the current literature. These included response to diagnosis, varied response to intellectual disabilities, concern for the future, work, roles and relationships, impact of fathers upon child development, fathers and service providers, and fathers needs and coping strategies (Davys et al, 2016). While some of these themes included data on father stress and well-being, not enough studies touched on this topic to justify a separate mental health theme. The review revealed various common findings, as well as areas of disagreement within the literature. In terms of similarities, the shock and distress expressed in response to initial diagnosis were commonly reported across all sizes of studies included in the review. Adaptation and adjustment of fathers over time was also referred to in many papers. Fears and concerns for their offspring's future was another commonality, as was seeking out information as a coping method, and the difficulty of being fully involved in caregiving due to the need to maintain full-time employment.

Research areas which report mixed results were also identified by this review, with stress and well-being levels among the most varied. As previously discussed in this chapter, some studies report caregiving to have a negative impact on father mental health, while others found no difference between fathers of a son/daughter with intellectual disabilities and fathers of typically developing offspring. Quality of and satisfaction with their marriage and social lives also drew differing results in the literature, with some reporting lower levels of satisfaction and others reporting no difference. These differences between studies may be attributed to a range of variables discussed under the 'factors mediating the impact of caring' section of this chapter, such as methodological differences, or data being collected at different stages of the caring journey.

While this review provided a useful summary of existing evidence on the experiences of fathers, it was limited to fathers of a son/daughter up to age 22 and so does not include fathers who have been in a caregiving role for older adults with intellectual disabilities. As both individuals with intellectual disabilities and their parents are living into older age, it is also important to gain an understanding of the impact on fathers' mental health and well-being as their child moves into adulthood.

1.6 Policy context

1.5 .1 Traditional gender roles

There is a strong cultural tradition of women being viewed as caregivers and men being viewed as ill-suited to caring roles (Clapton, 2017). This idea has been supported by the Scottish health and welfare services which have historically viewed women as homemakers and men as breadwinners (Torr, 2003). Men were considered to be auxiliary parents, due to the assumption that mothers were the main caregivers and men the main breadwinners within the family unit. This view was influential in the development of child and family services (Clapton, 2013). However, in the 1990s fathers began to enter the discussion on family life. In their report for the Joseph Rowntree Foundation, Burghes and colleagues noted the growing interest in the role of fathers (Burghes et al, 1997).

Despite this interest in the role of fathers, in many ways, mothers continue to be viewed as the main caregivers within the household (Lamb, 2010). This is demonstrated by how fathers and mothers are represented in the media and by public services. For example, an image-based study conducted by the Fathers Network Scotland investigated the way that fathers were depicted throughout family services offered by central and local government, the NHS and third sector agencies (Fathers Network Scotland, 2013; 2016). This research found that the way fathers were written about and the visual images used in leaflets, posters, websites and other publicity material conveyed the impression that children and family services were just for women. For example, A Pathway of Care for Vulnerable Families from the Scottish Government (Scottish Government, 2011a) which was for ‘pre and post birth for both mother, child, family’ contained twenty-nine references to ‘mother’ and not a single reference to ‘father’. Local Government’s social services, the NHS and Third Sector organisations also tended to feature father-free imagery when depicting families. The Fatherhood Institute expressed disappointment over the lack of father inclusion in services: ‘...current service provision in the UK for vulnerable families is generally based on an assumption at odds with the evidence and with the child’s perspective – that fatherhood is an optional and marginally significant “add-on” for children, unlike motherhood, which is an essential’ (Burgess, 2009).

The Fatherhood Institute also found that fathers are not generally perceived as participating in care, with parenting guides, magazines, computer games and books in the UK continuing to represent fathers as not engaged in caregiving (Burgess & Davies, 2017).

1.6.1 Policies to support carers

Changes in policy surrounding family carers represent changing societal attitudes and recognition at the governmental level that father involvement is important, and that they require more support. UK policy documents related to carers and fathers are discussed in this section. Due to the volume of policy documents produced by the UK and Scottish Governments on carers, the discussion is restricted to a selection of key documents which directly relate to carers' experiences in the current climate. A full list of all relevant carer policy documents is included in Appendix A.

In terms of support for carers, the Care Act 2014 stipulated that local authorities have a duty to provide services to address carers' needs as soon as they meet the eligibility criteria. The 2014 Act removed the condition that carers needed to provide 'regular' and 'substantial care' in order to be eligible for an assessment, as had previously been the case. By introducing a broader definition of carers, this act widened access to carer assessments and services (Brimblecombe et al, 2017). More recently, the Carers (Scotland) Act 2016, which came into effect on 1st April 2018, aims to provide more consistent support for carers to make caregiving more sustainable. Under this act, an Adult Carer Support Plan must be drawn up to identify carers' needs and personal outcomes, local authorities must provide support to carers based on their individual needs identified in their support plan, and information and advice services must be provided for carers within the local authority (Scottish Executive, 2016).

While policies to support carers have become more flexible, and tailored to meet individual carers' needs, the current political climate in the UK has resulted in carers experiencing challenges to obtaining services. The current climate can be traced back to the UK government's response to the 2007-08 financial crisis, where the government took on the debts of banks and insurance companies while implementing austerity programmes to reduce that debt. Resulting cuts in social care services, jobs, wages, pensions and benefits in the public sector have been justified by the current administration as necessary to reduce the gap between tax revenue and government spending (Krugman, 2013; Reed & Lawson, 2011).

Ginn (2013) challenges the necessity or validity of these policies as vulnerable groups are largely the ones who 'bear the brunt of the cuts'. Since the crisis: 'the scale of reductions in spending and provision are almost certainly without precedent in the history of adult social care' (Fernandez et al, 2013). As a result, only a minority of working carers report that they receive the necessary services to continue balancing their working and caring responsibilities (Brimblecombe et al, 2016; Milne et al, 2013). A recent rise in the UK state pension age also disproportionately impacts carers. This alteration gives older carers who are nearing retirement age very little time to adjust their retirement plans and caring responsibilities (Ginn, 2013). With recent reforms to the Welfare system within the UK, the rising cost of living and the extra costs associated with providing care, family carers are currently caught in what has been described as 'the perfect storm' (Carers UK, 2014).

1.6.2 Inclusion of fathers in policies

From the reviewed policy documents above, it is apparent that the Scottish and UK Governments have taken some steps to address the needs of unpaid carers. However, policies related to carers have tended to assume that unpaid family carers are female, and so fathers have remained largely under-represented in the policy context. However, various recent policies have been implemented which directly address the needs of fathers who provide care.

In 2011, the UK government introduced an 'additional paternity leave' of six months in order to facilitate shared parenting during the first year of a child's life, after the mother has returned to work. However, it was necessary to take this leave continuously and was not very flexible. Shared Parental Leave 2014 was introduced to allow families to divide their allotted paid leave based on what suited their particular needs. Up to 50 weeks of leave and 37 weeks of pay can be shared between parents under this act, and parents can choose to take time off at the same time. However, a number of stipulations must be met before fathers can actually make use of this leave. For example, fathers must give their employers at least 8 weeks notice, have been in continuous employment for at least twenty-six weeks by the end of the fifteenth week prior to the due date and remain in employment until the week before Shared Parental Leave is taken. The pay is also not as generous as statutory maternity pay. While this is an improvement on previous legislation, it has been argued that Shared Parental Leave is problematic and does not provide fathers with enough incentive to use it (Atkinson, 2017). It also continues to put the focus on mothers as main carers and fathers as auxiliary carers.

By 2012, the Scottish Government's National Parenting Strategy specifically noted the importance of fathers. The Strategy included a bi-annual fathers roundtable meeting where fathers would serve in an advisory capacity on national policy, and ensure the interests of fathers were included in the implementation of the National Parenting Strategy (Scottish Government, 2012). The Carers (Scotland) Act 2016, which aims to provide better and more consistent support for carers, also addresses the issue of improving support for paternal carers (Scottish Government, 2011a).

It is particularly important to consider fathers' needs when drafting national policies as legislative frameworks and institutional practices largely determine which parent serves as the main caregiver for their child. A large survey of over 8,000 UK residents found that such frameworks and practices reduced fathers' abilities to be as involved in caring as their partner (Olchawski, 2016). For example, 35% of employed fathers of children under 18 years of age said that men in their workplace who take time off to care for children are not supported, and 41% felt that they did not have enough time off after the birth of their child. This is likely to reinforce traditional gender roles around childcare, and makes it more difficult for fathers to be involved in caregiving. Policy makers and service providers cannot meet fathers' needs without reliable information on which factors impact their mental health. However, there is currently very little research on the impact of caring on fathers of a son/daughter with intellectual disabilities. Therefore, this project is timely and will provide a comprehensive and up-to-date understanding of the experience of fathers who care for a son/daughter with intellectual disabilities and the factors associated with their mental health. The direct involvement of fathers as part of this project will give fathers a voice in these discussions, something which is largely lacking in the existing literature.

1.7 Research Aims and Objectives

The following broad objectives informed this study:

1) To investigate the mental health and well-being of fathers who care for their son/daughter with intellectual disabilities and identify factors associated with poor mental health.
2) To increase our understanding of the experience of older fathers who have been caring over a prolonged period of time, to inform practitioners and policy makers of their needs.
3) To compare the father-child closeness of fathers with a son/daughter who has intellectual disabilities to fathers in the general population, and investigate how father-child closeness changes over time.

1.8 Outline of thesis and projects

The thesis provides an account of the experience of fathers of a son/daughter with intellectual disabilities, and the factors which impact their mental health and well-being. It is organised as follows:

Chapter Two: describes and justifies the theoretical frameworks which guided the thesis.

Chapter Three: provides an account of mixed methods approaches to research and discusses the benefits of this approach for meeting the objectives of the thesis.

Chapter Four: discusses the existing literature on the mental health and well-being of fathers of a son/daughter with intellectual disabilities, and identifies gaps in our current understanding of this topic.

Chapter Five: considers the qualitative approaches which influenced the qualitative study and justifies the decision to adopt a constructivist thematic analysis approach.

Chapter Six: discusses the key themes from the qualitative study and presents the thematic analysis derived from the interviews with fathers.

Chapter Seven: describes the methods used in the quantitative study.

Chapter Eight: presents the results of the quantitative study and summarises the self-reported father-child closeness and mental health of fathers of a child with intellectual disabilities compared to fathers in the general population.

Chapter Nine: presents a final discussion of the project which pulls together the implications of the three studies, identifies merits and limitations of the work, and provides recommendations for practitioners and policy makers.

Chapter 2: Theoretical underpinnings

This chapter presents a number of theoretical models which are potentially relevant to the experiences of fathers whose son/daughter has intellectual disabilities. The models are divided into two sections: stress and coping models, and caregiving models. While these theoretical models did not inform the qualitative phase of this study due to the qualitative methods selected, they contributed towards the design of the systematic review and meta-analysis and are revisited in the discussion chapter of this thesis.

2.1 Stress and coping models

As discussed in the Introduction Chapter to this thesis, there is evidence in the existing literature that caring for a son/daughter with intellectual disabilities can be a stressful activity. However, there is considerable variation in the degree of stress that caregivers experience, as well as how they adapt to their caring role (Horsley & Oliver, 2015; Yeandle, 2016). A number of frameworks have been utilised to analyse the extent of stress experienced by parents, as well as how they cope with such stress. These include the Transactional Model of Stress (Lazarus, 1985; Lazarus & Folkman, 1984), the Two-Factor Model of Psychological Well-being (Lawton et al, 1991), and the Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983).

2.1.1 Transactional Model of Stress (Lazarus & Folkman, 1984; Folkman et al, 1979)

In this model, stress is seen as a process, involving constant adjustments between an individual and their environment, known as transactions. Strategies can be utilised in order to combat the impact of a stressor. According to Lazarus and Folkman, stress occurs when transactions result in an individual perceiving a discrepancy between the challenges of a situation and their resources or ability to cope with that situation (Folkman, Schaefer, & Lazarus, 1979; Lazarus & Folkman, 1984). Therefore, there is no assumption that a particular event or issues is stressful, instead an individual appraises it in relation to their resources and determines whether it is perceived as stressful. Two processes are key to the transactional model of stress and coping: cognitive appraisal and coping.

Cognitive appraisal involves an individual making an assessment of the potential impact of a demand on their well-being, and whether their available resources will be sufficient to meet that demand. Two types of cognitive appraisal have been identified: primary appraisal and secondary appraisal. Primary appraisal assesses whether an event is likely to be stressful, benign or beneficial for the individual. When an event is perceived to be stressful, it will then go through further appraisals to determine the amount of damage already experienced, potential future harm, and what opportunities for personal growth are presented by the event. Secondary appraisal yields a judgement as to the adequacy of the available resources to meet the demand. Coping relates to problem solving efforts made by an individual when faced with a demand (Folkman et al., 1979; Lazarus, 1966). In this model, coping is so defined in order to prevent coping and outcome being conflated (Lazarus & Folkman, 1984). The type of coping engaged in will differ depending on the individual’s environment and resources. Coping strategies are most often divided into problem-focused and emotion-focused. Problem-focused coping involves attempting to alleviate stress directly by changing the environment or self through behaviours, such as changing or escaping the environment. Emotion-focused coping aims to reduce the emotional responses to the stressful environment or event, or the way in which these situations are experienced. For example, positive thinking can help an individual to feel in control of potentially stressful situations by taking an optimistic view.

In the context of fathers of individuals with intellectual disabilities, the Transactional Model of Stress suggests that fathers may not necessarily experience stress from their caring role as it depends on how the caring role is appraised and how fathers then deal with any potential stressors. For example, if a care service for their offspring with intellectual disabilities has closed down, and after evaluating their resources fathers feel that their income, social support, and other available care services are sufficient to cover the family’s needs, then they should not perceive the event as stressful. Alternatively, if they feel that there are no other services in their area and they cannot afford to hire an individual carer, then they could perceive this event as stressful.

Support for the transactional model of stress has previously been documented in studies on the mental health and coping strategies of carers of individuals with intellectual disabilities (Edwards & Cooper, 1988; Essex et al, 1999; McDougall et al, 2004; Quine & Pahl, 1991). Quine and Pahl (1991) investigated this model in the context of stress experienced by mothers of children with severe intellectual disabilities. A regression analysis found that child characteristics and coping resources explained 55% of the variance in stress in mothers. The finding that coping resources mediated the effect of child characteristics on stress provides support for the transactional model. McDougal and colleagues (2004) also found an influence of individual appraisal and perceived resources on stress in parents of children with Rett syndrome. The findings of this study suggested that parents employed both emotion-focused and problem-focused coping strategies.

This model has received criticism due to its focus on subjective appraisals, making it difficult to test the model, and also neglects to consider individual factors which are associated with carer stress such as disturbed sleep (Hill & Rose, 2010). However, external more objective variables should not be ignored as the reality of the demands placed on carers is not necessarily subjective, such as reduction in household income when caring full-time or what type of everyday assistance their offspring requires. Edwards and Cooper (1988) also challenge the linear direction of the model and suggest that in some situations coping may occur before appraisal, such as in an emergency when there is no time to appraise the situation (e.g. when their offspring falls ill) or when a routine is established so there is no need to appraise what is to be done (e.g. a care plan for emergencies has been established for the individual with intellectual disabilities), as an automatic coping behaviour has already been established.

2.1.2 Two Factor Model of Psychological Well-being (Lawton et al., 1991)

An alternative model has been put forward by Lawton and colleagues (1991) who proposed a two-factor model of psychological well-being with two independent pathways to caregiving outcomes. In the first pathway, perceived challenging characteristics of the cared-for individual, such as behaviour problems, are associated with perceptions of caregiving burden which in turn affect negative caregiver mental health outcomes. In the second pathway, perceived positive characteristics of the cared-for person, such as having a positive relationship with the caregiver or experiencing personal growth through caring, are related to perceptions of the positive effects of caring, which in turn affect positive caregiver outcomes such as life satisfaction. According to this model, these processes can operate in parallel (Lawton et al., 1991). Therefore, a parent may experience both positive and negative outcomes from caring for their offspring with intellectual disabilities.

Support for the two-factor model of caregiving has been demonstrated in studies of parents of adults with intellectual disabilities (Pruchno et al, 1996; Smith, 1996). Pruchno and colleagues' (1996) study on older mothers of adults with intellectual disabilities reported that the mother's health, offspring behaviour problems, and help needed from the mother predicted negative appraisals, while the relationship between the mother and their offspring predicted positive appraisals. This supports the existence of positive and negative components of well-being as independent but related constructs. In the same year, Smith (1996) also reported that greater subjective burden was associated with negative well-being outcomes, while greater caregiving satisfaction was associated with positive well-being outcomes in mothers of adults with intellectual disabilities.

Hill and Rose (2010) pose two possible criticisms of the two-factor model. Firstly, the model is very specific about the variables which exert influence at each stage of the process. On the one hand, this offers clear guidance for the researcher. However, it also limits the situations in which the model may be used. For example, the existence of different coping strategies which parents can operationalise to arrive at the model's positive outcome (carer satisfaction) are not clearly represented. Therefore, this model does not give a full account of the experience of parenting an individual with intellectual disabilities. The second criticism is directed towards the causal ordering of variables within the model. In contrast to the work of Lazarus and Folkman (1984), the characteristics of the individual with intellectual disabilities are not portrayed as the primary stressors. The conditions and behaviours of the cared-for person and carers' health are present in the Lawton model, but they are not shown as causally preceding resources that carers may draw on to support them in their role, such as social support (Hill & Rose, 2010).

2.1.3 Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983)

The Double ABCX Model was proposed by McCubbin and Patterson (1983) as an adaptation of Hill's (1958) ABCX Model. The original ABCX model put forward that characteristics of a stressor event (A), the family's existing resources (B) and their perception of the stressor (C) all contributing towards mediating the experience of the stress (X) (Hill, 1958). When this model is applied to the current area of research, the stressor refers to the birth of the child with intellectual disabilities. Parental resources (B) serve to minimise the impact of the initial stressor and reduce the likelihood of a crisis. These can include a strong social support system, high income, and effective formal support services. For example, social support has been positively associated with parental well-being in families of an individual with an intellectual disability in a number of studies (Hartnett et al., 2008; White & Hastings, 2004). There is also evidence that the family's socioeconomic condition influences parental mental health (Emerson & Gwynnyth, 2008). Parental cognitions or perceptions (C) are how the parent appraises their offspring and their caring role. A number of recent studies have reported the positive appraisals of parents caring for their son/daughter with intellectual disabilities. Positive experiences which have been reported include opportunities to make a difference or learn (Hastings et al., 2005; Taunt & Hastings, 2002), positive aspects of their offspring e.g. happy disposition

(Griffith & Hastings, 2014; Rapanaro et al, 2008; Taunt & Hastings, 2002) and improved family relationships (Scorgie & Sobsey, 2000).

The Double ABCX model builds on this by focussing on events over time, rather than a single stressor event. In this way, following a stressful event there may be a pile-up of stressors (Aa), family resources may have built up over time (Bb), their perceptions of the stressor may have evolved over time (Cc) and the outcome is the family adaptation and maladaptation (McCubbin & Patterson, 1983). Family resources (Bb) may relate to financial resources such as household income, or to other types of resources such as having relatives who are prepared to look after the individual with intellectual disabilities to give the parents a break, or emotional support provided by other parent carers. More formal supports and services would also fall under this category, such as access to day centres and respite. Perceptions of the stressor (Cc) could include overall family adjustment to having a son/daughter with intellectual disabilities, or perceptions of the impact of their offspring on the family e.g. new skills learned, wider world view developed, or perceived negative impact on family members.

The Double ABCX model has been used extensively to investigate stress and coping in families of children with disabilities. Saloviita and colleagues (2003) aimed to predict the adaptation of parents whose child had intellectual disabilities, using the ABCX Model. The characteristics of the child (the Aa factor), predicted only 8% of the stress of fathers, family resources (the Bb factor) accounted for 33% of the stress of fathers, and family perception of the situation (the Cc factor) explained 37% of the stress of fathers (Saloviita et al., 2003). Jones and Passey (2005) also explored parental stress in families of children with intellectual disabilities and challenging behaviour using the Double ABCX model. Parents who believed their lives were not controlled by their child with a disability and who coped by focusing on family integration, co-operation, and were optimistic tended to show lower overall stress than families who did not adopt this approach (Jones & Passey, 2005). Minnes and colleagues (2007) tested the Double ABCX Model among parents of children with intellectual disabilities and reported that perceived caregiver stress was found to significantly mediate the relationship between maladaptive behaviour and depression. Carer perceptions of ageing and stress also significantly mediated the relationship between carer health and depression (Minnes et al., 2007). More recently, a study which tested the Double ABCX Model found evidence that perceptions of a stressor play an important part in mediating the relationship between challenging behaviour and stress (Rose et al, 2016).

Despite the popularity of this model, a number of issues with the use of this model to explain family stress and coping have been identified. A limitation of the Double ABCX Model, is the lack of a clear definition of what is meant by a 'crisis'. This term could refer to individual life events, which are conceptualised adequately within earlier models of stress or it could refer to more significant family problems (Hill & Rose, 2010). For single or widowed fathers of individuals with intellectual disabilities, a crisis could refer to the father experiencing a sudden illness and their son/daughter with intellectual disabilities having no one to care for them while they are unwell. This could result in their offspring not receiving appropriate care and support during this time, or being given a crisis placement by the local council. Alternatively, an increase in challenging behaviour exhibited by an individual with intellectual disabilities could result in their fathers being unable to keep them safe or look after them adequately, particularly as their child enters adulthood and becomes bigger and stronger. Minnes and colleagues (2007) also highlight a weakness of the Double ABCX approach, which is the lack of consensus on which variables are included in the model and the instruments used to measure these variables. For example, father health could be included in the model as a pile-up stressor (aA), a resource (bB), or as an outcome (xX) variable. This has led to various studies placing the same variables in very different positions within the model.

2.1.4 Overview of Stress and Coping Models

The above models all propose that a number of inter-linked factors contribute towards stress experienced by fathers of a son/daughter with intellectual disabilities. The importance of parental cognitions on influencing paternal stress are also emphasised in these models (Rose et al., 2016). This supports the idea that having a son/daughter with intellectual disabilities does not inevitably result in poor mental health outcomes for parents (Hastings & Taunt, 2002; Taunt & Hastings, 2002).

Despite this similarity, the models do differ in a number of ways. The Transactional Model of Stress and Coping, and the Two-Factor Model of Psychological Well-being focus on the level of the individual, whereas the Double ABCX Model of Family Adaptation focuses on family dynamics. Whilst the Double ABCX Model and the Transactional Model do allow for positive perceptions and outcomes, the Two-Factor Model appears to go one stage further, by acknowledging that positive and negative outcomes can occur simultaneously. It suggests that separate mechanisms exist for positive and negative outcomes, thus allowing for carers to experience these outcomes in parallel. A further difference between the models is the mechanisms that are hypothesised for the Transactional Model and the Double ABCX Model, compared to the Two-Factor Model. In the first two models, negative experiences may lead to positive outcomes, through the parent recognising the challenge of the event or situation and striving to meet it, thus enhancing their self-esteem (Hill & Rose, 2010). By contrast, the Two-Factor Model does not allow for this mechanism.

Overreliance on stress and coping models when accounting for parent outcomes has been challenged by McConnell and Savage (2015). They note that as the vast majority of studies in the field are correlational, it is important not to assume that family dysfunction or distress is causally linked to the presence of an individual with intellectual disabilities within the family unit. Other factors such as low socioeconomic status must be considered. This factor has been demonstrated to be causally related to mild intellectual disabilities, parental mental health and family dysfunction (Lupien et al, 2001; Park & Turnbull, 2002; Povee et al, 2012). The high levels of mental ill-health found among families of individuals with intellectual disabilities might therefore be attributable to pre-existing socioeconomic disadvantage. This is supported by a series of population-based studies over the last decade which have reported that associations between poor paternal mental health and child disability is significantly reduced when socioeconomic disadvantage is considered (Emerson, 2012; Emerson et al., 2010; Olsson & Hwang, 2008).

From these critiques, it is apparent that no single model described above fully captures the complete experience of fathers of a son/daughter with intellectual disabilities (Hill & Rose, 2010). Models which focus on the stress and coping responses fail to consider the whole experience of caring, such as transition periods or the long-term nature of care required for some individuals with intellectual disabilities. Models which address the wider aspects of caring and have some relevance to the current study are now considered.

2.2 Caregiving models

As discussed in the introductory chapter of this thesis, parent carers often continue caring into old age as their offspring with intellectual disabilities are now living longer than in previous generations (Bibby, 2013; Cairns et al., 2013; O'leary et al., 2018). Given this shift, it is particularly important to consider the longitudinal and multidimensional nature of caring. A number of caregiving models have been proposed over the years which attempt to take these aspects of caregiving into consideration, in order to capture the full experience of carers. These models are discussed in the section below and include the Model of Intergenerational Caregiving (Bowers, 1987, 1988), the Model of Family Caregiving (Nolan et al, 1995), Stages in Dementia Caregiving (Wilson, 1989a, 1989b), the Multidimensional Model of Caring and Coping (Nolan et al., 1996).

2.2.1 Model of Intergenerational Caregiving (Bowers, 1987, 1988)

Bowers (1987, 1988) conducted a qualitative study of middle-aged offspring caring for ageing parents with dementia to investigate the stages of caregiving that an individual carer may experience. The resulting model defined care according to the meaning and purpose of caring, as described by carers themselves. In this study, Bowers found that carers defined types of caregiving by purpose rather than by task and this is reflected by the categories in the model (Bowers, 1987). As the model was based on family carer perspectives, it captures the meanings that carers assign to their caring experience, which was also the aim of the current study. In Bower's original model, caregiving was devised of five distinct yet often overlapping categories which are outlined in table 1 and described in further detail below: anticipatory care, preventative care, supervisory care, instrumental care, and protective care (Bowers, 1987).

Table 1- Bowers' (1987, 1988) Model of Intergenerational Caregiving

Categories of care	**Summary of care category**
Anticipatory care	Future need is anticipated by carers and plans put in place, or life decisions made to account for this.
Preventative care	Preventative action is taken to reduce the likelihood of illness, accident etc.
Supervisory care	Direct intervention is now provided for everyday tasks.
Instrumental care	Physical caregiving tasks are undertaken.
Protective care	Carers involvement is hidden to maintain the individual's sense of independence and self-esteem.

Anticipatory care is based on anticipated future need and informs carers' life decisions. 'Just in case' was a key conceptual part of this category with carers putting plans in place, just in case it was necessary. This type of care is usually hidden from the cared-for person so as to preserve their dignity and sense of independence. This type of care was usually described by carers who did not live with their parents. Preventive care referred to tasks which were undertaken to prevent illness, accident, physical and mental deterioration. For example, the parents may discreetly monitor the diet of their son/daughter with intellectual disabilities to try to encourage a healthier diet. Alternatively, parents may ask other people in their child's life to remind them to complete certain actions that prevent ill-health, such as visiting the dentist or doctor. This is more active than anticipatory care and is seen as monitoring at a distance. The cared-for person may also be unaware of this type of care. Supervisory care is when the cared-for person requires direct assistance, such as help with actually taking medication. The cared-for person may be aware of their carer's actions but the carer usually tries to minimize this. Instrumental care is the category of care on which most research is based, where the carer is actually ‘doing’ something for the cared-for person, such as washing them. The cared-for person is aware of their need for care and Bowers suggests that carers find this type the least stressful and the least important.

Protective care is the final category within Bowers’ model. When carrying out this type of care, the carer aims to maintain the self-esteem of the cared-for person by minimizing their involvement. Bowers feels that carers find this most difficult as they are trying to protect the person from the knowledge of their need for care. While carers often see this as the most difficult and stressful, it is also considered to be the most important type of caring. This type of caring can serve as a barrier to other types of caring, such as instrumental care, as maintaining the illusion that care is not taking place may limit the carer’s ability to perform direct caregiving tasks. Many carers felt that they had gone through a role reversal by caring for their parents, although interviewed parents seemed unaware of this (Bowers, 1987). This category of care was later relabelled ‘preservative care’ to capture the importance of maintaining the cared-for individual’s sense of self (Bowers, 1988). How this last phase of care in the model operates will depend on the type of relationship between carer and cared-for person, as well as their specific needs. Therefore, this type of care will look very different when applied to a parent caring for their offspring with intellectual disabilities, as there is no ‘role reversal’. The maintenance of skills described in this stage of caregiving applies specifically to individuals who experience a reduction in such skills e.g. due to a deteriorating condition such as dementia. However, for individuals with intellectual disabilities the focus is more likely to be on building and maintaining new skills. Therefore, for fathers of a son/daughter with intellectual disabilities, ‘protective’ or ‘preservative care’ is likely to involve taking steps to increase their offspring’s life skills and independence in order to preserve their dignity and respect their transition into adulthood. For example, supporting their son/daughter to make decisions about their own care or how they spend any money that they earn through employment or benefits. This may be particularly true for individuals with milder intellectual disabilities who wish to lead a separate and independent life, or eventually move out of their parents' home. Although fathers may struggle to support this transition if they are concerned about how their son/daughter will cope without more intensive support.

Of the categories of care in this model, only instrumental care involves the physical caregiving tasks often associated with caring, while for some carers, most of the actual work that makes up a carer's role is invisible (Bowers, 1987). Yet services are more likely to focus on instrumental care when assessing carer need, rather than the invisible aspects of caring. By only focusing on the last two categories, research and services miss the importance of a carer's role prior to direct intervention by the carer. However, this may not apply to parents of a son/daughter with intellectual disabilities, as parents have presumably been caring for their child throughout their childhood. Therefore, direct intervention has been set as the precedent for caring. Nolan notes that this model only considers the carers' perspective, specifically for dementia, and focused only on care between generations rather than care carried out by other family members. The model therefore, does not take account of parents caring for their children. The majority of carers included in the study which informed this model were female (2/33) and so these categories may be different for male carers, given the existing research which suggests that males and females respond differently to the demands of caring (Di Novi et al, 2015; Mencap UK, 2017; Walker, 2010).

2.2.2 Model of Family Caregiving (Nolan et al., 1995)

Nolan and colleagues (1995) built on Bowers' (1987, 1988) model to address some limitations associated with the original model. Bowers' model was developed to apply to a relatively narrow group of carers, those caring for an ageing parent with dementia. Potential reciprocity between the carer and cared-for person, and perspectives of the cared-for person were not accounted for. There was also no consideration of longitudinal caregiving, and so anticipatory care was only associated with the early stages of the caregiving process (Nolan et al., 1995). This does not make it a very good fit for the current study, as parents of individuals with intellectual disabilities are often caring for their offspring long term.

Nolan’s model was developed over a series of studies (Keady & Nolan, 1993a, 1993b; Nolan, 1986; Nolan & Cunliffe, 1991; Nolan & Grant, 1992), some of which were not directly focused on typologies of care, but rather on evaluation of service provision for carers. As can be seen from table 2, the resulting model expanded aspects of Bowers’ model as well as redefining and adding certain categories of care. Nolan’s model made no alterations to Bowers’ preventative, supervisory and instrumental care. However, the changes to the other care categories are represented in table 2 and discussed in further detail below.

Table 2: Nolan and colleagues' (1995) Model of Family Caregiving

Categories of care	**Summary of care category**
Anticipatory care	Anticipation of future need continues throughout the caring process, not just in the initial stages.
Preventative care	Preventative action is taken to reduce the likelihood of illness, accident etc.
Supervisory care	Direct intervention is now provided for everyday tasks.
Instrumental care	Physical caregiving tasks are undertaken.
Protective care	Action is taken to maintain the self-esteem of the cared-for person, until this is no longer beneficial or possible.
Protective care	Preservation of the self-esteem, skills and interests of the cared-for person.
(Re)constructive care	Assistance is provided to construct or reconstruct a sense of identity or value.
Reciprocal care	Mutual caregiving activities are performed by both the carer and cared-for person in order to support one another.

Unlike Bower, Nolan believes that anticipatory care is not just an activity which takes place before caring, but throughout the caring journey. This definition is more in keeping with the experiences of parents whose son/daughter has intellectual disabilities, as such anticipatory care may have been happening throughout their child’s life. His interpretation of anticipatory care also challenges Bowers’ definition, as Nolan sees this type of care as changing in nature over time, and as likely to become a shared activity later in the caregiving journey. For example, as the individual with intellectual disabilities ages, they may express their own preferences for future care options. Therefore, when other forms of care are required, this does not negate anticipatory care but moves the anticipation of future care needs from one of possibility to one of definite need. The question which carers must ask themselves becomes not ‘what will I do if?’ but ‘what will I do when?’ (Nolan et al., 1995). While individuals with intellectual disabilities may or may not be involved in this type of shared discussion, as parents of a son/daughter with intellectual disabilities age they begin to ask themselves the second version of this question in an attempt to plan for their child’s future care (Grey et al., 2018). This type of future anticipation is divided into two categories in Nolan’s model: speculative anticipation and informed anticipation. Speculative anticipation exists in the absence of adequate information on which to base the extent or type of the cared-for person’s future needs. Inadequate information at this stage may lead to over or under estimate of the amount of care needed. On the other hand, informed anticipation takes place when the carer does have access to adequate information for future planning. As Nolan suggests, anticipatory care has a number of important implications for planning and providing services for individuals with intellectual disabilities and their family carers (Nolan et al., 1995).

Protective care, as described by Bowers (1987) involved shielding the cared-for person from the knowledge that they required care and preserving their sense of self. Nolan counters that this strategy may work in the short-term but is usually neither sustainable nor desirable in the long-term. Nolan cites the paternalistic aspect of this type of care as the reason for its inappropriateness. Yet for fathers of individuals with intellectual disabilities this may be an appropriate type of care, given that they are in fact the parents rather than children of the cared-for person. When these children enter adulthood, it is desirable that they begin to learn the skills necessary to gain more independence, and at this point ‘protective care’ may no longer be appropriate or achievable to the same extent that it was during their childhood. This is particularly true for those with milder intellectual disabilities who may be able to live a more independent life. In Nolan's (1995) model, preservative care involves preserving not just the dignity and self-esteem of the cared-for person, but also their skills and interests. However, this is only practical up to a point. Charmaz (Charmaz, 1987) argues that it is important to develop new skills to replace old ones when the individual has a disability. Desperately trying to maintain previous skills and tasks may not be in the carer or cared-for person's best interest in the long term, if this is not feasible. However, Charmaz's work focussed on individuals who are chronically ill, not those with intellectual disabilities. For individuals with intellectual disabilities, developing self-care and other skills are an advantage, particularly as their parents age and are no longer able to complete as many physical tasks. However, this depends on the degree of disability and needs of each individual. (Re)constructive care builds on the past and also seeks to develop new and valued roles for the cared-for person. Nolan emphasises that this type of care is most successful when both the carer and cared-for person have realistic expectations. In cases of illness this is re-constructive but for intellectual disabilities it may be constructive.

A failure to fully recognise the existence of and importance of reciprocal care is one of Nolan's key criticisms of Bowers' model. Given that her model was developed to represent the types of care provided for people with dementia, it is perhaps understandable why this was not a key component of Bowers' model, particularly in the later stages of dementia (Nolan et al., 1995). The extent of reciprocal care may vary depending on individual circumstances, yet it forms an important aspect of caregiving, and may involve not just instrumental care but other categories of care. Research into the experiences of older parents who care for an adult with intellectual disabilities, supports the existence of and importance of reciprocal care (Perkins & William, 2013; Williams & Robinson, 2001), making this category an important addition to the model. As well as providing practical and emotional support for parents, reciprocal care has also been demonstrated to bolster the self-esteem of individuals with intellectual disabilities (Williams & Robinson, 2001). Providing such reciprocal care could also be a challenging role for the individual with intellectual disabilities, and potentially limit their opportunities in life, as it can for other carers (Yeandle, 2016).

2.2.3 Stages in Dementia Caregiving (Wilson, 1989a, 1989b)

An alternative eight stage model of family caregiving was developed by Wilson and colleagues (1989a), based on interviews conducted with twenty family carers of individuals with dementia. From this work, Wilson determined that family caregivers were constantly faced with negative choices and the challenges of coping with their caring role. It was therefore necessary for strategies to be developed in order to deal with the situation, and to reduce the negative outcomes of caring (Wilson, 1989b). Carers adopted various coping strategies, and these differed depending on the stage of caregiving journey. After creating the original model, Wilson (1989b) later elaborated on the final three stages of care and categorised theses stages as 'surviving on the brink'. The stages in Wilson's model are summarised in table 3.

Nolan (1996) notes that this model does not include the potentially positive side of caring, but rather focusses on the negative aspects of each caregiving stage. However, he acknowledges that it does provide a useful illustration of the coping strategies adopted at each phase of the caregiving trajectory. While the previous three models provide an account of the different stages that carers pass through when caring for a family member with dementia, they do not provide a framework for the experiences of fathers who care for their son/daughter with intellectual disabilities throughout their life, as these models do not take transition periods and ageing family carers into account. However, given that this model is based on the experiences of carers of people with dementia, it is unlikely to closely resemble the journey of a father caring for a son/daughter with intellectual disabilities.

Table 3- Wilson's (1989) Model of stages in caregiving for family members with dementia [adapted from Nolan and colleagues (1996)]

Stages of caregiving	Summary of caregiving stage
Noticing	Gradual awareness of aberrant behaviour on the part of the family member. This stage is only acknowledged in retrospect.
Discounting/ normalising	Trying to find out as much as possible about the unusual behaviour, and seeking a rationalisation e.g. old age.
Suspecting	Realising that something is seriously wrong.
Search for explanations	Searching for explanations from medical professionals.
Recounting	Reappraising unusual behaviour in light of the diagnosis.
Taking it on	Taking on the caring responsibilities due to a lack of perceived alternative options. The potential implications of this choice are largely unknown.
Going through it	Facing the specific challenges involved in caring and developing strategies for dealing with these challenges. The cared-for person becomes increasingly dependent on the carer.
Turning it over	Realising that caring is taking too much of a toll on the carer, and that alternative care options are required. Even after the cared-for person moves into a residential home, the carer continues to be actively involved.

2.2.4 Multidimensional Model of Caring and Coping (Nolan et al., 1996)

Wilson’s previous (1989a, 1989b) model was adapted and refined by Nolan and Keady from work conducted over a number of years with 58 carers of individuals with dementia (Keady & Nolan, 1993, 1994a, 1994b, 1995a, 1995b). The carers included in these studies were purposively sampled to include those who were new to their caring role, those who had been caring for a number of years, and those whose caring role had come to an end. This enabled Nolan and colleagues (1996) to identify key transition points in the carers’ journey, and he believes that these are important for determining the type of support that carers require at different stages of the caregiving trajectory. The resulting model reflects the experiences of carers with a range of needs and caregiving situations. It can therefore be applied to carers at different points in their caring journey.

Two broad sets of processes in this model were identified by Nolan and colleagues (1996). These were labelled ‘common processes’ which capture elements common to each stage of the model, and ‘stage-specific processes’ which are unique to an individual stage. The ‘common processes’ of the model are summarised in table 4 and ‘stage-specific processes’ are discussed in further detail below. The ‘common processes’ of this model are somewhat comparable to the Transactional Model of Stress (Lazarus & Folkman, 1984; Folkman & Lazarus, 1985) described earlier in this chapter, in that they acknowledge that carers appraise challenging situations and then assess which action to take in order to meet such challenges. This model also adds a process where the effectiveness of the action is evaluated. This additional step would enable carers to learn from their experience and would inform their response to a similar challenge experienced in the future.

Six stage-specific processes make up Nolan’s (1996) model. The first stage of the model ‘building on the past’ considers the nature and quality of past interactions between the carer and cared-for person. In cases such as caring for a child with intellectual disabilities (where there may be no previous interactions as caring began at birth) this can be building on the past with other family members such as parents and other siblings (Grant et al, 2003).

Table 4- Common processes in Nolan's (1996) Multidimensional Model of Caring and Coping

Process	Summary of process
Acknowledging the challenge	Recognising that a response to the situation is required and assessing whether it poses a threat or a challenge.
Balancing the books	Reviewing the resources available to them to deal with the situation.
Clarify the alternatives	Identifying the possible courses of action.
Decide what to do	Selecting a course of action.
Evaluates the consequences	Reappraising the effectiveness of the action taken.

These past interactions can shape current support as the relationship developed between the carer and various family members can dictate who the carer turns to for emotional and practical support. Nolan and colleagues (1996) also note that throughout the caregiving journey parents build on the knowledge gained from past experiences to inform future decision making. Strategies for successfully obtaining respite and other services for their offspring with intellectual disabilities may inform how fathers request such services in the future. In this way, ‘building on the past’ is an important aspect of caregiving throughout the caring journey.

The second stage of the model is ‘recognizing the need’, which involves carers becoming aware of their changing relationship with the cared-for person. This stage usually occurs following a diagnosis from a medical professional (Grant et al., 2003). If a child’s intellectual disabilities, such as in the case of Down syndrome, are recognised before birth then this stage can also occur before birth by parents learning about the condition and attempting to prepare for the birth. However, this depends upon the parents understanding of such a diagnosis in terms of their child’s future support needs. The child’s individual development and support needs may also not be apparent for a number of years. The manner in which this diagnosis is given has a profound effect on carers with tactless or insensitive comments causing distress (Nolan et al., 1996; Thomson et al., 2017). Grant and colleagues (2003) note that a delayed diagnosis may also occur, with parents experiencing a growing suspicion that something is wrong. The uncertainty of this time is often described as an incredibly stressful period for parents.

‘Taking it on’ is the third stage of the model, which occurs when there is a recognition that the relationship has changed and a more formally recognised role of carer begins. For carers of people with dementia this process involves deciding whether to take on the role of carer. Nolan and colleagues (1996) argue that carers should be provided with all the necessary information in order to make an informed decision and encouraged to think through the potential implications of their decision, but acknowledge that genuine choice is often absent. For many parents of a son/daughter with intellectual disabilities, there is no real choice because they are determined to do all they can to care for and love their child (Cairns et al., 2013; Towers, 2009). At this stage, the strength of relationships within the family can be severely tested, as parents struggle to balance their many commitments and experience doubt over their own caregiving abilities (Grant et al., 2003). For parents of a son/daughter with intellectual disabilities, ‘taking it on’ also does not mark a move into a caring role as parents expect to care for their children during childhood. Rather, this stage could be interpreted as parents gaining an understanding of the specific support needs of their child and taking on the challenge to obtain necessary supports and services for their son/daughter.

The fourth stage of the model is labelled ‘working through it’ and has been compared with the ‘going through it’ stage in Wilson’s (1989a, 1989b) model, although Nolan and colleagues (1996) argue that the language used in their model is a more appropriate representation of the active processes that carers go through. During this stage, carers are providing instrumental care but also anticipatory, protective, preservative, reconstructive and reciprocal care for their offspring. The main aim of this stage is to maximise the positives and minimise the negatives of the caring role. When carers achieve this, they experience satisfaction (Nolan et al, 1996). As in Bowers' (1987, 1988) 'preservative care', in this stage carers strive to maintain their offspring's self-esteem and independence. During this process carers become the experts in their son/daughter's care (Burgess, 2009; Davys et al, 2016). This stage is also often the first contact that carers have with formal services. If professionals working within these services do not acknowledge parents' expertise, a distrust towards such services may be formed (Nolan et al, 1996). This stage in the caregiving model appears to be one of the most applicable to parents of a son/daughter with intellectual disabilities due to the focus on actively providing different types of care, and making contact with services. However, unlike individuals with degenerative conditions, carers of individuals with intellectual disabilities aim to build rather than 'maintain' their child's independence.

Many carers wish to continue caring for their offspring with intellectual disabilities for as long as possible (Bibby, 2013; Taggart et al., 2012), and during their later years they often report the development of a reciprocal caring relationship (Perkins & William, 2013; Williams & Robinson, 2001). Despite this, there may come a point where continuing as a carer may no longer be in the interest of either the carer or the individual with intellectual disabilities. This is captured in 'reaching the end', the fifth stage of Nolan and colleagues (1996) model. The decision to look for caring alternatives may occur due to the failing health of the carer, poor mental health and strain of caring, or challenging behaviour exhibited by their offspring (Grey et al., 2018). Many carers experience guilt at this stage for considering alternatives, which can be hard to manage. However, at a certain point most carers acknowledge that it is necessary to investigate caring alternatives for when they are no longer able to physically care for their son/daughter or they themselves are no longer around to do so (Cairns et al., 2014). Until parents reach the stage of being unable to care there are generally very few housing options available in the UK for their child, unless a crisis occurs which prevents parents continuing in their caring role (Bigby, 2004; Braddock et al, 2001; Duffy, 2013).

The final stage of the model is named 'a new beginning?' and describes the process of carers letting go of what had been an important part of their identity over the years, and attempting to deal with the change in their circumstances. This can be a very difficult time for carers as the they lose what has become an important part of their identity and purpose in life (Grant et al., 2003). However, giving up their role as the main caregiver does not necessarily mean that parents will no longer care for their son/daughter, but that they may take on a slightly less arduous role (Nolan et al., 1996).

Grant and colleagues (2003) note that a major advantage of the model is that the stages are relatively predictable, which can assist professionals and caregivers to identify and prepare for future stages. Suitable interventions and service provision can therefore be planned around this model. Nolan and colleagues (1996) describe their model as a means of identifying key transition points that occur during the caregiving journey, as well as the factors which influence caregiver decision making. While this model identifies important transitions that carers pass through, and considers how their needs change over their caring trajectory, there are a number of issues with relying on this model to provide a useful framework within which to consider the needs and experiences of fathers. The 'taking it on' stage in this model is not an appropriate fit for carers of individuals with intellectual disabilities as many parents feel that they do not have a choice to begin caring once their child is born, since this is an expected role of parents. However, this may be more applicable for older generations of parents when it was culturally acceptable to send your child to an institution if they had an intellectual disability. These parents were often given the choice of leaving the hospital without their child, and so did not 'take on' the role of parent. This is also not a transition in the relationship between the carer and cared-for person as this stage describes, but rather the beginning of their relationship. The model also focusses on the maintenance of the cared-for person's skills to continue their independence. While for adolescents and adults with intellectual disabilities, these skills must be developed from scratch before they can be maintained, as the individual does not have such skills at the beginning of the caring relationship.

2.2.5 Overview of Caregiving Models

Each of the caregiving models included in this chapter was informed by research with carers of people with dementia, which restricts the transferability of these frameworks to carers of individuals with intellectual disabilities. Nolan and colleagues' (1996) Multidimensional Model of Caring and Coping was based on the experiences of carers at different stages of the caring journey and focusses upon key transition points within this journey, making it more applicable to the experiences of a wide range of carers of people with a deteriorating condition. While Bowers' (1987, 1988) model can be considered to include temporal aspects of caregiving, with carers progressing through the various stages as the health of the cared-for person deteriorates, Wilson and colleagues' (1989a, 1989b) model, as well as Nolan and colleagues' (1996) model do so more explicitly. Despite accounting for the long-term nature of caring, and the progression through different stages, these models do not fully capture the experiences of fathers of a son/daughter with intellectual disabilities. For parents of a son/daughter with intellectual disabilities the caring role begins at their child's birth and continues into adulthood, and in some cases until the parents' death (Cairns et al, 2013). Therefore, models which represent caring as a role that the carer gradually adopts are inaccurate when considering this population.

Some of the above models do include certain important elements of caring for a son/daughter with intellectual disabilities, such as positive aspects of caring and reciprocal care. Models proposed by Nolan and colleagues (1995, 1996), although not the frameworks developed by Bowers' (1987, 1988) and Wilson (1989a, 1989b), do address the more positive aspects of caring. While Bowers' (1987, 1988) model provides a useful framework for understanding the focus that caregiving tasks have at different stages, it does not address reciprocity of care, which has been demonstrated to be an important aspect of the caring relationship between family carers and individuals with intellectual disabilities (Perkins & William, 2013; Williams & Robinson, 2001). Nolan and colleagues (1995) extended the work of Bowers by adding two further elements, reconstructive care and reciprocal care. Wilson's (1989a, 1989b) model also fails to acknowledge the role of reciprocal care, and places its focus upon the negative choices which carers are forced to make in their caring role. As has been previously discussed, caregiving can be a highly rewarding experience (Cairns et al., 2014; Horsley & Oliver, 2015; Rowbotham et al., 2011; Taunt & Hastings, 2002), and models which do not take this into account are overlooking an important aspect of the caring relationship for fathers of a son/daughter with intellectual disabilities.

In addition to positive outcomes of caring and reciprocal care, a caregiving model for fathers of individuals with intellectual disabilities would need to take account of the fact that this is a very heterogeneous population with different abilities and support needs. Such a model would need to consider the prolonged nature of caring that many carers experience, and how the caring relationship can change over time as the individual with intellectual disabilities enters adulthood and the father enters older age. Assisting their son/daughter to develop skills necessary to increase their independence would be an important part of a model which considered the experience of this type of carer. The impact of ageing on the physical and mental health of fathers, and their ability to complete certain caregiving tasks, as well as reciprocal care would form part of this later stage in such a model. Thinking about or laying down plans for when caring is no longer possible would likely be the last stage in the caregiving model.

2.3 Summary

This chapter has outlined and discussed various relevant models of stress, coping, and caregiving which were deemed relevant to the current study. As the available caregiving models depict the experience of carers of an adult with dementia, they were not deemed appropriate for representing the experience of a father of a son/daughter with intellectual disabilities. The Double ABCX Model of Family Adaptation was deemed the most appropriate model of stress and coping for the current study and guided the selection of search terms for the systematic review and meta-analysis of father carer’s mental health and well-being. This model was chosen to inform this phase of the study due to the successful application of the model to mothers of offspring with intellectual disabilities in previous studies

(Jones & Passey, 2005; Minnes et al., 2007; Rose et al., 2016; Saloviita et al., 2003). The model's inclusion of positive perceptions, and the recognition that a stressful event can lead to a positive outcome, were considered important for the present study as these ideas are supported by existing research into the experiences of family carers of a person with intellectual disabilities (Horsley & Oliver, 2015; Perkins & William, 2013; Williams & Robinson, 2001). The following chapter will present the rationale for the mixed-methods approach to this project.

Chapter 3: Mixed Methods

This PhD project used a 'mixed-methods' approach to address the research aims. It is comprised of three studies: one qualitative and two quantitative. The methodological approach taken for each of the three studies is detailed in later chapters. This chapter considers the rationale for adopting a mixed-methods approach and discusses the design of the current study.

3.1 The Study Design

3.1.1 Strengths and limitations of mixed-methods research

Both qualitative and quantitative data were considered necessary for this project as there are a number of advantages to the adoption of a mixed-methods research approach associated with the current study. The core assumption of this form of inquiry is that the combination of qualitative and quantitative methodology provides a more complete understanding of a phenomenon than either approach can do so alone (Creswell & Garrett, 2008; Johnson et al., 2007). Had the study attempted to collect data on fathers' experiences through a purely quantitative element, the same richness of experience could not have been obtained as is possible through the collection of qualitative data. Many phenomena are difficult if not impossible to measure using only quantitative methods, such as opinions, feelings, beliefs, and values. Interviews enable the researcher to discuss participants' feelings and opinions in detail, and affords the opportunity of asking fathers to elaborate on or clarify points that they make. The qualitative element of this study also enabled the researcher to learn about the aspects of participants personal, social and political environments which impact fathers' experiences as carers. On the other hand, if a solely qualitative project had been conducted, this would not have allowed the researchers to form a larger picture of the experiences of fathers of a son/daughter with intellectual disabilities from around the UK. In this way, by mixing methods the limitations of one method can be offset by the strengths of the other and provide clarification (Wisdom et al, 2012).

While the use of a mixed methods research design provides a number of advantages for researchers, they are also associated with unique challenges.

Creswell and Plano Clark (2017) emphasise the importance of skilled researchers being involved in mixed methods projects to ensure that sufficient skills and experiences for both qualitative and quantitative methods exist within the research team. In addition, researchers must have a solid grounding in mixed methods procedures for integrating both sets of data. In order to address this potential challenge and prepare for this project, the researcher undertook a tailored training programme to become familiar with the appropriate qualitative and quantitative methodology, as well as mixed methods procedures. Issues of time and resources must also be considered in a mixed-methods design. This research approach involves collecting and analysing more types of data than in either solely qualitative or quantitative research. Qualitative data collection and analysis is also often more time intensive. Thus, the time and resources required to achieve this must be evaluated early on in the design of such a project. The researcher carefully constructed a timeline to allow for necessary skill acquisition, planning, data collection and analysis for this project.

3.1.2 Mixed-methods research designs

Having elected to conduct a mixed methods study, the particular research design must be determined. Mixed methods studies are either fixed or emergent in nature. In fixed designs, all details of the study design are agreed at the start of the project. This approach is often theory driven and aims to test the proposed hypothesis. By contrast, emergent designs allow the researcher to develop their ideas in the early stages of the project rather than determining the use of quantitative and qualitative methods in advance. These are more exploratory and do not define all variables in advance. Due to the lack of information currently available on fathers of individuals with intellectual disabilities, an emergent design was selected as the most appropriate method for exploring their mental health and experiences. This decision allowed the project to develop over the course of the PhD, for each phase to be informed by the discoveries of the previous phase, and for any necessary alterations in the project.

Among the most widely promoted mixed methods designs are those of Creswell and Plano Clark (2003; 2007; 2011; 2017) who currently advocate for just three core designs: explanatory sequential designs which involve an initial quantitative phase followed by a qualitative phase to follow up on particular results from the initial phase, exploratory sequential designs involve where a qualitative study is followed by the development of an approach, research question, or tool to be tested quantitatively, and convergent designs where the analysis of the qualitative and quantitative phase are brought together for the purpose of combining or comparing results.

The focus of these designs is one of purpose, as Creswell and Plano Clark (2011) identify this as the most important aspect to guide the type of design selected for research. Therefore, the design selected for an individual study must be appropriate to answer the research questions being asked. To address the research questions of the current study, an explanatory sequential design was initially selected, where a qualitative project would follow up on the results of a quantitative project. However, due to delays in accessing the desired dataset for the quantitative study, this sequence was reversed and a sequential exploratory design was chosen. In addition to addressing the time constraints involved in this PhD, this alteration was also deemed to be acceptable due to the limited knowledge on the experiences of fathers, making this design an appropriate vehicle to explore the phenomenon. The sequential approach allowed the choice of participants for the qualitative study to be informed by the findings of the systematic review and meta-analysis. Using a qualitative study phase then provided an exploration of the topic to generate ideas and concepts which could be applied to the later quantitative study (Onuegbuzie et al, 2010). An exploration of elements of the emergent theory developed from the qualitative phase was possible through the selected exploratory sequential design (Morse, 1998). This was considered to be an important process due to existing gaps in the literature on the impact of caring on fathers of a son/daughter with intellectual disabilities. The three-phase approach to the project, given its sequential design, also made it more manageable for a single PhD researcher to implement.

In sequential exploratory designs, the balance of components is usually slightly unequal, with more weight being given to the qualitative element. However, this was seen as an advantage in the current study as it was necessary to collect in-depth data on the experiences of fathers to supplement the limited existing research on this topic. It was important to ensure that the qualitative phase of the project was fully integrated with the quantitative phase, as lack of integration has been identified as a common oversight in mixed methods research (Bryman, 2017; O'Cathain et al, 2007). In order to ensure this, a theme was identified in the qualitative study which was particularly important to fathers, and the contents of this theme directly informed research questions asked in the quantitative phase of the project. As this design is sequential it was also more time consuming than other types of mixed methods research. However, as this was a PhD project, it was necessary to adopt an approach which allowed a single researcher to complete all elements of the project.

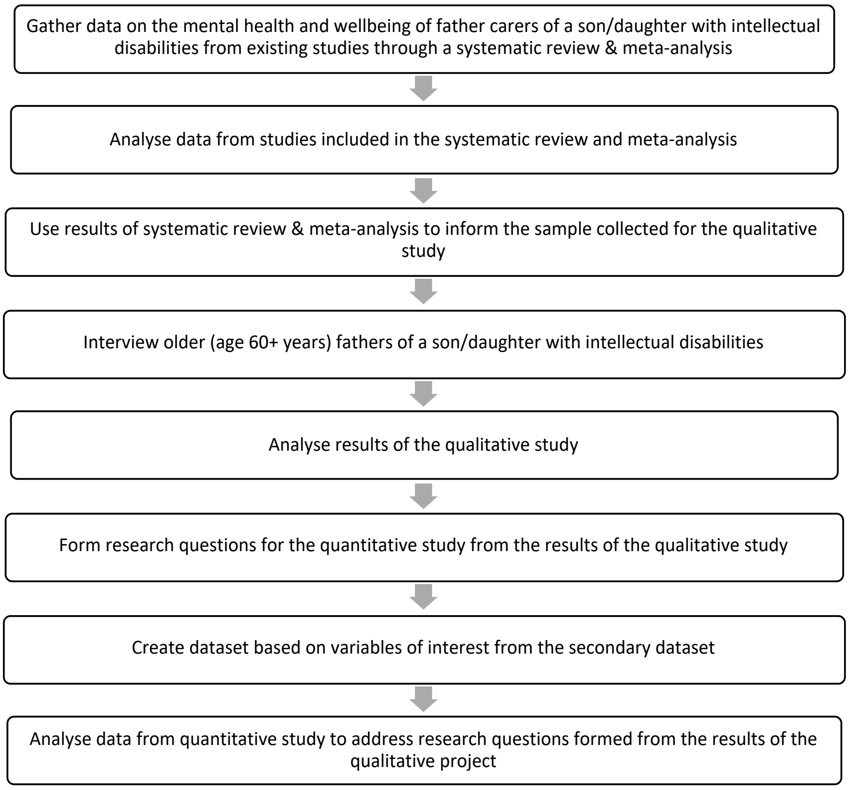
Having adopted an exploratory sequential mixed methods design, the specific steps involved in the project are outlined in figure 1. In the first step, quantitative data was gathered from existing studies of father carer mental health in the form of a systematic review and meta-analysis. This phase highlighted the limited number of studies which separately report data on fathers' mental health and well-being. After it was determined that quantitative data would not be available in time to proceed with the quantitative study immediately after the completion of the systematic review and meta-analysis, a decision was made to conduct an exploratory qualitative study which would inform the direction of the later quantitative study. The results of the systematic review and meta-analysis were used to inform the recruitment of fathers for a qualitative study which investigated the experiences of fathers and the factors which impact on older (60+) fathers' mental health and well-being. This particular group was chosen for a number of reasons. The systematic review and meta-analysis detailed in Chapter Four identified a lack of studies which included this age group of fathers. This is a particularly serious omission due to the growing cohort of older fathers of people with intellectual disabilities, which was discussed in the first chapter of this thesis, and our limited understanding of fathers' experiences.

In exploratory sequential mixed methods designs, an integrative data analysis procedure is adopted to collect and analyse the qualitative data and build a quantitative instrument, or research question based on the qualitative results. In order to do this the qualitative data must first be analysed for themes and codes to describe the experiences of the individuals. Next, a decision must be made about which research questions should be tested in the quantitative study. Accordingly, the final stage of the project involved the analysis of a secondary data set, addressing research questions which were guided by one of the key themes of the qualitative study. The methods used for each phase of the project will be discussed in further detail in later chapters.

3.1.3 Evaluating mixed methods designs

Validity and quality remain a major issue in mixed methods research, which is of particular concern given the importance of this aspect of a research project. Despite the increasing popularity of mixed-methods research designs, the means of evaluating such studies remains poorly defined (Halcomb & Hickman, 2015). However, an increasing number of researchers are now investigating how quality in mixed methods studies can best be conceptualised and operationalised (Curry & Nunez-Smith, 2015; Dellinger & Leech, 2007; Fabregues & Molina-Azorin, 2017; Heyvaert et al, 2013; O'Cathain, 2010; Tashakkori & Teddlie, 1998).

Figure 1: Steps in the final design of the current project



Gather data on the mental health and wellbeing of father carers of a son/daughter with intellectual disabilities from existing studies through a systematic review & meta-analysis

Analyse data from studies included in the systematic review and meta-analysis

Use results of systematic review & meta-analysis to inform the sample collected for the qualitative study

Interview older (age 60+ years) fathers of a son/daughter with intellectual disabilities

Analyse results of the qualitative study

Form research questions for the quantitative study from the results of the qualitative study

Create dataset based on variables of interest from the secondary dataset

Analyse data from quantitative study to address research questions formed from the results of the qualitative project

The lack of consensus on evaluation frameworks makes choosing which quality criteria to adhere to when planning a mixed methods research design something of a challenge for researchers. An alternative approach to this problem was put forward by Creswell and Plano Clark (2017), who suggest that adopting a one-size-fits-all approach to evaluation criteria is not appropriate or helpful. Instead, researchers should consider the particular validity threats inherent in the specific mixed methods design that they have selected, and adopt strategies to minimise these threats. For example, in the current exploratory sequential design the validity threats and strategies to reduce these threats are outlined in table 5. This approach to quality criteria was adopted for the current study to ensure that the selected criteria were suitable for maintaining rigour in the specific design chosen for the project.

Table 5- Adapted from 'Designing and Conducting Mixed Methods Research' Creswell & Plano (2017)

Validity Threat	**Strategies to Minimise Threats**
Not building the quantitative research questions based on the qualitative results	Make explicit how major qualitative findings are used to inform the development of specific elements of the quantitative feature. This will be detailed in the quantitative methods chapter of the thesis.
Not developing rigorous quantitative features	An established nation-wide dataset will be used for secondary data analysis. Use systematic procedures to design the data analysis plan, extract, and analyse the data.
Selecting participants for the quantitative test that are the same individuals as the qualitative sample	Use a large sample of individuals whose data was previously collected for the secondary dataset. Participant recruitment methods will be detailed in the qualitative and quantitative methods chapters of the thesis.

This chapter has provided an account of the logic behind selecting a mixed methods approach to answering the study’s research questions, the strengths and weaknesses of this approach, the specific typology followed and evaluation criteria adhered to in the current project. The following chapter will present the methodology and results of the first phase of the PhD project: a systematic review and meta-analysis.

Chapter 4: Systematic Review and Meta-Analysis (Study 1)

4.1 Introduction

As discussed in the introductory chapter of this thesis, the impact of caring for a son/daughter with intellectual disabilities varies between individuals. Since not all family units are the same and not all parents of individuals with intellectual disabilities report a negative effect of caring on their mental health and well-being, it is important to investigate the psychological processes which determine how or why certain parents may be affected. While some variables within the family unit cannot be changed (e.g. age, gender, type of intellectual disability), policy can be adapted to best assist those most at risk and parents' psychological processes can be directly targeted for change through therapeutic intervention (Hastings & Beck, 2004). One model which attempts to account for the variability in the differences in family adaptation to stress, and was identified as an appropriate model for investigating the mental health and well-being of parent carers of individuals with intellectual disabilities in Chapter Two, is the Double ABCX family crisis model (McCubbin & Patterson, 1983).

Due to the limited understanding of the impact of caring on fathers, this study focussed on the mental health and well-being of fathers who have a son/daughter with intellectual disabilities. It is important to further our understanding of the mental health of fathers compared to mother carers, and to fathers in the general population, in order to understand how caring impacts fathers specifically. Following the ABCX model of stress, this study also sought to investigate which factors related to father resources and father cognitions or perceptions which moderated the impact of caring. This knowledge will enable service providers and policy makers to better meet the needs of fathers caring for a son/daughter with intellectual disabilities.

In order to investigate what is currently known about the mental health of fathers of a son/daughter with intellectual disabilities, and which factors impact their mental health, a systematic review and meta-analysis was undertaken. A systematic review is a rigorous method of locating, synthesising and analysing original research in order to answer a specific set of questions on a particular topic. It is considered to be the gold standard for summarising what is known about an issue. Boland and colleagues identified ten basic steps in conducting a systematic review (Boland et al, 2017). These steps are as follows: 1) planning the review, 2) performing scoping searches, identifying the review question and writing the protocol, 3) literature searching, 4) screening titles and abstracts, 5) obtaining papers, 6) selecting full-text papers, 7) data extraction, 8) quality assessment, 9) analysis and synthesis, 10) writing up, editing and disseminating.

A narrative summary of the included studies is produced as a result of a systematic review. A meta-analysis works in conjunction with a systematic review by allowing statistical analysis of the results of those included studies. By combining the results from two or more studies, a meta-analysis can increase statistical power of the review and provide a single numerical value of the overall treatment effect. Studies included in the meta-analysis must have a common outcome measure. For example, when conducting a meta-analysis on studies which report on mental health of fathers, studies must use a similar mental health measure e.g. they must all produce a measurement of depression, rather than one paper measuring psychosis and another measuring bipolar disorder. During the narrative analysis and synthesis stage of a systematic review, a meta-analysis can be conducted by adding three additional steps. First, the extent to which the included studies are heterogeneous must be established. Next, the summary effect size and the extent of publication bias is calculated. Finally, subgroup analysis and a meta regression is conducted to determine if there are subsets of data that capture the summary effects.

Systematic reviews and meta-analyses are considered to be forms of evidence-based practice. Evidence based practice involves the integration of clinical experience, patient values, and the highest quality research evidence, into decisions made surrounding patient care and treatment (Sackett, 1997). Systematic reviews meet this criterion due to the scientific methods they employ which aim to reduce the likelihood of systematic error. Schlosser describes evidence-based practice as the ‘preferred approach’ for professionals who wish to remain accountable while delivering services for patients (Schlosser, 2006). As evidence-based practice must be informed by the most up-to-date and high-quality research available, conducting a systematic review and meta-analysis is a means of providing this information for practitioners in a synthesised format. It was deemed important to conduct a systematic review and meta-analysis as part of this thesis project in order to provide professionals with original evidence on fathers’ mental health, as well as to identify any gaps in existing knowledge and to inform the direction of this thesis.

A systematic review and meta-analysis were conducted to investigate the available research to date on the impact of caring for a son/daughter with intellectual disabilities on the mental health and well-being of fathers. This overarching research question was informed by the ABCX model of stress and coping, and was answered by the following sub questions in this systematic review:

1) Does the mental health and well-being of fathers of a son/daughter with intellectual disabilities differ from:
i) fathers in the general population?
ii) mother carers of a son/daughter with intellectual disabilities?

2) Is the mental health and well-being of fathers of a son/daughter with intellectual disabilities moderated by paternal resources such as:
i) paternal financial resources
ii) paternal social support
iii) formal services and supports

3) Is the mental health and well-being of fathers of a son/daughter with intellectual disabilities moderated by paternal perceptions of the:
i) characteristics of the child
ii) impact the child has on the father

iii) impact the child has on the family unit

4.2 Methods

4.2.1 Selection of studies

The review was prospectively registered with the International Prospective Register of Systematic Reviews (PROSPERO, registration number: CRD42017075898). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was followed.

The literature search was conducted on 1st July 2018. The specific search strategy included relevant terms for intellectual disabilities, carers and mental health (Appendix B). The following databases were searched: Psych INFO, EMBASE, Medline, and CINAHL. The initial search was conducted by a single researcher, with a second researcher searching a random selection of the retrieved papers: 10% of titles, and 10% of abstracts. The reasons for any discrepancies in paper selection were identified and resolved through discussion. Authors were contacted for further information where it was not clear if the study met the inclusion criteria. Reference lists of included papers and papers which referenced included studies were also scrutinised. A PRISMA flow diagram (Moher, 2009) was completed, detailing the reasons for excluding studies (figure 1).

Strict inclusion and exclusion criteria were used to select papers:

Inclusion criteria

- Father’s son/daughter has received a diagnosis of intellectual disability. Definitions of intellectual disability were accepted such as an IQ equal to or greater than two standard deviations below the population mean. In studies where no IQ is provided, we accepted fathers of children who were described as having an ‘intellectual disability’, ‘learning disability’, or any of the equivalent terms set out on our list of search strategy (terms 1-5) in Appendix B.
- Fathers aged 16 years and above
- Fathers of all ethnicities

•Observational studies such as cohort, case-control and cross-sectional studies
•Accepted measures of father carer's mental health and well-being included validated mental health and well-being measures e.g. the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) (Tennant et al, 2007) and validated measures of specific mental health conditions e.g. Beck depression inventory (BDI) (Beck et al, 1996).
•Studies from peer reviewed journals
•Papers written in the English language

Exclusion criteria
•Studies where father carer's data were not separately reported
•Grey literature

4.2.2 Data extraction

Data from each study were extracted using a data extraction form to collect information about the author, publication year, country, setting, type of study, population characteristics, methodology, outcome measures, key findings and limitations of the study. When studies did not clearly meet the inclusion criteria, authors were contacted to request additional information or clarification.

4.2.3 Quality and risk of bias assessment

The quality of all the selected studies were assessed in a systematic way, ensuring all the domains included in a systematic review of tools to assess quality of observational studies were included (Sanderson et al, 2007). This included the clarity of the stated aims, methodology (including age/gender standardisation, and whether group differences in disease prevalence rates were considered), design, participant selection, study size, measures used, data collected, analyses employed, results, biases, generalisability, conflicts of interests, and ethical procedures. Additionally, in order to generate a "score" we added up the number of items on the Oxford Critical Appraisal Skills Programme Checklist (CASP, 2014) that were addressed in each study. The reliability of the appraisal was checked by the appraisal being conducted and compared by two of the authors. The CASP scores assigned to each included study are displayed in Appendix C and tables 5-7. For each item on the CASP checklist a score of low risk, unclear risk or high risk was given. The following classification was given to rate the risk of bias for each study overall:

Rating A= low risk of bias in all 7 domains
Rating Bx= uncertain risk of bias in x domains, low risk of bias in all other domains
Rating Cyx= high risk of bias in y domains, uncertain risk of bias in x domains, low risk of bias in all other domains

4.2.4 Data Preparation

Initially, descriptive analysis of the studies was completed. Meta-analysis was undertaken using Review Manager Software. All outcome measures from the included studies reported outcomes on a continuous scale. The mean, standard deviation (SD) and number of subjects in the sample of fathers and the comparison group sample were extracted from each paper, and the unbiased standardised mean difference (SMD) calculated. A negative mean difference indicated poorer mental health for the comparison group than for fathers. For papers which included more than one group of fathers (e.g. fathers of offspring with Down syndrome and fathers of offspring with fragile x syndrome), data for these two groups were entered separately into the meta-analysis. Effect size was interpreted as: SMD <0.40= small, SMD 0.40 TO 0.70= moderate, SMD >0.70= large.

4.2.5 Heterogeneity and publication bias

Variability in results among studies on the same topic is called heterogeneity. While some variation between studies is expected, when heterogeneity is high this indicates that there is statistically significant variation in treatment effect beyond chance. Studies which are not methodologically rigorous or have small sample sizes may overestimate treatment effects and increase the rate of heterogeneity in the meta-analysis. The Chi-squared statistic I^2 (Higgins et al, 2003) indicates how much heterogeneity is present across the studies. It is not influenced by how many studies are in the meta-analysis, unlike some other test statistics, and can be interpreted in a similar manner regardless of the type of outcome data or effect measurement. It is therefore appropriate for this analysis as the included papers used a range of mental health measures. Higgins and colleagues propose that 0% equals no heterogeneity, 25% equals low heterogeneity, 50% equals medium heterogeneity, and 75% equals high heterogeneity. High heterogeneity implies dissimilarity in the included studies, and a meta-analysis should be conducted with caution. However, there is no consensus on the degree of heterogeneity which is acceptable between studies for a meta-analysis to be conducted, it is up to the discretion of the researcher (Israel & Richter, 2011). For the purposes of this study, Higgins guidelines will be used to evaluate the heterogeneity of included studies but the value of the I^2 statistic will be interpreted with caution.

The two most frequently used models to conduct a meta-analysis are the fixed-effects and random-effects models, which each have different assumptions. The fixed effect model makes the assumption that the true effect of a treatment is the same in all studies. By deciding to conduct a meta-analysis the researcher makes the assumption that the studies have enough in common that it makes sense to synthesize the information. However, this does not mean that an assumption can be made that the true effect size is exactly the same in all the studies. For example, if studies in a meta-analysis sample different age groups or ethnicities then the size of the treatment effect may be more pronounced in some groups. Random effects models assume that studies were drawn from different populations and these differences may impact the treatment effect. It is also assumed that there is a distribution of true effect sizes between the studies included in a meta-analysis. Random effects models were selected for this analysis due to the different populations (e.g. fathers of individuals with different types of intellectual disabilities, fathers of different ages) and measures (e.g. different measures of mental health) which were used in the included studies. Funnel plots were used to assess the impact of publication bias.

4.2.6 Sensitivity analysis

The impact of a studies risk of bias rating on the pooled SMD was ascertained using sensitivity analysis. This was done by removing data from the meta-analysis for each included study, one-by-one and beginning with the lowest ranked papers, in order to determine the effect of each individual study on the pooled SMD.

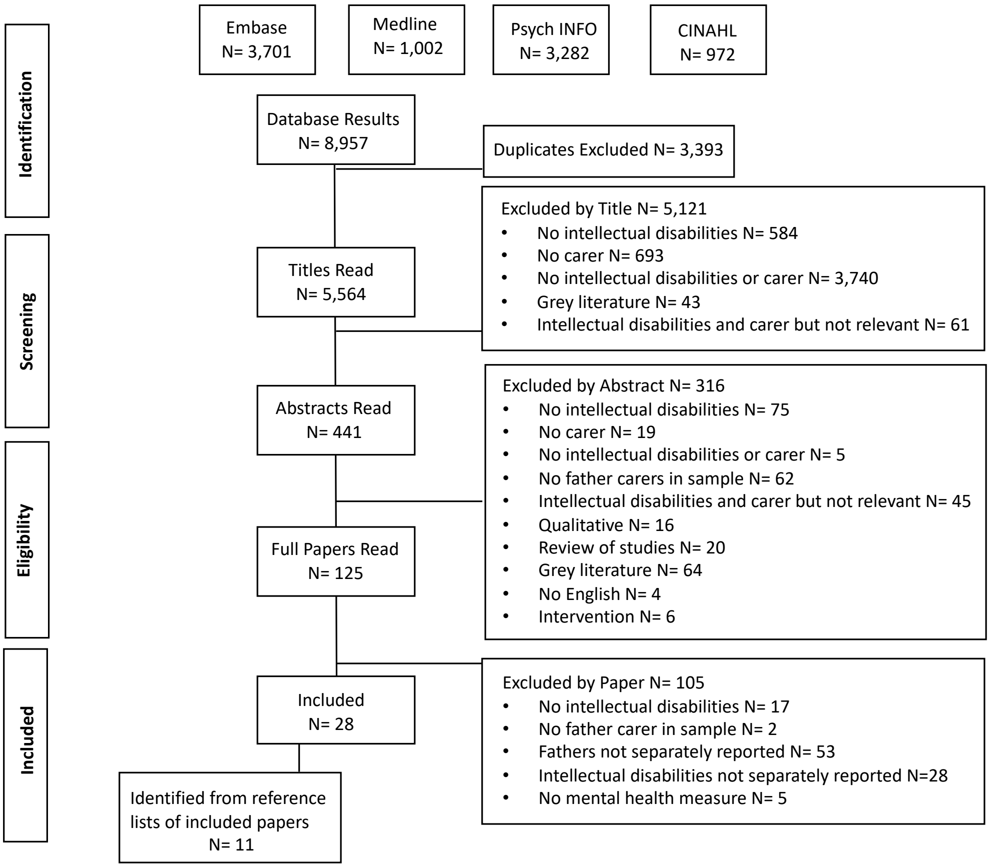
4.2.7 Sub-group analysis

The analysis was done by different subgroups based on different mental health conditions measured in the papers. These included anxiety, depression, stress and general mental health and well-being.

4.3 Results

A total of 30 papers were initially retrieved using the search strategy which met the inclusion criteria. The flow chart documents the number of papers included/excluded at each stage after reading titles, abstracts, and full papers, and the reasons for exclusions (figure 2). The first and second researchers fully agreed on all the titles and abstracts to be included at these stages, so further discussions were not required. Three authors were contacted and responded to requests for additional information (Azeem et al., 2013; Glidden et al, 2006; Glidden & Natcher, 2009; Hartley et al, 2012). As a result of acquiring further information from the authors, the papers from Glidden and colleagues were excluded from the review, bringing the total number of included studies to 28.

Figure 2: Systematic review flow chart



Of the 28 results, 20 studies (Azar & Badr, 2010; Foster et al., 2010; Gerstein et al, 2009; Giallo et al., 2015; Griffith et al., 2011; Gupta & Kaur, 2010; Hedov et al, 2000; Islam et al, 2013; Marchal et al., 2017; McCarthy et al, 2006; Norlin & Broberg, 2013; Olsson & Hwang, 2002, 2006, 2008; Rowbotham et al., 2011; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008) met the inclusion criteria and had appropriate data for the meta-analysis. The results of the remaining 8 papers which met the systematic review inclusion criteria but were not suitable for a meta-analysis are presented descriptively. Each of the research questions are addressed below with a descriptive analysis, followed by the results of the meta-analysis, where this was possible. A meta-analysis of all relevant papers was conducted first, followed by subgroup analysis. As papers examined different measures of mental health, the included papers which address possible differences in mental health between fathers and other populations were divided into subgroups based on those which measured depression, stress, anxiety, and general mental health. Subgroup analysis was also conducted of the papers which included 50% or more fathers in the study sample. Risk rating scores for each study in the meta-analysis are displayed in Appendix C.

4.3.1 Question 1. Does the mental health and well-being of fathers of a son/daughter with intellectual disabilities differ from: Fathers in the general population?

Regarding the first research question, table 6 presents the nine studies which report the impact of caring on fathers of a son/daughter with intellectual disabilities, compared to fathers in the general population (Emerson et al., 2010; Giallo et al., 2015; Hartley et al., 2012; Hedov et al., 2000; MacDonald et al, 2010; Marchal et al., 2017; Norlin & Broberg, 2013; Olsson & Hwang, 2001, 2006). The outcome measures used in these studies were the Centre for Epidemiologic Studies Depression Scale (Devins & Orme, 1985), the Becks Depression Inventory (Beck et al., 1996), the Swedish version of the SF-36 (Sullivan et al, 1995), the Distress Thermometer for Parents (Haverman et al., 2013), Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995), K6 Scale (Kessler et al., 2002), Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), Questionnaire on Resources and Stress (Friedrich et al, 1983) and the Parental Perceptions Inventory (Hymovich, 1984). These studies were from Australia (N=1), the UK (N=1), Ireland (N=1), Sweden (N=5) and the Netherlands (N=1). Of the included papers, the age of the fathers was reported by Olsson and Hwang (2006) with a mean of 43 years (SD 6.3), Hedov et al (2000) with a mean age of 39.6 years (SD 6.0), Hedov et al (2002) with a mean age of 39.6 (SD 5.9), Marchal et al (2010) with a mean age of 47.8 (SD 5.4), Norlin et al (2013) with a mean age of 35.3 (SD 6.1).

Marchal and colleagues (2017) investigated father distress levels among fathers of children aged 11-13 years old with Down Syndrome. The study found that distress scores were significantly higher for fathers of children with Down Syndrome than controls. In Giallo et al's study (2015), fathers of a son/daughter with intellectual disabilities (aged 3-15 years) reported significantly higher levels of depression and stress, but not anxiety, than normative data for the Australian adult general population. Fathers of children with intellectual disabilities reported higher levels of stress on these three items but showed no significant difference from control fathers on the other seventeen items. Both depression and stress scores were found to be higher in fathers of children with intellectual disabilities by Norlin and colleagues (2013). A study by Emerson (2010) compared fathers of children with severe and less severe cognitive delay to fathers of children with no delay when their child was aged 3 and aged 5. Fathers of children with severe delay were more likely to be at risk of psychiatric disorder than fathers of no delay only when their child was 5 years old. Fathers whose child had less severe delay were more likely to be at risk of psychiatric disorder than fathers of no delay when their child was 3 and 5 years old. MacDonald and colleagues (2010) reported higher depression and anxiety scores among fathers of children aged 6-18 years old with intellectual disability, compared to fathers of children in the general population. In another study, depression scores of fathers of a child under 17 years of age with intellectual disabilities were compared to a general population comparison group in Sweden (Olsson & Hwang, 2006). Results of this comparison found that fathers' depression scores were higher than fathers whose child did not have intellectual disabilities. Hedov et al (2000) measured self-reported mental health in fathers of children with and without Down syndrome aged 3.5 to 7 years of age. Fathers of children with Down syndrome reported significantly worse mental health than fathers of typically developing children. A later study by Hedov et al (2002) reported significant differences between fathers with and without a child with intellectual disabilities on three of twenty stress items.

Only one paper found no significant difference between the mental health and well-being of fathers of children with and without intellectual disabilities. A study by Olsson and Hwang (2001) compared fathers of children under 16 years of age with and without intellectual disabilities. No difference in depression scores was found between groups.

Table 6: Included studies of fathers of a son/daughter with intellectual disabilities vs fathers in the general population

Author & Year	ID Fathers	TD fathers	Son/daughter with ID	Measures	Methodology	Results	Critique
Marchal et al (2017)	N= 44 Age M 47.8 (SD 5.4) The Netherlands	N= 52	N= 44 DS Age 11-13yrs	*ID:* Parent report *Parental Mental Health:* The Distress Thermometer for Parents	Recruited from participation in a medication trial for people with DS Cross sectional study	Total distress: ID M 6.3 (SD 5.9) vs TD M 3.5 (SD 4.8) $p<.05$	CASP Score= C2,2 -ID measure not reported -Level of ID not reported -Only parents of ‘healthy’ children with DS were included, so may not be representative

							-95%CI not reported
Giallo et al (2015)	N= 315 Age not reported Australia	Men and women in general population N=497 Age not reported	N= 315 Age M 7.8 yrs (SD 5.5) 69.8% male ID level: Mild-profound,	*ID*: Measure not reported *Parental Mental Health:* Depression Anxiety and Stress Scale	Recruited from families involved in a previous study (Hudson et al, 2003; 2008). Cross sectional study	Depression: ID M 6.95, SD 7.89 vs TD M 5.02, SD 7.54 $p<.05$ Anxiety: ID M 3.49, SD 5.24 vs TD M 3.36, SD 5.07 $p>.05$ Stress: ID M 11.0, SD 8.24 vs TD M	CASP Score= B3 -Father sample from those enrolled to participate in a child behaviour management programme- so not be representative -Includes children with ID+ASD in the sample

						8.10 SD 8.40 *p*<.05	-Mental health score based on distress in the past week
Norlin et al (2013)	N= 46 ID Age M 35.3 (SD 6.1) Sweden	N= 141 Age M 36.4 (SD 5.8)	N= 58 Age M 41 months (SD 27.8) 62.1% males	*ID:* Not reported *Parental Mental Health:* Becks Depression Inventory	Recruited by staff at service centres for families of children with disabilities Cross sectional study	Depression: ID fathers M -21.5 (SD 11.2) vs TD M -23.3 (SD 12.5) *p*<.05 Stress: ID M 9.9 (SD 8.1) vs TD M	CASP Score= B2 -Did not report ID measure used -Confidence intervals not reported

						5.1 (SD 3.8) *p*<.05	
Emerson et al (2010)	Wave 1: N= 18,552 Wave 2: N= 15,590 families Wave 3: N= 15,246 families Age not reported UK		Wave 1= 9 mths old Wave 2= 3 yrs old Wave 3= 5yrs old	*ID:* Bracken Basic Concept Scale, Naming Vocabulary subscale from British Ability Scale II *Parental Mental Health:* K6 Scale	Secondary data analysis of Millennium Cohort Study (waves 1-3) Families eligible to receive child benefit, born 09/2000 and 01/2002 Longitudinal study	Severe Delay: Risk of psychiatric disorder when child was 5 (ID 14% vs TD 8%, OR=1.82, *p*<.05) Less severe delay: Risk of psychiatric disorder when child was 3 (ID	CASP Score= B3 - Young children in sample so possible not all those with ID have been identified -Follow-up not long enough to identify ID diagnosed later in development

						14% vs TD 7%, OR=1.93, 95%, $p< .05$) and 5 years old (ID 15% vs TD 8%, OR=1.99, $p<.05$).	-Level of ID not reported -Parent age not reported
MacDonald et al (2010)	N= 53 Age not reported Ireland	N= Males from large, community, non-clinical sample of males (Crawford et al. 2001)	N= 99 Age M 11 yrs 10 months (SD 42.85)	*ID:* Not reported *Parental Mental Health:* Parent and Family Problems subscale of	Recruited from ID services Cross sectional study	Depression: ID 7.1% vs TD 2% $p<.05$ Anxiety: ID 10.1% vs TD 8% $p<.05$	CASP Score= B1 -95%CI's not reported -Level of ID not reported -parent age not reported

				Questionnaire on Resources and Stress, Hospital Anxiety and Depression scale			
Olsson et al (2006)	N= 179 Age M 43yrs (SD 6.3) Sweden	N= 196 Age M 42yrs (SD 6.9)	N= 179 Age M 8.1yrs (SD 4.3) 62% males	*ID:* Parent reports *Parental Mental Health:* Beck's Depression Inventory	Recruited from community-based programmes providing services to families of disabled children	Depression: ID M 4.1 (SD 4.8) vs TD M 5.4 (SD 5.7) $p<.05$	CASP Score= B2 -ID measured with parent reports -Level of ID not reported

					Cross sectional study		
Hedov et al (2002)	N= 79 Age M 39.6 (SD 5.9) Sweden	N= 82 Age M 38.3 (SD 5.8)	N= 79 DS Age M 4.7 (SD not reported)	*ID:* Not reported *Parental Mental Health:* Parental Perception Inventory	Recruitment method not reported Cross sectional study	3 of 20 stress items were sig different between ID and TD fathers: 'Extra demands on my time' *p*<0.01 'Feel stress when thinking of child's future' *p*<0.01 'Finding someone to	CASP Score= B3 -Recruitment method not reported -ID measure not reported -95%CI not reported

						stay with child’ $p<.05$	
Olsson et al (2001)	N= 120 Age not reported Sweden	N= 185	N=151 ID Age M 7.4yrs (SD 4.2) 60% males	*ID:* Medical provider’s classification *Parental Mental Health:* Becks Depression Inventory	Recruited from community-based programmes for families of children with disabilities Cross sectional study	Depression: ID M 5 vs TD 4.1 $p>.05$	CASP Score= B2 -Recruited from community programmes so may not represent families not accessing services -Parent age not reported

							-Confidence intervals not reported
Hedov et al (2000)	N= 79 Age M 39.6 (SD 6.0) Sweden	N= 100 Age M 36 (SD 5.6)	N= not reported Age M 4.7yrs (SD not reported)	*ID:* Not reported *Parental Mental Health:* SF 36- mental health domain	Recruited through paediatrician Cross sectional study	General mental health: ID M 79.2 (SD 17.9) vs TD M 87.1 (SD 16) $p<.05$	CASP Score= B1 -Confidence intervals not reported

4.3.2 Father vs General Population Meta-Analysis

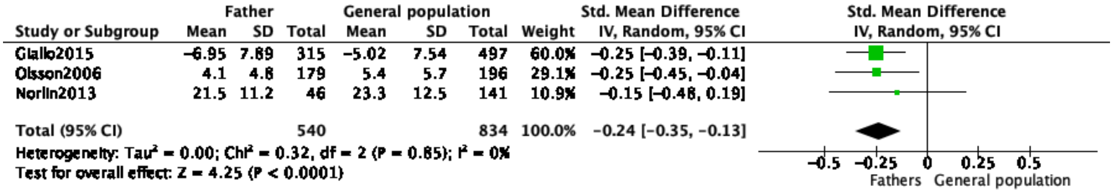
In Emerson's (2010) study, risk of psychiatric disorders rather than specific mental health conditions was reported, making it impossible to compare the results of this paper to the other studies which met our inclusion criteria. Data necessary for conducting a meta-analysis was not available in this paper or MacDonald et al's (2010), Olsson and Hwang's (2001), or Hedov et al's (2002) studies. As the control group in Giallo's (2015) study was the general population of Australian adults, it therefore contained both fathers and mothers and did not report the mental health of fathers in the general population separately. In order to address this issue, a meta-analysis was run including Giallo's study and then run again excluding this paper to determine if the results were significantly affected by its inclusion. There was no significant difference in results following the exclusion of the study. Of the studies which included sufficient data for a meta-analysis, Hedov et al (2000) and Marchal et al (2010) measured general mental health while Olsson and Hwang (2006), Norlin et al (2013) and Giallo et al (2015) measured depression, and so a meta-analysis was conducted separately for each of these types of mental health in fathers of a son/daughter with intellectual disabilities compared to fathers in the general population.

The forest plots below display the results of the meta-analysis. The boxes for each study in the forest plot indicate the size of the sample in that study, with bigger boxes representing a bigger sample size. The line through each box represents the 95% confidence interval. If the horizontal line crosses the line of no effect it indicates that the null value is within the confidence interval, and so could be the true value. Therefore, such a study does not indicate a statistically significant result. The diamond in each forest plot represents the point estimate and confidence interval when the studies are combined and averaged. The vertical points of the diamond show the point estimate while the horizontal point show the width of the confidence interval. As the diamonds (overall effect) do not cross the line of no effect and the results of the tests for overall effect are p<.05 in all of the forest plots, the standardised mean difference between mothers and fathers can be considered statistically significant for each comparison.

Each point on a funnel plot represents the effect estimate of a study in the meta-analysis. Studies with smaller sample sizes should be scattered towards the wider bottom part of the funnel, with larger studies scattered closer together and towards the top pointed section of the plot. In the absence of bias or study heterogeneity, the scatter in the funnel plot will be due to sampling variation and the plot should be shaped like a funnel pointing upwards. This was the case for each funnel plot produced for the analysis, and so it can be concluded that the plots do not indicate significant bias or study heterogeneity.

Figure 3 displays the results of the comparison of depression scores in fathers versus fathers in the general population. The studies by Olsson and Hwang (2006) and Giallo (2015) had statistically significant effects. However, the confidence interval from the Norlin et al (2013) study crossed the line of no effect. The pooled SMD for depression was -0.24 (95% CI -0.45, -0.04; *p*<.001). When Giallo's study was excluded from the analysis the pooled standardised mean difference (SMD) was -0.25 (95% CI -0.39, -0.11, *p*<.001). The overall effect size showed a significant difference between mothers and fathers depression scores, with fathers experiencing higher depression levels. The effect size was small and there was no evidence of statistical heterogeneity between studies in the depression meta-analyses, with I^2=0%.

Figure 3: Forrest plot of father vs general population depression

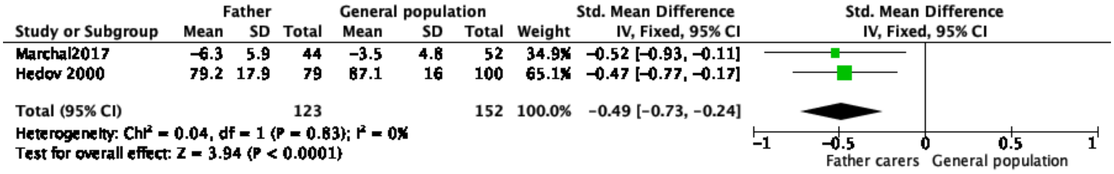


	Father			General population				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Giallo2015	−6.95	7.89	315	−5.02	7.54	497	60.0%	−0.25 [−0.39, −0.11]
Olsson2006	4.1	4.8	179	5.4	5.7	196	29.1%	−0.25 [−0.45, −0.04]
Norlin2013	21.5	11.2	46	23.3	12.5	141	10.9%	−0.15 [−0.48, 0.19]
Total (95% CI)			540			834	100.0%	−0.24 [−0.35, −0.13]

Heterogeneity: $Tau^2 = 0.00; Chi^2 = 0.32, df = 2 (P = 0.85); I^2 = 0\%$
Test for overall effect: Z = 4.25 (P < 0.0001)

Figure 4 displays the results of the comparison of general mental health scores in fathers of a son/daughter with intellectual disabilities versus fathers in the general population. The studies by Hedov et al (2000) and Marchal (2017) had statistically significant effects. The pooled standardised mean difference (SMD) was -0.49 (95% CI -0.73, -0.24, *p*<.001). The effect size was moderate and there was no evidence of statistical heterogeneity between studies, with I^2=0%. The overall effect size showed a significant difference between fathers of a son/daughter with intellectual disabilities and fathers in the general population scores, with fathers of a son/daughter with intellectual disabilities experiencing poorer mental health.

Figure 4: Forrest plot of father vs general population general mental health



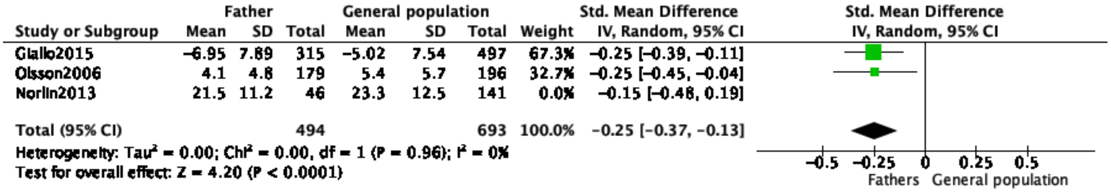
	Father			General population				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI
Marchal2017	−6.3	5.9	44	−3.5	4.8	52	34.9%	−0.52 [−0.93, −0.11]
Hedov 2000	79.2	17.9	79	87.1	16	100	65.1%	−0.47 [−0.77, −0.17]
Total (95% CI)			123			152	100.0%	−0.49 [−0.73, −0.24]

Heterogeneity: $Chi^2 = 0.04$, $df = 1$ ($P = 0.83$); $I^2 = 0\%$

Test for overall effect: $Z = 3.94$ ($P < 0.0001$)

A sub analysis was conducted on studies where fathers made up 50% of the sample to test whether low numbers of fathers in study samples affected the results of the meta-analysis, although this was only possible for the depression meta-analysis. Effect sizes increased slightly for all meta-analyses when these alterations were made. However, these changes did not result in the effect sizes moving to a larger categorisation e.g. from a small effect size to a medium effect size. These results are displayed in figure 5.

Figure 5: Forrest plot of father vs general population depression (sub-analysis)



	Father			General population				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Giallo2015	−6.95	7.89	315	−5.02	7.54	497	67.3%	−0.25 [−0.39, −0.11]
Olsson2006	4.1	4.8	179	5.4	5.7	196	32.7%	−0.25 [−0.45, −0.04]
Norlin2013	21.5	11.2	46	23.3	12.5	141	0.0%	−0.15 [−0.48, 0.19]
Total (95% CI)			494			693	100.0%	−0.25 [−0.37, −0.13]

Heterogeneity: $Tau^2 = 0.00$; $Chi^2 = 0.00$, $df = 1$ ($P = 0.96$); $I^2 = 0\%$

Test for overall effect: $Z = 4.20$ ($P < 0.0001$)

4.3.3 Mothers and fathers of a son/daughter with intellectual disabilities?

The 21 studies presented in table 7 compared the mental health and well-being of mothers and fathers with a son/daughter with intellectual disabilities (Azar & Badr, 2010; Azeem et al., 2013; Dabrowska & Pisula, 2010; Foster et al., 2010; Giallo et al., 2015; Griffith et al., 2011; Gupta & Kaur, 2010; Hedov et al, 2002; Hedov et al., 2000; Islam et al., 2013; Marchal et al., 2017; McCarthy et al., 2006; Norlin & Broberg, 2013; Olsson & Hwang, 2001, 2002, 2006, 2008; Rowbotham et al., 2011; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008).

The studies took place in Pakistan (N=1), Sweden (N=7), Poland (N=1), the Netherlands (N=1), India (N=3), Lebanon (N=1), Australia (N=3), the United Kingdom (N=1), and the United States of America (N=3). Age was not reported for six of these studies (Gerstein et al., 2009; Giallo et al., 2015; Gupta & Kaur, 2010; Islam et al., 2013; Olsson & Hwang, 2001, 2002), while the others reported that the majority of parents were in their 30s and 40s.

The outcome measures used in these studies were The Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995), DSM criteria for anxiety and depression, General Health Questionnaire (Goldberg, 1981), Hassles and Uplifts Scale (De Longis et al, 1988), Parenting Daily Hassles Measure (Gavidia-Payne et al, 1997), Symptom Checklist-35 (Derogatis, 1993), Family Interview for Stress and Coping in Mental Retardation (Girimaji, 1999), Centre for Epidemiologic Studies Depression Scale (Devins & Orme, 1985), Questionnaire on Resources and Stress (Holroyd, 1987), Becks Depression Inventory (Beck et al., 1996), Hospital Anxiety and Depression Scale (Griffith et al., 2011), Short Form Health Survey-36 (Sullivan et al., 1995), the Distress Thermometer for Parents (Haverman et al., 2013), Quick Stress Assessment Test (Van, 1995) and the Parental Perception Inventory (Hymovich, 1984).

Sixteen of these studies reported significantly poorer mental health and well-being for mothers compared to fathers of individuals with intellectual disabilities, the majority of which were from countries of western culture. In Giallo's (2015) Australian study, mothers reported significantly higher depressive, anxiety and stress scores than fathers. Mothers of young children with intellectual disabilities (average age of 41 months) were also found to have lower overall well-being than fathers in Norlin's (2013) study. Mothers in Gerstein and colleagues' (2009) study of children with intellectual disabilities reported significantly higher stress scores than fathers when their child was 48 months and 60 months. Similarly, significant differences in mental health scores were found between mothers and fathers of children with Down Syndrome in Dabrowska and colleagues' (2010) study. In Stoneman's (2007) study, mothers of a child with Down Syndrome did not report significantly higher rates of depression and stress than fathers, although a significant difference was apparent for parents of children with other types of intellectual disabilities. A study of parents of children with Smith-Magenis Syndrome found moderate to high levels of depression and anxiety among both parents (Foster et al., 2010). Fathers in this sample had significantly better general mental health, but levels of anxiety and depression were not significantly different from mothers. However, this sample only contained 13 fathers to 90 mothers, which may account for these results.

A number of studies in Sweden by Olsson and Hwang also found poorer mental health in mothers than fathers. Mothers of children aged 5 years and under with intellectual disabilities had lower levels of well-being than fathers (Olsson & Hwang, 2008). Mother well-being was also more affected than father well-being when there was a young child with intellectual disabilities in the family (Olsson & Hwang, 2006). A third study by the authors found that mothers of children aged 16 years old and younger with intellectual disabilities had higher depression scores than fathers (Olsson & Hwang, 2002). A final study by Olsson and Hwang also found that mothers of children under 16 years of age had higher depression scores than fathers (Olsson & Hwang, 2001). Another Swedish study also reported that fathers and mothers of children aged 3.5 to 7 years of age with Downs Syndrome had poorer mental health scores (Hedov et al., 2000). A later study by Hedov and colleagues found significant differences between mothers and fathers on two of twenty stress items, although no other differences were significant (Hedov et al., 2002).

A number of studies in the Middle East and Asia also identified significant differences between the mental health of mothers and fathers. Azeem and colleagues (2013) reported that a significantly higher proportion of mothers in Pakistan had anxiety, depression or both compared to fathers of a child with intellectual disabilities aged 2 to 18 years of age. A large study of families with a son/daughter with intellectual disabilities in India, aged 4 to 30 years of age, (Upadhyaya & Havalappanavar, 2008) found that mothers experienced significantly higher stress than fathers. A further study from India reported significant differences in stress levels in mothers of children aged 9-15 years of age, compared to fathers (Gupta & Kaur, 2010). Islam et al (2013) also found significant difference between stress scores for mothers and fathers of children with intellectual disabilities in India.

Rowbotham and colleagues (2011) reported a different pattern. Their study found no significant difference in mental health scores between mothers and fathers of a child with intellectual disabilities. However, this was a small study of only twelve families and so may not be representative of other families in Australia. The children included in this study may also not be representative of those who exhibit challenging behaviour, a factor associated with parental well-being, as their adaptive and problem behaviour scores generally fell within the normal range. This may indicate that the children had milder intellectual disabilities than children in the other samples included in this review, although level of intellectual disabilities was not reported in this paper.

Four other studies found similar mental health scores for mothers and fathers in their sample. Stress and general mental health were found to be similar in a study which focussed on mothers and fathers of children with Fragile X Syndrome, with no significant differences between groups (McCarthy et al., 2006). Marchal and colleagues (2017) also reported no significant difference in levels of overall distress for mothers and fathers of children with Down Syndrome. A study in Lebanon by Azar and colleagues (2010) found no significant difference in stress levels between mothers and fathers. High levels of stress were reported by both parents in this study. Griffith and colleagues' (2011) study of children aged 2-19 years with a range of intellectual disabilities did not find significantly poorer mental health for mothers than fathers. In general, these studies contained small sample sizes and so the parents in the samples may not be representative of fathers and mothers in the population of parents with a child with intellectual disabilities. For example, Giffith's (2011) study divided parents into small groups by type of intellectual disability, with less than 15 fathers per group. However, the main differences between the studies which found significant gender effect on mental health and those which did not was their quality ratings. The sixteen papers which reported significant differences in mental health scores had an average quality rating of B2, while the five papers which reported no significant differences had an average quality rating of B5. Therefore, higher quality papers did generally detect a difference in mental health, with mothers experiencing poorer mental health than fathers.

Table 7: Included studies of mothers vs fathers of a son/daughter with intellectual disabilities

Author & Year	Fathers	Comparison Group	Son/daughter with ID	Measures	Methodology	Results	Critique
Marchal et al (2017)	N= 44 Age M 47.8 (SD 5.4) The Netherlands	N= 76 Age M 45.9 (SD 4.1)	N= 86 11-13 yrs ID level not reported	*ID:* Not reported *Parental Mental Health:* The Distress Thermometer for Parents	Recruited from participation in a medication trial for people with DS Cross sectional study	Distress: Mother M 7.5 (SD 6.7) vs father M 6.3 (SD 5.9) *p*>.05	CASP Score= C2,2 -A healthy subgroup of children with DS were used -ID measure not reported -Leve of ID not reported -95%CI not reported
Giallo et al (2015)	N= 315 Age not reported	From same family (subset of N=110)	N= 315 Age M 7.8 yrs (SD 5.5)	*ID:* Not reported *Parental Mental Health*:	Recruited from a previous study (Hudson et al, 2003; 2008).	Depression: Mother M 6.95 (SD 7.89) vs father M 5.02 (SD 7.54) *p*<.05	CASP Score= B3 -Sample from those enrolled in a child behaviour

	Australia	Age not reported	69.8% male ID level: mild-profound	Depression Anxiety and Stress Scale, Parenting Hassles Scale	Cross sectional study	Anxiety: Mother M 3.49 (SD 5.24) vs father M 3.36 (SD 5.07) $p<.05$ Stress: Mother M 11.0 (SD 8.24)vs father M 8.10 (SD 8.40) $p<.05$	management programme- so not representative -Includes children with ID+ASD in the sample -Mental health score based on distress in the past week
Azeem et al (2013)	N= 99 Age M 42.9yrs (SD 8.8) (99 married couples)	N= 99 Age M 37.4yrs (SD 8.8)	N= 100 Age M 10.5yrs (SD 5) 30% male	*ID:* Slosson IQ Test *Parental Mental Health:* DSM-IV criteria by	Recruited from health centres Cross sectional study	Sig higher proportion of mothers had anxiety, depression or both compared to fathers $p<0.05$	CASP Score= B3 -95%CI's not reported -Different combinations of comorbidities are not separately reported. -Type of ID not specified

	Pakistan		ID: Mild-profound	trained psychologist			
Islam et al (2013)	N= 40 Age not reported India	N= 70 Age not reported	N= Not reported Age not reported	*ID:* Not reported *Parental Mental Health:* Quick Stress Assessment Test	Recruited from ID schools and organisations Cross sectional study	Stress: Mother M 31.56 (SD 12.47) vs father M 34.27 (SD 11.7), *p*<.05	CASP Score= B5 -ID measure not reported -Parent and child age not reported -95%CI not reported
Norlin et al (2013)	N= 46 Age M 35.3 (SD 6.1) Sweden	N= 58 Age M 34.0 (SD 5.3)	N= 58 Age M 41 months (SD 27.8) 62.1% males	*ID:* Not reported *Parental Mental Health:* BDI-2r	Recruited at service centres for families of children with disabilities	Depression Mothers M -12.4 (SD 3.8) vs fathers M -21.5 (SD 11.2), *p*<.01	CASP Score= B2 -Did not report ID measure used -95%CIs not reported

					Cross sectional study	Stress Mothers M 10.8 (SD 8.2) vs fathers 9.9 (SD 8.1) $p>.05$	
Griffiths et al (2011)	N= 39 Angelman syndrome= 12 Age M 42.38 (SD 4.82) Cornelia de Lange syndrome= 14	N= 47 Angelman syndrome= 14 Age M 41.79 (SD 6.04) Cornelia de Lange syndrome= 15	Angelman syndrome N= 15 Age M 10.07 (4.79) Cornelia de Lange syndrome N= 16 Age M 11.75 (SD 3.49)	*ID:* Vineland adaptive behaviour scale *Parental Mental Health:* Questionnaire on Resources and Stress-Short form	Recruited from a database held by research team, and national parent support groups Cross sectional study	Anxiety: Angelman syndrome Mother M 11.71 (SD 3.97) vs father 10.42 (SD 4.72) $p>.05$ Cornelia de Lange Mother M 8.93 (SD 4.73) vs father 5.85 (SD 4.35) $p>.05$ Cri du Chat	CASP Score= B3 -Level of ID not reported -95%CIs not reported -Small number of fathers in sample

	Age M 47.6 (SD 10.38) Cri du chat syndrome= 13 Age M 41.92 (SD 4.92) UK	Age M 47.31 (SD 8.90) Cri du chat syndrome= 18 Age M 39.56 (SD 5.22)	Cri du chat syndrome N= 18 Age M 7.83 (SD 4.66)			Mother M 9.49 (SD 2.90) vs father M 9.0 (SD 4.16) *p*>.05 Depression: Angleman syndrome Mother M 8.57 (SD 3.08) vs father M 8.50 (SD 4.49) *p*>.05 Cornelia de Lange Mother M 7.30 (5.03) vs father M 4.29 (SD 2.62) *p*>.05 Cri du Chat Mother M 7.36	

						(3.42) vs father M 6.92 (SD 4.09) $p>.05$ Stress: Angleman syndrome Mother M 26.31 (SD 8.17) vs father M 20.75 (SD 10.07) $p>.05$ Cornelia de Lange Mother M 19.76 (8.78) vs father M 16.18 (SD 98.67) $p>.05$ Cri du Chat Mother M 20.94 (7.23) vs father M	

						16.68 (SD 5.52) *p*>.05	
Rowbotham et al (2011)	N= 12 45- 55 yrs Australia	N= 12 (from same family) 45-55 yrs	N= 12 Age M 24yrs (SD not reported) 58% females	ID: Adaptive Behavioural Scale Parental Mental Health: General Health Questionnaire-28	Recruited through public and private-sector groups providing services to carers of adults with intellectual disabilities Cross sectional study	Depression: Father M 1.33 (SD 2.10), mother M 1.33 (SD 0.89) *p*>.05 Anxiety/Insomnia: Father M 4.83 (SD 3.07) mother M 4.00 (SD 2.97) *p*>.05	CASP Score= B4 -Small sample of parents known to services -Parents carried out ID measure -Level of ID not reported -95%CI not reported
Azar et al (2010)	N= 46	N= 101	N= 147 Age 5-12	*ID:* Not reported	Recruited from special education centres	Stress: Mother M 92.97 (SD 24.72) vs	CASP Score= B3 -ID measure not reported

	Age M 47.70 (SD 14.33) Lebanon	Age M 39.79 (SD 7.39)	ID level: mild-severe	*Parental Mental Health:* Parenting Stress Index	Cross sectional study	father M 92.62 (SD 23.69) $p > .05$	-95%CI not reported
Dabrowska et al (2010)	N= 27 Age M 34.9 (SD 6.1) Poland	N= 27 Age M 32.8 (SD 6.1)	N not reported Males age M 4.3 (SD 1.58) Females age M 4.3 (SD 1.48) 55.6% males	*Parental Mental Health:* Questionnaire of Resources and Stress, Coping Inventory for Stressful Situations	Recruited from centres for early intervention, therapy centres or kindergartens Cross sectional study	Mothers experienced higher stress levels than fathers $p < .05$	CASP Score= B3 -95%CI not reported -Small sample size -Level of ID not reported -Young children in sample so possible not all those with ID have been identified.

Foster et al (2010)	N= 15 Age M 42.07yrs (SD 9.85) USA	N= 97 Age M 41.36yrs (SD 9.6)	N= Not reported	*ID:* Not reported *Parental Mental Health:* Center for epidemiologic studies depression scale, Becks Anxiety Inventory, Caregiver well-being scale	Recruited through parent and researcher Smith-Magenis syndrome list serve Cross sectional study	Depression: Fathers M 43.7 (SD 12.2) vs mothers M 36.7 (SD 11.6) $p>.05$ Anxiety: Fathers M 31.8 (SD 9.2) vs mothers M 30.9 (SD 8.5) $p>.05$ General mental health: Fathers M 135.8 (SD 21.5) vs mothers M154.0 (SD 27.0)	CASP Score= C1,2 -Very small number of fathers in sample -95%CI not reported -Level of ID not reported

						$p<.05$	
Gupta et al (2010)	N= 35 Age not reported India	N= 30 Age not reported	N= Not reported Age 9-15 yrs	*ID:* Not reported *Parental Mental Health:* Quick Stress Assessment Test	Recruited from schools for children with ID Cross sectional study	Stress: Mother M 18.13 (SD 7.270) vs father M 15.07 (SD 7.680), $p<0.05$	CASP Score= B3 -Parent age not reported -ID measure not reported -95%CI not reported
Gerstein et al (2009)	N= 115 Age not reported (married couples)	N= 115 Age not reported	N= 115 3yrs old	*ID:* Bayley Scales of Infant Development II *Parent Mental Health:*	Recruited from community agencies serving families of children with ID Longitudinal study	Mothers reported higher Parenting Daily Hassles score than fathers at 48 [t(80)=3.366, $p<0.001$] and 60 months	CASP Score=B2 -Level of ID not reported -Parental age not reported -95%CI not reported

	USA			Parenting Daily Hassles measure		[t(72)=3.462, *p*<0.001]	
Olsson et al (2008)	N= 49 Age M 36.2yrs (SD 6.4) Sweden	N= 62 Age M 34.8yrs (SD 6.0)	N= 62 0-5yrs	*ID:* Reported by centres *Parental Mental Health:* Beck's Depression Inventor-2r	Recruited from centres providing support to families of children with disabilities Cross sectional study	Depression: Mothers M -21.4 (SD 10.9) vs fathers M -12.4 (SD 13.9) *p*<0.01	CASP Score= B1 -95%CI not reported
Upadhyaya (2008)	N= 628	N= 628 Age <35-74	N= 628 Age 4-30 yrs	*ID*:	Recruited from those who attended the	Stress: Father M 50.00 (SD 8.183), mother M	CASP Score= B2 -Parent mean age not reported

	Age <35-71 India		61.6% male	Binet-Kamath test of intelligence *Parental Mental Health:* Family interview for stress and coping in mental retardation	Karnataka Institute of Mental Health, Dharwad, during the year 2002 and 2003. Cross sectional study	54.98 (SD 10.34), t=9.48, *p*<0.001	-95%CI not reported -Level of ID not reported
Stoneman et al (2007)	N=50 Age M 37 yrs (SD 6.9)	N= 50 Age M 34yrs (SD 5.7)	N= 50 (29 DS, 21 other ID)	*ID:* Not reported, Temperament Assessment Battery	Recruited from early intervention programmes, pre-schools, parent groups and	Depression: DS mother M 7.43 (SD 6.09) vs father M 6.24 (SD 5.34) *p*>.05	CASP Score= B3 -ID measure and level of ID not reported -Comparison group contains

	(married couples) USA		Age 4.8yrs (SD not reported) 50% Male	*Parental Mental Health:* Centre for Epidemiologic Studies Depression Scale, Questionnaire on Resources and Stress, Family Support Scale	referrals from community members. Cross sectional study	Other ID mother M 15.35 (SD 10.13) vs father M 10.47 (SD 9.15) $p<.05$	some children with autism -95%CI not reported
McCarthy el al (2006)	N= 28	N= 39	N= 40	*ID* Reported by family	Recruited from Fragile X society	Depression: Mother M 52.77 (SD 9.93) vs father	CASP Score= B2 -Level of ID not reported -95%CI not reported

	Age M 41.5yrs (SD 6.91) Australia	Age M 39.8yrs (SD 5.3)	Age M 10.4yrs (SD 3.59)	*Parental Mental Health:* Brief Symptom Inventory, Questionnaire on Resources and Stress	Cross sectional study	M 54.93 (SD 9.14) *p*>.05 Stress: Mother M 19.87 (SD 9.11) vs father M 18.18 (SD 8.55) *p*>.05	-Parents reported on child with highest support needs
Olsson et al (2006)	N= 179 mean age 43yrs (SD 6.3) (married couples)	N= 179 mean age 39.8yrs (SD 6.2)	N= 179 Age M 8.1yrs (SD 4.3) 62% males	*ID:* Parent reports *Parental Mental Health:* Beck's Depression Inventory	Recruited from community-based programmes providing services to families of disabled children	Mother well-being was more affected than fathers p<0.05	CASP Score= B2 -ID measured with parent reports -Level of ID not reported -95%CI not reported

	Sweden				Cross sectional study		
Hedov et al (2002)	N= 70 Age M 39.6 (SD 5.9) Sweden	N= 86 Age M 37.6 (SD 5.5)	N= Not reported Age 3.5-7 yrs	*ID*: Not reported *Parental Mental Health:* Parental Perception Inventory	Recruitment method not reported Cross sectional study	2 of 20 stress items were sig different between mothers and fathers 'Feeling worn out' was higher in mothers, $p<0.05$ 'Concerned for spouses health' was higher in fathers, $p<0.05$	CASP Score= B3 -Recruitment method not reported -ID measure not reported -95%CI not reported
Olsson et al (2002)	N= 115 Age not reported	N= 144 Age not reported	N= 151 Age M 7.4yrs (SD 4.2)	*ID:* Parent reports	Recruited from community based programmes for	Depression: Mothers M 9.2 (SD 7.4) vs fathers M 5.1 (SD 5.0) $p<0.01$	CASP Score= B2 -ID measured through parent reports -95%CI not reported

	Sweden		60% males	*Parental Mental Health:* Becks depression inventory	families of disabled children Cross sectional study		
Olsson et al (2001)	N= 120 Age not reported Sweden	N= 145 Age not reported	N=151 Age M 7.4yrs (SD 4.2) 60% males	*ID:* Medical provider's classification *Parental Mental Health*: Becks Depression Inventory	Recruited from community-based programmes for families of children with disabilities Cross sectional study	Depression: Father M 5 vs mother M 9.2, $p<.05$	CASP Score= B2 -Recruited from community programmes so may not represent families not accessing services -Parents age not reported -95%CI not reported
Hedov et al (2000)	N= 79	N= 86	N= not reported	*ID:* Not reported	Recruited through paediatrician	General mental health:	CASP Score= B1 -95%CI not reported

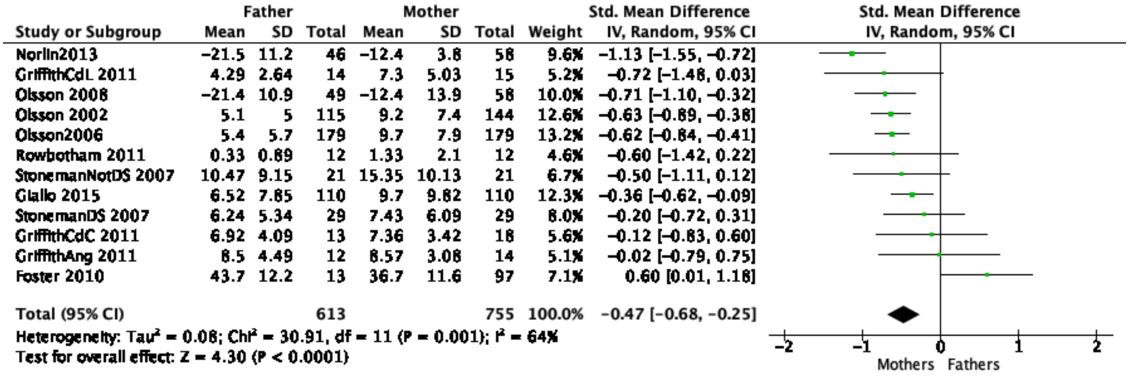
	Age M 39.6 (SD 6.0) Sweden	Age M 37.8 (SD 5.0)	Age M 4.7yrs (SD not reported)	*Parental Mental Health:* SF 36 mental health domain	Cross sectional study	Fathers M 79.2 (SD 17.9) vs mothers M 74 (SD 18.2) *p*<.05	

4.3.4 Father vs Mother Meta-Analysis

Studies by Azeem et al (2013), Dabrowska and Pisula (2010), Hedov et al (2002), and Olsson and Hwang (2001) were not included in the meta-analysis as the necessary data was not provided in the paper. All other relevant papers were included in the following meta-analysis. As the studies focussed on different mental health conditions (depression, anxiety, stress, general mental health and well-being), separate analyses were conducted to compare studies which reported each of these conditions individually.

Figure 6 displays the results of the comparison of depression scores in fathers versus mothers. The studies by Foster (2010), Giallo (2015), Norlin (2013), and Olsson and Hwang (2002, 2006, 2008) had statistically significant effects. However, the other studies crossed the line of no effect. The pooled standardised mean difference (SMD) for was -0.47 (95%CI -0.68, -0.25; *p*<.001). For the depression meta-analysis, the I^2=64% and so there is a moderate level of heterogeneity between studies. The overall effect size showed a significant difference between mothers and fathers depression scores. From this we can say mothers experienced higher levels of depression than fathers.

Figure 6: Forrest plot of father vs mother depression



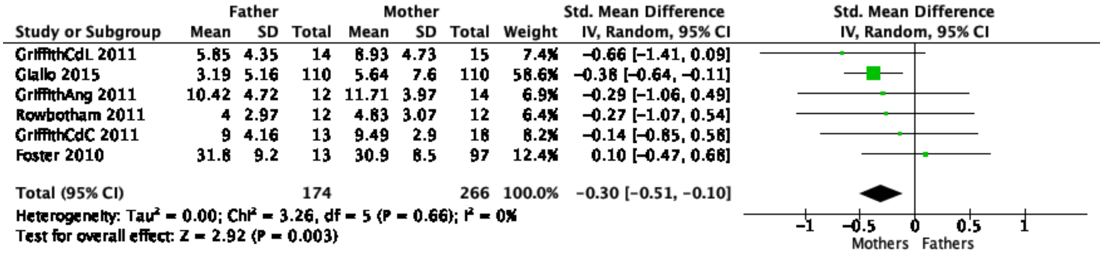
	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Norlin2013	−21.5	11.2	46	−12.4	3.8	58	9.6%	−1.13 [−1.55, −0.72]
GriffithCdL 2011	4.29	2.64	14	7.3	5.03	15	5.2%	−0.72 [−1.48, 0.03]
Olsson 2008	−21.4	10.9	49	−12.4	13.9	58	10.0%	−0.71 [−1.10, −0.32]
Olsson 2002	5.1	5	115	9.2	7.4	144	12.6%	−0.63 [−0.89, −0.38]
Olsson2006	5.4	5.7	179	9.7	7.9	179	13.2%	−0.62 [−0.84, −0.41]
Rowbotham 2011	0.33	0.89	12	1.33	2.1	12	4.6%	−0.60 [−1.42, 0.22]
StonemanNotDS 2007	10.47	9.15	21	15.35	10.13	21	6.7%	−0.50 [−1.11, 0.12]
Giallo 2015	6.52	7.85	110	9.7	9.82	110	12.3%	−0.36 [−0.62, −0.09]
StonemanDS 2007	6.24	5.34	29	7.43	6.09	29	8.0%	−0.20 [−0.72, 0.31]
GriffithCdC 2011	6.92	4.09	13	7.36	3.42	18	5.6%	−0.12 [−0.83, 0.60]
GriffithAng 2011	8.5	4.49	12	8.57	3.08	14	5.1%	−0.02 [−0.79, 0.75]
Foster 2010	43.7	12.2	13	36.7	11.6	97	7.1%	0.60 [0.01, 1.18]
Total (95% CI)			613			755	100.0%	−0.47 [−0.68, −0.25]

Heterogeneity: $Tau^2 = 0.08; Chi^2 = 30.91, df = 11 (P = 0.001); I^2 = 64\%$

Test for overall effect: $Z = 4.30 (P < 0.0001)$

Figure 7 displays the results of the comparison of anxiety scores in fathers versus mothers. The study by Giallo (2015), had statistically significant effects. However, the other studies crossed the line of no effect. The SMD showed a small effect size -0.30 (95%CI -0.51, -0.10; *p*<.01). There was no evidence of statistical heterogeneity between studies, with I^2=0%. This indicates that mothers experienced higher levels of anxiety than fathers.

Figure 7: Forrest plot of mother vs father anxiety



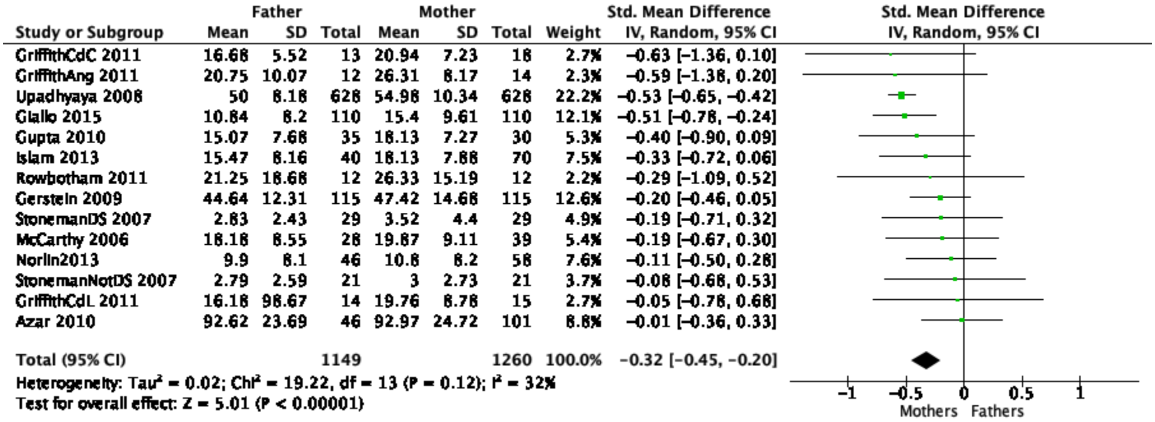
	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
GriffithCdL 2011	5.85	4.35	14	8.93	4.73	15	7.4%	−0.66 [−1.41, 0.09]
Giallo 2015	3.19	5.16	110	5.64	7.6	110	58.6%	−0.38 [−0.64, −0.11]
GriffithAng 2011	10.42	4.72	12	11.71	3.97	14	6.9%	−0.29 [−1.06, 0.49]
Rowbotham 2011	4	2.97	12	4.83	3.07	12	6.4%	−0.27 [−1.07, 0.54]
GriffithCdC 2011	9	4.16	13	9.49	2.9	18	8.2%	−0.14 [−0.85, 0.58]
Foster 2010	31.8	9.2	13	30.9	8.5	97	12.4%	0.10 [−0.47, 0.68]
Total (95% CI)			174			266	100.0%	−0.30 [−0.51, −0.10]

Heterogeneity: Tau² = 0.00; Chi² = 3.26, df = 5 (P = 0.66); I² = 0%

Test for overall effect: Z = 2.92 (P = 0.003)

The results of the stress meta-analysis are displayed in figure 8. Studies by Giallo (2015) and Upadhyaya (2008) showed statistically significant effects, while all other studies crossed the line of no effect. The SMD for stress was small -0.32 (95%CI -0.45, -0.20; *p*<.001). The I^2=32% for stress and so there is a small level of heterogeneity between studies. The results show that mothers reported higher levels of stress than fathers.

Figure 8: Forrest plot of father vs mother stress



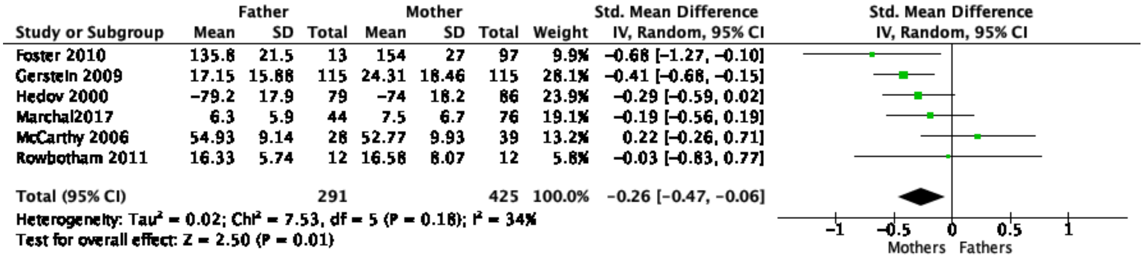
	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
GriffithCdC 2011	16.68	5.52	13	20.94	7.23	18	2.7%	−0.63 [−1.36, 0.10]
GriffithAng 2011	20.75	10.07	12	26.31	8.17	14	2.3%	−0.59 [−1.38, 0.20]
Upadhyaya 2008	50	8.18	628	54.98	10.34	628	22.2%	−0.53 [−0.65, −0.42]
Giallo 2015	10.84	8.2	110	15.4	9.61	110	12.1%	−0.51 [−0.78, −0.24]
Gupta 2010	15.07	7.68	35	18.13	7.27	30	5.3%	−0.40 [−0.90, 0.09]
Islam 2013	15.47	8.16	40	18.13	7.88	70	7.5%	−0.33 [−0.72, 0.06]
Rowbotham 2011	21.25	18.68	12	26.33	15.19	12	2.2%	−0.29 [−1.09, 0.52]
Gerstein 2009	44.64	12.31	115	47.42	14.68	115	12.6%	−0.20 [−0.46, 0.05]
StonemanDS 2007	2.83	2.43	29	3.52	4.4	29	4.9%	−0.19 [−0.71, 0.32]
McCarthy 2006	18.18	8.55	28	19.87	9.11	39	5.4%	−0.19 [−0.67, 0.30]
Norlin2013	9.9	8.1	46	10.8	8.2	58	7.6%	−0.11 [−0.50, 0.28]
StonemanNotDS 2007	2.79	2.59	21	3	2.73	21	3.7%	−0.08 [−0.68, 0.53]
GriffithCdL 2011	16.18	98.67	14	19.76	8.78	15	2.7%	−0.05 [−0.78, 0.68]
Azar 2010	92.62	23.69	46	92.97	24.72	101	8.8%	−0.01 [−0.36, 0.33]
Total (95% CI)			1149			1260	100.0%	−0.32 [−0.45, −0.20]

Heterogeneity: Tau² = 0.02; Chi² = 19.22, df = 13 (P = 0.12); I² = 32%

Test for overall effect: Z = 5.01 (P < 0.00001)

Finally, figure 9 displays the results of the comparison of general mental health scores in fathers versus mothers. The studies by Foster (2010) and Gerstein (2009), had statistically significant effects. However, the remaining studies all crossed the line of no effect. The SMD showed a small effect size was -0.26 (95%CI -0.47, -0.06, *p*<.001). There was evidence of a small degree of statistical heterogeneity between studies, with I^2=34%. This result shows that mothers experienced poorer mental health than fathers.

Figure 9: Forrest plot of father vs mother general mental health

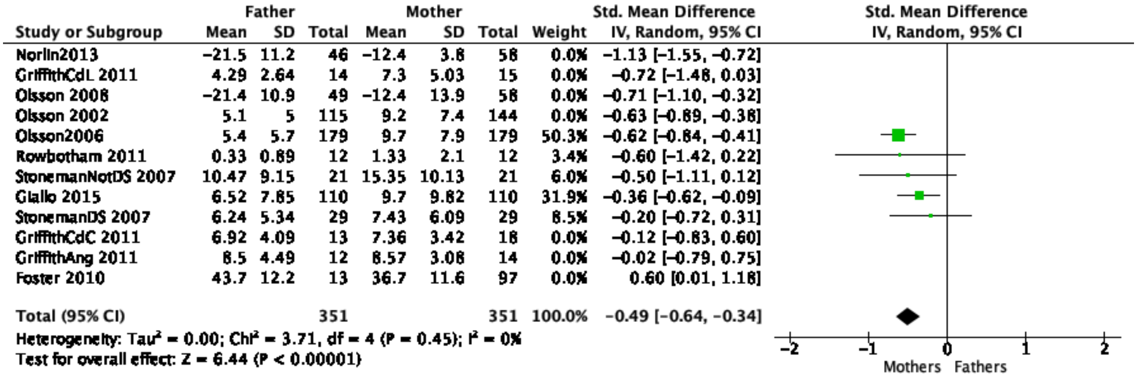


	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Foster 2010	135.8	21.5	13	154	27	97	9.9%	−0.68 [−1.27, −0.10]
Gerstein 2009	17.15	15.88	115	24.31	18.46	115	28.1%	−0.41 [−0.68, −0.15]
Hedov 2000	−79.2	17.9	79	−74	18.2	86	23.9%	−0.29 [−0.59, 0.02]
Marchal2017	6.3	5.9	44	7.5	6.7	76	19.1%	−0.19 [−0.56, 0.19]
McCarthy 2006	54.93	9.14	28	52.77	9.93	39	13.2%	0.22 [−0.26, 0.71]
Rowbotham 2011	16.33	5.74	12	16.58	8.07	12	5.8%	−0.03 [−0.83, 0.77]
Total (95% CI)			291			425	100.0%	-0.26 [-0.47, -0.06]

Heterogeneity: $\mathrm{Tau}^2 = 0.02$; $\mathrm{Chi}^2 = 7.53$, df = 5 ($P = 0.18$); $I^2 = 34\%$
Test for overall effect: $Z = 2.50$ ($P = 0.01$)

A sub analysis was conducted on studies where fathers made up 50% of the sample to test whether low numbers of fathers in study samples affected the results of the meta-analysis, and the results are displayed in figures 10-13. The pooled standardised mean difference (SMD) for depression between father and mother carers changed from -0.47 to -0.49, from -0.30 to -0.36 for anxiety, from -0.32 to -0.39 for stress, and from -0.26 to -0.38 for general mental health. Effect sizes increased slightly for all meta-analyses when these alterations were made. However, these changes did not result in the effect sizes moving to a larger categorisation e.g. from a small effect size to a medium effect size.

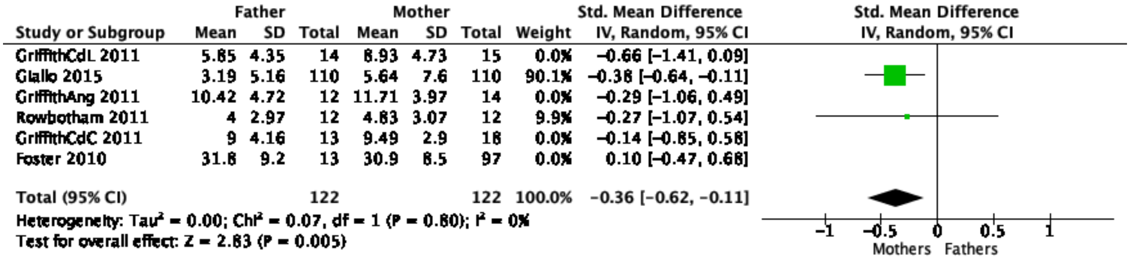
Figure 10: Forrest plot of father vs mother depression (sub-analysis)



	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Norlin2013	−21.5	11.2	46	−12.4	3.8	58	0.0%	−1.13 [−1.55, −0.72]
GriffithCdL 2011	4.29	2.64	14	7.3	5.03	15	0.0%	−0.72 [−1.48, 0.03]
Olsson 2008	−21.4	10.9	49	−12.4	13.9	58	0.0%	−0.71 [−1.10, −0.32]
Olsson 2002	5.1	5	115	9.2	7.4	144	0.0%	−0.63 [−0.89, −0.38]
Olsson2006	5.4	5.7	179	9.7	7.9	179	50.3%	−0.62 [−0.84, −0.41]
Rowbotham 2011	0.33	0.89	12	1.33	2.1	12	3.4%	−0.60 [−1.42, 0.22]
StonemanNotDS 2007	10.47	9.15	21	15.35	10.13	21	6.0%	−0.50 [−1.11, 0.12]
Giallo 2015	6.52	7.85	110	9.7	9.82	110	31.9%	−0.36 [−0.62, −0.09]
StonemanDS 2007	6.24	5.34	29	7.43	6.09	29	8.5%	−0.20 [−0.72, 0.31]
GriffithCdC 2011	6.92	4.09	13	7.36	3.42	18	0.0%	−0.12 [−0.83, 0.60]
GriffithAng 2011	8.5	4.49	12	8.57	3.08	14	0.0%	−0.02 [−0.79, 0.75]
Foster 2010	43.7	12.2	13	36.7	11.6	97	0.0%	0.60 [0.01, 1.18]
Total (95% CI)			351			351	100.0%	-0.49 [-0.64, -0.34]

Heterogeneity: $\mathrm{Tau}^2 = 0.00$; $\mathrm{Chi}^2 = 3.71$, df = 4 ($P = 0.45$); $I^2 = 0\%$
Test for overall effect: $Z = 6.44$ ($P < 0.00001$)

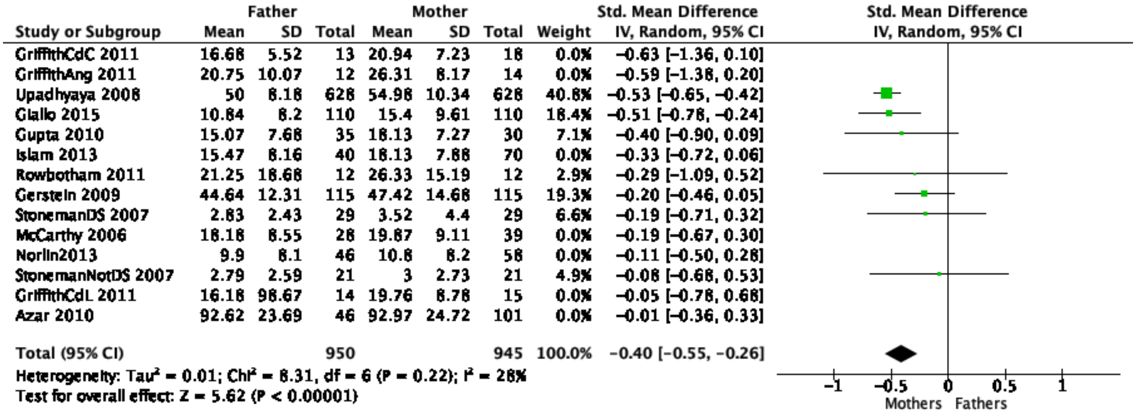
Figure 11: Forrest plot of father vs mother anxiety (sub-analysis)



	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
GriffithCdL 2011	5.85	4.35	14	8.93	4.73	15	0.0%	−0.66 [−1.41, 0.09]
Giallo 2015	3.19	5.16	110	5.64	7.6	110	90.1%	−0.38 [−0.64, −0.11]
GriffithAng 2011	10.42	4.72	12	11.71	3.97	14	0.0%	−0.29 [−1.06, 0.49]
Rowbotham 2011	4	2.97	12	4.83	3.07	12	9.9%	−0.27 [−1.07, 0.54]
GriffithCdC 2011	9	4.16	13	9.49	2.9	18	0.0%	−0.14 [−0.85, 0.58]
Foster 2010	31.8	9.2	13	30.9	8.5	97	0.0%	0.10 [−0.47, 0.68]
Total (95% CI)			122			122	100.0%	-0.36 [-0.62, -0.11]

Heterogeneity: $\mathrm{Tau}^2 = 0.00$; $\mathrm{Chi}^2 = 0.07$, df = 1 ($P = 0.80$); $I^2 = 0\%$
Test for overall effect: $Z = 2.83$ ($P = 0.005$)

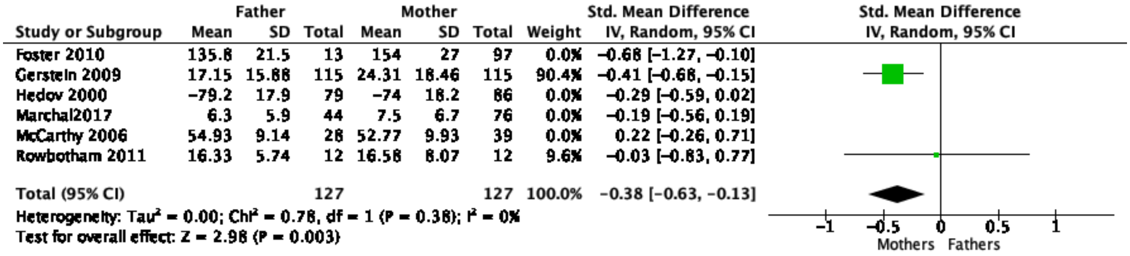
Figure 12: Forrest plot of father vs mother stress (sub-analysis)



	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
GriffithCdC 2011	16.68	5.52	13	20.94	7.23	18	0.0%	−0.63 [−1.36, 0.10]
GriffithAng 2011	20.75	10.07	12	26.31	8.17	14	0.0%	−0.59 [−1.38, 0.20]
Upadhyaya 2008	50	8.18	628	54.98	10.34	628	40.8%	−0.53 [−0.65, −0.42]
Giallo 2015	10.84	8.2	110	15.4	9.61	110	18.4%	−0.51 [−0.78, −0.24]
Gupta 2010	15.07	7.68	35	18.13	7.27	30	7.1%	−0.40 [−0.90, 0.09]
Islam 2013	15.47	8.16	40	18.13	7.88	70	0.0%	−0.33 [−0.72, 0.06]
Rowbotham 2011	21.25	18.68	12	26.33	15.19	12	2.9%	−0.29 [−1.09, 0.52]
Gerstein 2009	44.64	12.31	115	47.42	14.68	115	19.3%	−0.20 [−0.46, 0.05]
StonemanDS 2007	2.83	2.43	29	3.52	4.4	29	6.6%	−0.19 [−0.71, 0.32]
McCarthy 2006	18.18	8.55	28	19.87	9.11	39	0.0%	−0.19 [−0.67, 0.30]
Norlin2013	9.9	8.1	46	10.8	8.2	58	0.0%	−0.11 [−0.50, 0.28]
StonemanNotDS 2007	2.79	2.59	21	3	2.73	21	4.9%	−0.08 [−0.68, 0.53]
GriffithCdL 2011	16.18	98.67	14	19.76	8.78	15	0.0%	−0.05 [−0.78, 0.68]
Azar 2010	92.62	23.69	46	92.97	24.72	101	0.0%	−0.01 [−0.36, 0.33]
Total (95% CI)			950			945	100.0%	−0.40 [−0.55, −0.26]

Heterogeneity: Tau^2 = 0.01; Chi^2 = 8.31, df = 6 (P = 0.22); I^2 = 28%
Test for overall effect: Z = 5.62 (P < 0.00001)

Figure 13: Forrest plot of father vs mother general mental health (sub-analysis)

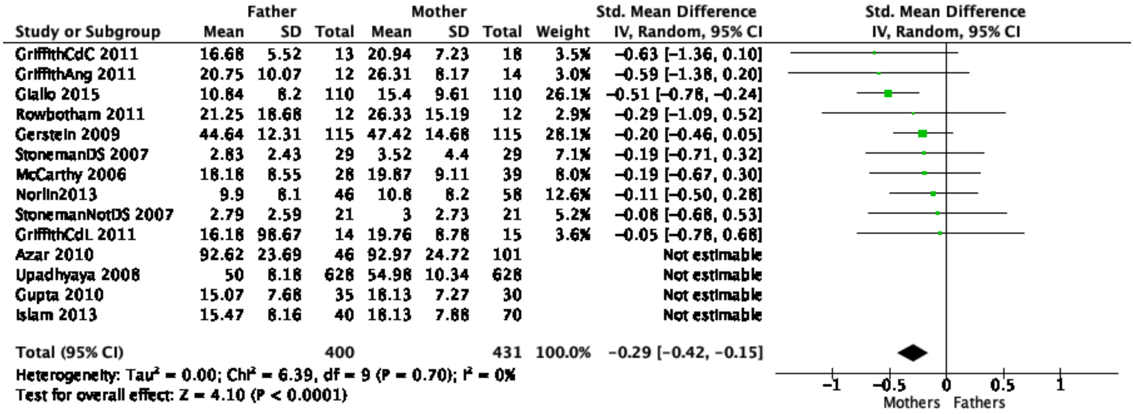


	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Foster 2010	135.8	21.5	13	154	27	97	0.0%	−0.68 [−1.27, −0.10]
Gerstein 2009	17.15	15.88	115	24.31	18.46	115	90.4%	−0.41 [−0.68, −0.15]
Hedov 2000	−79.2	17.9	79	−74	18.2	86	0.0%	−0.29 [−0.59, 0.02]
Marchal2017	6.3	5.9	44	7.5	6.7	76	0.0%	−0.19 [−0.56, 0.19]
McCarthy 2006	54.93	9.14	28	52.77	9.93	39	0.0%	0.22 [−0.26, 0.71]
Rowbotham 2011	16.33	5.74	12	16.58	8.07	12	9.6%	−0.03 [−0.83, 0.77]
Total (95% CI)			127			127	100.0%	−0.38 [−0.63, −0.13]

Heterogeneity: Tau^2 = 0.00; Chi^2 = 0.78, df = 1 (P = 0.38); I^2 = 0%
Test for overall effect: Z = 2.98 (P = 0.003)

Due to the range of cultural contexts involved in the included papers, a further sub analysis was run to determine the impact of including the minority of studies from Asia and the Middle East into analysis of primarily western cultures. Only studies from western cultures were included in the meta-analyses for depression, anxiety and general mental health in fathers vs mothers, and so it was not necessary to rerun this analysis. With the removal of four papers from Lebanon and India, the pooled standardised mean difference (SMD) for stress between father and mother carers moved from -0.32 (95%CI -0.42, -0.15; *p*<.001) to -0.29 (95%CI -0.56, -0.20, *p*<.001). The effect size remained small and there was no evidence of statistical heterogeneity between studies, with I^2=0 %. These results are displayed in figure 14.

Figure 14: Forrest plot of father vs mother stress (western cultures only)



	Father			Mother				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
GriffithCdC 2011	16.68	5.52	13	20.94	7.23	18	3.5%	−0.63 [−1.36, 0.10]
GriffithAng 2011	20.75	10.07	12	26.31	8.17	14	3.0%	−0.59 [−1.38, 0.20]
Giallo 2015	10.84	8.2	110	15.4	9.61	110	26.1%	−0.51 [−0.78, −0.24]
Rowbotham 2011	21.25	18.68	12	26.33	15.19	12	2.9%	−0.29 [−1.09, 0.52]
Gerstein 2009	44.64	12.31	115	47.42	14.68	115	28.1%	−0.20 [−0.46, 0.05]
StonemanDS 2007	2.83	2.43	29	3.52	4.4	29	7.1%	−0.19 [−0.71, 0.32]
McCarthy 2006	18.18	8.55	28	19.87	9.11	39	8.0%	−0.19 [−0.67, 0.30]
Norlin2013	9.9	8.1	46	10.8	8.2	58	12.6%	−0.11 [−0.50, 0.28]
StonemanNotDS 2007	2.79	2.59	21	3	2.73	21	5.2%	−0.08 [−0.68, 0.53]
GriffithCdL 2011	16.18	98.67	14	19.76	8.78	15	3.6%	−0.05 [−0.78, 0.68]
Azar 2010	92.62	23.69	46	92.97	24.72	101		Not estimable
Upadhyaya 2008	50	8.18	628	54.98	10.34	628		Not estimable
Gupta 2010	15.07	7.68	35	18.13	7.27	30		Not estimable
Islam 2013	15.47	8.16	40	18.13	7.88	70		Not estimable
Total (95% CI)			400			431	100.0%	−0.29 [−0.42, −0.15]

Heterogeneity: Tau² = 0.00; Chi² = 6.39, df = 9 (P = 0.70); I² = 0%
Test for overall effect: Z = 4.10 (P < 0.0001)

4.3.4.1 Risk of Bias

Appendix C provides the risk of bias details for each of the papers included in the meta-analysis. There were three studies with a B1 rating (Hedov et al., 2000; MacDonald et al., 2010; Olsson & Hwang, 2008) six studies with a B2 rating (Gerstein et al., 2009; McCarthy et al., 2006; Norlin & Broberg, 2013; Olsson & Hwang, 2002, 2006; Upadhyaya & Havalappanavar, 2008), five with a B3 rating (Azar & Badr, 2010; Giallo et al., 2015; Griffith et al., 2011; Gupta & Kaur, 2010; Stoneman, 2007), and one with a B5 rating (Islam et al., 2013), one with a C1,2 rating (Foster et al., 2010), one with a C1,3 rating (Rowbotham et al., 2011), and one with a C2,2 rating (Marchal et al., 2017). In all papers, the factors which returned a rating of 'unclear risk' were deemed to be of limited concern and so all papers were considered reliable evidence.

4.3.4.2 Sensitivity analysis

Sensitivity analysis was conducted on the depression, anxiety, stress, and general mental health comparisons individually. Studies are removed in order of risk-of-bias rating, and studies with smaller samples were removed first where multiple studies had the same rating. The pooled SMD for depression scores changed slightly as the lowest rated studies were removed from the analysis (from -0.47 to -0.56), which marked the largest change among SMD results. Pooled SMD for anxiety changed from -0.30 to -0.37, and SMD for general mental health changed from -0.26 to -0.22. Pooled SMD for stress did not change with the removal of the lowest rated papers.

4.3.5 Question 2. Is the mental health and well-being of fathers of a son/daughter with intellectual disabilities moderated by paternal resources?

Table 8 displays the studies which address the third research question as to which factors relating to paternal resources moderate the impact of caring on fathers.

4.3.5.1 Paternal Financial Resources

Ten studies investigated whether paternal financial resources moderate the mental health and well-being of fathers of a son/daughter with intellectual disabilities (Azar & Badr, 2010; Dabrowska & Pisula, 2010; E. Emerson et al., 2010; Giallo et al., 2015; MacDonald et al., 2010; Norlin & Broberg, 2013; Olsson & Hwang, 2006, 2008; Rowbotham et al., 2011; Stoneman, 2007). These studies took place in Poland, the USA, Australia, Ireland, Sweden and India. Degree of participation in paid employment was used as a measure of financial resources in Olsson's (2006) study, which found that fathers' well-being increased with higher involvement in paid employment. Parental financial resources or socioeconomic status were measured in the other nine studies. Of these, Giallo et al (2015) reported that socioeconomic variables did not significantly predict the variance in stress, depression or anxiety symptoms in fathers. Dabrowska and colleagues (2010) also found no interaction effect between parents' gender, financial stress and child's diagnostic group.

However, seven studies found that socioeconomic resources had a significant impact on fathers' mental health and well-being. Norlin and Broberg (2013) calculated high economic risk in families, by combining receipt of income support with the family's ability to afford to participate in a number of social activities and own certain clothing items. Using this measure, high economic risk significantly impacted father well-being. Azar (2010) reported lower stress levels among fathers from families with higher incomes in Lebanon. MacDonald and colleagues (2010) examined anxiety levels among fathers whose partner did or did not work, and found higher anxiety levels when their partner did not work outside the house. Emerson et al (2010) found that matching fathers with and without a child with cognitive delay on the basis of socioeconomic circumstances reduced between group differences in the prevalence of fathers' psychiatric disorders by 45% to 11%. In fact, differences between fathers of children with different levels of intellectual disabilities disappeared after income differences between the groups were controlled. Stoneman and colleagues (2007) also found that reports of depression by fathers of a son/daughter with intellectual disabilities were predicted by lower family income. The age of parents in these studies ranged from early 30s to early 70s. A study of parents in India also found that family income was significantly associated with father stress levels of offspring aged 30 years and younger (Upadhyaya & Havalappanavar, 2008). For fathers of young children in Sweden, greater economic hardship was also associated with a higher risk of poor well-being (Olsson & Hwang, 2008).

It was not possible to conduct a meta-analysis with the above studies as sufficient data was only available in the Olsson and MacDonald papers, but the measurements of socioeconomic situation were not comparable.

4.3.5.2 Paternal social support

Table 8 also reports the four studies which addressed the impact of social support provided by a partner or spouse (Gerstein et al., 2009; Kilic et al, 2013; Norlin & Broberg, 2013; Norton, Dyches, Harper, Roper, & Caldarella, 2016). These studies were from Sweden, the USA, Turkey and India. Norton and colleagues (2016) investigated factors associated with two indicators of stress (severity and frequency) in fathers of children with Down Syndrome. Both of these indicators were significantly associated with the three assessed indicators of marital quality. In a Swedish study, quality of marital relationship significantly contributed to well-being in fathers whose child with intellectual disabilities was aged 10 years and younger (Norlin & Broberg, 2013). Kilic and colleagues (2013) measured fathers' and mothers' depression and anxiety scores against their marital adjustment scores. For fathers, depression and anxiety scores increased as their marital adjustment scores decreased. A decrease in daily parenting stress was associated with perceived marital adjustment by fathers of young children with intellectual disabilities in a study by Gerstein and colleagues (2009). Again, it was not possible to conduct a meta-analysis with the above studies due to a lack of comparable data.

4.3.5.3 Formal services and supports

Only one study which met the inclusion criteria of the systematic review investigated the effect of formal services and supports on father mental health and well-being. Norton and colleagues (2016) found that number of hours of respite care was negatively associated with stress levels in fathers.

4.3.6 Question 3. Is the mental health and well-being of fathers of a son/daughter with intellectual disabilities moderated by paternal perceptions?

Studies which address question three are detailed in table 8. The results are divided below by fathers' perceptions of characteristics possessed by their offspring, the child's impact on the father, the child's impact on the family unit, and other factors not previously addressed. It was not possible to run a meta-analysis on these variables due to a lack of necessary data in the papers.

4.3.6.1 Characteristics of the offspring

Type of intellectual disability

Four studies compared fathers of offspring with different types of intellectual disabilities (Griffith et al., 2011; Hartley et al., 2012; MacDonald et al., 2010; Stoneman, 2007). These studies were from the United States of America, the UK, and Ireland. MacDonald and colleagues (2010) found higher stress levels among fathers of children with autism than those with intellectual disabilities, and lower stress levels among those whose son/daughter had Down Syndrome than those whose offspring had other types of intellectual disabilities. Stoneman (2007) reported lower levels of depression for fathers whose child had Down Syndrome than those whose child had another type of intellectual disability e.g. Prader-Willi Syndrome, Fragile X Syndrome etc. Griffith and colleagues (2011) compared psychological distress among fathers whose child had Angelman, Cornelia de Lange, and Cri du Chat syndromes. Of these three syndromes, fathers of children with Angelman syndrome reported the highest levels of psychological distress, and fathers of children with Cornelia de Lange reported the lowest levels. However, only a very small sample of fathers were in each syndrome group and so firm conclusions cannot be drawn from this study. In Hartley's (2012) study no significant difference was found between fathers of children with Down Syndrome and Fragile X Syndrome in terms of psychological well-being.

Level of intellectual disability

Two studies compared the impact of level of intellectual disability on fathers' mental health and well-being (Azeem et al., 2013; Emerson et al., 2010). These studies were conducted in Pakistan and the UK. In Azeem and colleagues' (2013) study there was no association between fathers' anxiety, depression or both, and degree of intellectual disability in their child. Emerson (2010) compared parental mental health when their child was 3 and then 5 years of age. Fathers of a child with severe cognitive delay were more likely to be at risk of psychiatric disorder than fathers of a child with no delay only when the child was 5 years old. Fathers of a child with less severe cognitive delay were more likely to be at risk of psychiatric disorder than fathers of a child with no delay when the child was 3 and 5 years old.

Challenging Behaviour

Challenging behaviour was taken into account when assessing paternal mental health in six studies (Giallo et al., 2015; McCarthy et al., 2006; Norlin & Broberg, 2013; Rowbotham et al., 2011; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008). These papers were from Australia, Sweden, Indian, and the USA. Child behaviour difficulties were identified as significantly predicting father stress, as well as depressive and anxiety symptoms (Giallo et al., 2015). In Norlin and Broberg's (2013) study, fathers well-being was significantly impacted by the presence of self-injurious and stereotypic behaviours in their child. The study by Stoneman (2007) also reported that having a child with a more difficult temperament predicted father depression scores. Challenging behaviour was also identified as a factor which impacted father stress in a study of Indian families (Upadhyaya & Havalappanavar, 2008). Challenging behaviour has also been associated with higher levels of stress in fathers of children with Fragile X

Syndrome (McCarthy et al., 2006). In contrast, the study by Rowbotham and colleagues (2013) failed to find an impact of adult child behaviour problems on fathers' mental health. However, this study only contained 12 fathers in the sample and so these unexpected results may be attributed to insufficient power due to the small sample size.

4.3.6.2 Impact the child has on the father?

One study addressed the impact that children had on the father and its relationship to father mental health. Giallo and colleagues (2015) reported that fathers own needs, stress arising from child behaviour, and low parenting satisfaction significantly predicted depressive, anxiety and stress symptoms. Foster and colleagues (2010) also found evidence that the fathers' perception of their child was associated with mental health outcomes. Fathers who perceived more benefits of having a child with Smith Magenis Syndrome reported higher levels of well-being, than those who perceived fewer benefits.

Impact the child has on the family unit?

None of the studies which met the inclusion criteria of the systematic review investigated the impact the child had on the family unit and its relationship to father mental health and well-being.

4.3.6.3 Other factors identified in the included studies

Coping Strategies

Two studies from the USA and Poland investigated the impact of coping strategies that fathers use (Dabrowska & Pisula, 2010; Hartley et al., 2012). Dabrowska and Pisula (2010) investigated the impact of coping strategies on well-being of fathers of preschool children with Down Syndrome. Emotion-orientated coping (focusing activity on reduction of emotional tension) was found to predict parental stress but not task-orientated coping (focusing activity on solving problems). Hartley (2012) compared the well-being of fathers of children with Down Syndrome, Fragile X Syndrome and Autism. While there was a significant difference of mental health between the groups, there was no significant difference in the use of coping strategy by diagnostic group of paternal psychological well-being.

Maternal mental health

Maternal depressive symptoms were also associated with fathers’ well-being in a study by Hartley and colleagues (2012). Higher levels of maternal depressive symptoms were a significant positive predictor of paternal depression.

Table 8: Factors associated with poor father mental health

Author & Year	Fathers	Son/daughter with ID	Measures	Methodology	Results	Critique
Norton et al (2016)	N= 62 Age M 39.06 (SD 8.53) USA	Age M 10.95 (SD 7.66)	*ID:* Not reported *Parental Mental Health:* Hassles and Uplifts Scale *Marital Quality:* Revised Dyadic Adjustment Scale, Revised Experiences in Close	Recruited through local and regional organisations and social media Cross sectional study	No significant relationship between marital quality and stress	CASP Score= B3 -ID measure not reported -ID level not reported -95%CI not reported

			Relationships Questionnaire			
Giallo et al (2015)	N= 315 Age not reported Australia	Age M 7.8 yrs (SD 5.5) 69.8% male ID level: Mild-profound	*ID:* Not reported *Parental Mental Health:* Depression Anxiety and Stress Scale, Developmental Behaviour Checklist, Parenting Hassles Scale, Parenting Sense of Competence Scale, Sources of Support	Recruited from families involved in a previous study (Hudson et al, 2003; 2008). Cross sectional study	Socioeconomic factors DID not significantly predict depression, anxiety, or stress Child behaviour difficulties, parenting stress from child's behaviours and needs, fathers own needs, low parenting satisfaction did significantly predict depression, anxiety and stress	CASP Score= B3 -Sample from those enrolled to participate in a child behaviour management programme- so not representative -Includes children with ID+ASD in the sample -Mental health score based on distress in the past week

			Socioeconomic Factor: Index of Relative Socio-economic status			
Azeem et al (2013)	N= 99 Age M 42.9yrs (SD 8.8) (99 married couples) Pakistan	Age M 10.5yrs (SD 5) 30% male ID: mild-profound	*ID:* Slosson IQ Test *Parental Mental Health:* Anxiety & Depression- DSM-IV criteria by trained psychologist.	Recruited from health centres in Pakistan Cross sectional study	There was no significant association between father's anxiety, depression or both and degree of ID in their children	CASP Score= B3 -95%CI's were not reported for parental mental health scores. -95%CI not reported for different levels of ID -Type of ID not specified

Kilic et al (2013)	N= 150 Age M 36.6yrs (SD 8.2) Turkey	Age M 8.1yrs (SD 4.0) 59.3% males	*ID:* Not reported *Parental Mental Health:* Beck Depression Inventory, State-Trait Anxiety Inventory *Social Support Factor:* Birtchnell Marital Partner Evaluation Scale,	Recruited from rehabilitation centre, handicapped education and cooperation association Cross sectional study	Depression and anxiety scores increased as father marital adjustment scores decreased ($p<0.01$)	CASP Score= B2 -ID measure and level of ID not reported -95%CI not reported

			Multidimensional Scale of Perceived Social Support			
Norlin et al (2013)	N= 46 Age M 35.3 (SD 6.1) Sweden	Age M 41 months (SD 27.8) 62.1% males	*ID:* Not reported *Parental Mental Health:* Becks Depression Inventory	Recruited by staff at service centres for families of children with disabilities Cross sectional study	Depression scores decreased as marital quality increased (t= -2.84, p<0.01) High economic risk increased (t= 2.16, p<0.05) Depression increased as problem behaviours increased (t= 3.06, p<0.01)	CASP Score= B2 -Did not report ID measure used -95%CI not reported
Hartley et al (2012)	N= 105 (59 DS, 46 FXS)	DS N= 59 Age M 15.2yrs (SD 3.0) 69.6% male	*ID:* Medical reports & genetic testing, Wide Range Intelligence Test,	Recruited from local media advertisements, newsletters to disability organisations, brochures and postings in clinics.	Additional children with a disability and higher level of maternal depressive symptoms were sig positive predictors of paternal	CASP Score= B3 -95%CI not reported -Some of ASD group had ID

	Age not reported USA	FXS N= 46 Age M 15.6yrs (SD 2.6) 79.5% male ASD N= 135 Age M 16.0yrs (SD 2.8) 72.3% male	Vineland screener, Stanford-Binet Intelligence Scale, Scales of independent behaviour revised *Parental Mental Health:* Centre of Epidemiological Studies Depression Scale, Questionnaire of resources and stress, Multidimensional coping inventory	Disability listservs and a university research registry Cross sectional study	depression. Model predicted 15% of variance in depression and 20% variance in pessimism	-Behaviour problems reported by mothers rather than fathers.

Griffiths et al (2011)	Angelman syndrome N= 12 Cornelia de Lange syndrome N= 14 Cri du chat syndrome N= 13	Angelman syndrome Age M 10.07 (4.79) Cornelia de Lange syndrome Age M 11.75 (SD 3.49) Cri du chat syndrome Age M 7.83 (SD 4.66)	*ID:* Vineland adaptive behaviour scale (VABS-II) *Parental Mental Health:* Questionnaire on Resources and Stress-Short form	Recruited from a database held by research team, and national parent support groups Cross sectional study	Anxiety: Angelman syndrome M 10.42 (SD 4.72) Cornelia de Lange M 5.85 (SD 4.35) Cri du Chat M 9.0 (SD4.16) Depression: Angleman syndrome M 8.50 (SD 4.49) Cornelia de Lange M 4.29 (SD 2.62) Cri du Chat M 6.92 (SD 4.09)	CASP Score= B3 -Level of ID not reported -Confidence intervals not reported -Small number of fathers in sample

					Stress: Angleman syndrome M 20.75 (SD 10.07) Cornelia de Lange M 16.18 (SD 98.67) Cri du Chat M 16.68 (SD 5.52)	
Rowbotham et al (2011)	N= 12 45- 55 yrs Australia	Age M 24yrs (SD not reported) 58% females	*ID:* Adaptive Behavioural Scale (as reported by parents) *Parental Mental Health:* General Health Questionnaire-28	Recruited through public and private-sector groups providing services to carers of adults with ID Cross sectional study	None of the measures were significantly related to care-giving satisfaction.	CASP Score= B4 -Small sample of parents known to services -Level of ID not reported

			Social Support Factor: ‘How satisfied with partners caregiving and emotional support?’ Likert scale			
Dabrowska et al (2010)	N= 27 Age M 34.9 (SD 6.1)	55.6% males	*Parental Mental Health:* Coping Inventory for Stressful Situations *Socioeconomic Factor:*	Recruited from centres for early intervention, therapy centres or kindergartens Cross sectional study	No significant difference in coping styles between groups	CASP Score= B3 -95%CI not reported -Small sample size -Level of ID not reported -Young children in sample so possible not all those with

			Questionnaire of Resources and Stress for Families with Chronically Ill or Handicapped Members short form			ID have been identified.
Emerson et al (2010)	Wave 1: N= 18,552 Wave 2: N= 15,590 Wave 3: N= 15,246 families Age not reported	Wave 1= 9 mths old Wave 2= 3 yrs old Wave 3= 5yrs old	*ID:* Bracken Basic Concept Scale, Naming Vocabulary subscale from British Ability Scale II *Parental Mental Health:* K6 Scale,	Secondary data analysis of Millennium Cohort Study (waves 1-3) Families eligible to receive child benefit, born 09/2000 and 01/2002 Longitudinal study	Matching on the basis of socioeconomic circumstances reduced between group differences by 11% to 45%. Severe Delay: Fathers more likely to be at risk of psychiatric disorder than fathers of no delay only when child was 5	CASP Score= B3 -Young children in sample so possible not all those with ID have been identified -Follow-up not long enough to identify ID diagnosed later in development -Level of ID not reported

	UK		*Socioeconomic Factor:* Highest qualification, employment status, social class, income poverty, housing situation, welfare benefits, material hardship		years old (14% vs 8%, $p<.031$) Less severe delay: Fathers more likely to be at risk of psychiatric disorder than fathers of no delay only when child was 3 (14% VS 7%) and 5 years old (15% vs 8%, $p=.020$)	
Foster et al (2010)	N= 15 Age M 42.07yrs (SD 9.85)	Age not reported	*ID:* Not reported *Parental Mental Health:*	Recruited through parent and researcher Smith-Magenis syndrome list serve Cross sectional study	Fathers who perceived more benefits of having a child with ID reported higher carer well-being ($p<0.01$).	CASP Score= C1,2 -Small number of fathers in sample -Confidence intervals not reported

	USA		Caregiver well-being scale *Parental Perceptions:* Psychosocial impact scale (benefit finding subscale)			
MacDonald et al (2010)	N= 99 Age not reported Ireland	N= 53 DS N= 30 other ID Age not reported	*ID:* Not reported *Parental Mental Health* Parent and Family Problems subscale of Questionnaire on Resources and	Recruited from ID services Cross sectional study	Fathers of children with DS reported lower stress levels: (M 3.02, SD 3.43) than fathers of children with other types of ID: (M 5.00, SD 4.63), *p*=0.019 Fathers whose partner worked outside the home	CASP Score= B1 -95% CI's not reported -Level of ID not reported -parent age not reported

			Stress, Hospital Anxiety and Depression scale		reported lower anxiety (M 11.10, SD 4.10) than fathers whose partner didn't work (M 13.32, SD 4.30), p=0.019	
Gerstein et al (2009)	N= 115 Age not reported USA	3yrs old	*ID:* Bayley Scales of Infant Development II *Parent Mental Health:* Parenting Daily Hassles measure, Dyadic Adjustment Scale	Recruited from community agencies serving families of children with ID Longitudinal study	Marital adjustment was a protective factor against poor mental health at 36 months (B= -0.235 (SE=0.058), p<0.001)	CASP Score=B2 -Level of ID not reported -Parental age not reported -95%CI not reported

Olsson et al (2008)	N= 49 Age M 36.2yrs (SD 6.4) Sweden	Age 0-5yrs	*ID:* Reported by centres *Parental Mental Health:* Beck's Depression Inventor-2r *Socioeconomic hardship:* List of items parent would like but could not afford (adapted from Emerson et al, 2006)	Recruited from centres providing support to families of children with disabilities Cross sectional study	As economic hardship increased well-being decreased Model predicted 42% of the variance	CASP Score= B1 -Confidence intervals not reported
Stoneman et al (2007)	N=50	N= 29 DS	*ID:*	Recruited from early intervention programmes,	The 'DS advantage' disappeared after income	CASP Score= B3

	Age M 37 yrs (SD 6.9) USA	N= 21 other ID Age M 4.8yrs (SD not reported) 50% Male	Temperament Assessment Battery *Parental Mental Health:* Centre for Epidemiologic Studies Depression Scale, - Questionnaire on Resources and Stress, *Socioeconomic Factor:* Family income	pre-schools, parent groups and referrals from community members Cross sectional study	differences between groups were controlled. Reports of depression increased with lower family income (p<0.05)	-ID measure and level of ID not reported -Comparison group contains some children with autism -95%CI not reported

McCarthy el al (2006)	N= 28 Age M 41.5yrs (SD 6.91) Australia	Age M 10.4yrs (SD 3.59)	*ID:* Reported by family *Parental Mental Health:* Brief Symptom Inventory, Questionnaire on Resources and Stress	Recruited from the Fragile X society Cross sectional study	Child behaviour was the best predictor of BSI, accounting for 50% of the regression variance F(3,21)=8.95, $p<0.001$	CASP Score= B2 -Level of ID not reported -95%CI not reported -Parents reported on child with highest support needs
Olsson et al (2006)	N= 179 ID Age M 43yrs (SD 6.3) N= 196 TD Age M	Age M 8.1yrs (SD 4.3) 62% males	*ID:* Parent reports *Parental Mental Health:* Beck's Depression Inventory, Division	Recruited from community-based programmes providing services to families of disabled children Cross sectional study	Well-being increased with higher involvement in paid work	CASP Score= B2 -ID measured with parent reports -Level of ID not reported

	42yrs (SD 6.9) Sweden		of 15 child-care tasks measure *Socioeconomic Factor:* Level of involvement in paid work			
Olsson et al (2002)	N= 115 Age not reported Sweden	Age M 7.4yrs (SD 4.2) 60% males	*ID:* Parent reports *Parental Mental Health:* Becks depression inventory	Recruited from community based programmes for families of disabled children Cross sectional study	Sense of coherence did not significantly predict poor mental health	CASP Score= B2 -ID measured through parent reports -Confidence intervals not reported

			Parental Perceptions: Swedish version of the short Sense of Coherence scale			

4.4 Discussion

4.4.1 Father carer and general population mental health

Sixteen of the seventeen studies which compared father carer mental health to fathers in the general population found a significant difference between groups, with fathers of a son/daughter with intellectual disabilities experiencing poorer mental health (Emerson et al., 2010; Giallo et al., 2015; Hartley et al., 2012; Hedov et al., 2000; MacDonald et al., 2010; Marchal et al., 2017; Norlin & Broberg, 2013; Olsson & Hwang, 2001, 2006). This is in keeping with previous research which has found that family carers (usually mothers) experience poorer mental health than their peers in the general population (Cairns et al., 2014; Griffith & Hastings, 2014; Thomson et al., 2017). This meta-analysis also found fathers' mental health to be negatively impacted by having a child with intellectual disabilities.

4.4.2 Mother and father carer mental health

The majority of studies which compared the mental health of father and mother carers (Azeem et al., 2013; Foster et al., 2010; Gerstein et al., 2009; Giallo et al., 2015; Griffith et al., 2011; Gupta & Kaur, 2010; Hedov et al., 2002; Hedov et al., 2000; Islam et al., 2013; Norlin & Broberg, 2013; Olsson & Hwang, 2001, 2002, 2006, 2008; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008) indicated that there was a difference, with fathers exposed to a lower risk of depression, anxiety, stress or poor general mental health.

The meta-analysis revealed statistically significant differences in depression, anxiety, stress, and general mental health between mothers and fathers. There are a number of possible reasons for this gender difference. Mothers more often work part-time or give up work entirely to become the main caregiver for their child, while fathers who remain in the family unit are more often the main breadwinner (Powell, 2019). This usually results in mothers carrying out the majority of the care-giving and advocacy tasks for their child, which can be stressful due to the higher level of responsibility their role involves for their child's well-being.

Time spent outside the family home in a different role may also contribute to gender differences in parental mental health. The results of Olsson and Hwang's

(2006) study indicate a positive relationship between involvement in paid work and well-being for both mothers and fathers. If fewer mothers are in employment following the birth of a child with intellectual disabilities, this could in part explain the difference in mental health between parents. In Olsson and Hwang's study there was no difference in well-being between mothers who worked full-time and mothers who worked part-time. This suggests that taking a longer break from child care activities does not impact mother mental health, but that being in paid employment can be a protective effect. In particular, being in work can provide social contact, financial security, opportunities to expand their frame of reference, and a sense of purpose beyond their caring role, an identity outside of childcare activities and a means of achieving status and control outside of the household (Barnett & Hyde, 2001; Majumdar et al, 2005). However, there is no data to confirm this as the majority of studies did not record which parent provided most care for their child or the number of hours of employment outside of the home.

4.4.3 Paternal resources and perceptions

The results of papers included in this review showed some support for factors identified in the ABCX model of stress as mediators of mental health and well-being for fathers. There was mixed support for the impact of paternal financial resources on father carer mental health, although most studies reported that greater financial resources were associated with better father mental health (Azar & Badr, 2010; Emerson et al., 2010; MacDonald et al., 2010; Norlin & Broberg, 2013; Olsson & Hwang, 2006, 2008; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008). The link between socioeconomic circumstances and adult health and well-being in the general population is well established within the literature (Prag et al, 2016; Wilkinson & Pickett, 2009). The remaining studies found that socioeconomic factors did not impact father mental health (Dabrowska & Pisula, 2010; Giallo et al., 2015). Each of these studies measured financial resources using different measures and variables. That the two studies which used broad single item measures for socioeconomic status did not identify a significant impact of socioeconomic factors, may indicate that these measures were unable to capture accurate socioeconomic status for the fathers in these samples.

Social support, as measured by marital adjustment, was another factor which was investigated by studies included in this review (Gerstein et al., 2009; Kilic et al., 2013; Norlin & Broberg, 2013; Norton et al., 2016). Higher marital adjustment was associated with better mental health in each of these papers. These findings are in keeping with research on factors associated with better mental health in mothers of children with intellectual disabilities (Kersh et al, 2006), as well as with research on the general population (Falconier et al, 2015; Moore & Diener, 2019; Proulx et al, 2007).

The impact of the fathers' perception of the characteristics of their son/daughter was also explored. Four papers reported on the impact of type of intellectual disability (Griffith et al., 2011; Hartley et al., 2012; MacDonald et al., 2010; Stoneman, 2007). It was not possible to compare the study by Griffith and colleagues (2011) to the other three papers as different types of intellectual disabilities were included in this sample. However, fathers of children with Down Syndrome were included in the other three papers. Hartley found no significant difference between the mental health scores of fathers whose teenager had Down Syndrome and those whose teenager had Fragile X Syndrome. However, Stoneman reported lower levels of depression for fathers who had a child with Down Syndrome, than those who had a child with another type of intellectual disability. MacDonald and colleagues (2010) also found lower stress levels among fathers of a child with Down Syndrome than fathers of a child with other types of intellectual disability. This is supported by previous research which has identified family carers of children with Down Syndrome as experiencing lower levels of impact than family carers of children with other types of intellectual disabilities (Abbeduto et al., 2004; Fidler et al., 2000; Hatton & Emerson, 2009; Tsai & Wang, 2009).

The studies by Stoneman and Hartley had similar sample sizes and both took place in the USA, while MacDonald's paper had twice the number of fathers in the sample and took place in Ireland. Stoneman and MacDonald's paper compared fathers of children with Down Syndrome to those with a range of intellectual disabilities, including but not limited to Fragile X Syndrome. It was not reported how many children in these samples had Fragile X Syndrome and so it is not possible to adequately compare the samples, with the sample in the Hartley paper. Another important difference between the studies is that the Hartley paper included parents whose child was on average slightly older (mean age 15.2 years) than the Stoneman paper (mean age 4.8 years), while age was not reported in MacDonald's paper. While Down Syndrome and Fragile X Syndrome are different types of intellectual disabilities, they are both characterised by facial features which can signal to the outside world that they have a disability. When a child has the type of disability which is apparent to members of the public, then people can identify that their child has different needs and can adjust their expectations for that child's abilities accordingly, and this may result in less stress for parents. Research into the experiences of parents of a child with 'invisible' disabilities, such as autism, have reported that as people do not usually realise that their child has a disability, they do not make allowances for their child and often presume that they are just badly behaved (Kelso et al, 2005; Lasser & Corley, 2008). This could contribute to the difference in stress levels for fathers of young children in the included papers.

Impact of level of intellectual disability on father mental health was also reported (Azeem et al., 2013; Emerson et al., 2010). Azeem found that degree of intellectual disability when the child was an average of 10.5 years of age was not associated with fathers' mental health. However, Emerson's longitudinal study reported poorer mental health when the child had severe cognitive delay than when the child had no delay at age 5, while there was no difference for those with less severe cognitive delay when the child was aged 3 and 5 years old. These mixed results reflect the inconsistent findings of the impact of level of intellectual disability on carer health within the general literature. While Emerson and colleagues (2010) found a significant effect of degree of cognitive delay in their sample, the impact of this variable on father mental health was no longer significant after controlling for between-group differences in socioeconomic circumstances. Therefore, as discussed in the introductory chapter of this thesis, the impact of level of intellectual disabilities appears to dissipate when other factors are taken into account.

The association between challenging behaviour and father mental health was only reported in six studies, five of which found a positive relationship (Giallo et al., 2015; McCarthy et al., 2006; Norlin & Broberg, 2013; Stoneman, 2007; Upadhyaya & Havalappanavar, 2008), and one of which found no such association (Rowbotham et al., 2011). The sample size in the Rowbotham paper was very small (N=12) and so the results of this study may not represent all fathers. Challenging behaviour has been well documented in the literature as a factor which impacts carer mental health and well-being (Blacher & Baker, 2007; Ekas & Whitman, 2010; Pruchno & Meeks, 2004). Studies which investigate carer well-being but do not take this into account are failing to consider a key factor.

4.4.4 Strengths and limitations

This study has a number of strengths. To the best of our knowledge this is the first meta-analysis on the mental health and well-being of fathers of a son/daughter with intellectual disabilities, and the factors which impact fathers' mental health. A robust methodology was employed and the quality of the included papers is high (rated B2 to B4 on risk-of-bias).

However, there were a limited number of studies that met the inclusion criteria, restricting the number and type of meta-analyses that could be run. There were also various issues with directly comparing the results of the studies in this review. For example, the studies used a variety of outcome measures, making direct comparisons between the papers difficult as measures may vary in how they define mental ill-health. The included papers were also from a range of countries with different cultural norms about attitudes towards parenting and mental health. In cultures with more traditional gender norms, limited participation in caregiving could lead to lower stress levels among fathers, as they would be less involved in the day-to-day caring activities, trying to access support services, and more time for socialising, hobbies, and self-care activities . Another potential difference to note is that resources and services available to parents from non-western countries were likely quite different from those available to parents in western countries. However, male roles and availability of resources and services are likely to vary, not only between countries but also within countries.

The impact of stigma that society attaches to having a child with intellectual disabilities may also affect fathers' mental health, even if they are not as involved in day-to-day caregiving as their partner. Stigma has been identified as a factor which can negatively affect families of people with disabilities in different cultures (Corrigan & Kleinlein, 2005; Corrigan et al, 2006; Mak & Cheung, 2008; Ostman & Kjellin, 2002; Tsang et al, 2003). A review of studies investigating stigma experienced by individuals with intellectual disabilities and their families in both western and non-western countries, identified a significant relationship between stigma and psychological factors (Ali et al, 2012). While the above studies report that the family unit experiences stigma in many countries, gender differences concerning stigma have been identified in some studies. For example, a study by Chang and colleagues (2009) who reported that Taiwanese mothers of children with intellectual disabilities experienced more shame resulting from stigma than did fathers. Yet, despite the potential influence of culture on father well-being, results of studies from Lebanon, Pakistan and India did not significantly differ from those of studies from western cultures.

It was also not possible to generate accurate age categories as many of the papers did not report the ages of their samples, and those that did focussed predominantly on middle aged parents. Of the studies which did report a mean age for parents and children in their sample, the mean age of the father ranged from 36.2 to 47.8 years, and the mean age of the child with intellectual disabilities ranged from 4.2 to 10.5 years of age (Azar & Badr, 2010; Azeem et al., 2013; Dabrowska & Pisula, 2010; Foster et al., 2010; Griffith et al., 2011; Hedov et al., 2002; Hedov et al., 2000; Marchal et al., 2017; McCarthy et al., 2006; Norlin & Broberg, 2013; Olsson & Hwang, 2002, 2006, 2008; Rowbotham et al., 2011; Stoneman, 2007). There is some evidence that carers face different stressors throughout the caregiving journey, such as after receiving a diagnosis (Rivard & Master-Smith, 2014) or at times of increased child care responsibility (Bostrom & Broberg, 2014; Rivard & Master-Smith, 2014). As a result, the findings of this meta-analysis may only apply to fathers in middle age with a young child, rather than younger or older fathers. Different stages of the caregiving experience may also impact mothers and fathers differently, such as diagnosis (Gerstein et al., 2009), starting primary school (Baxter et al, 1995; Wilder & Lillvist, 2017), transition from child to adult services (Biswas et al, 2017; Gillian & Coughlan, 2010). However, the scarcity of papers which reported the age of fathers in their sample prevented an examination of paternal mental health at different stages in the caring journey.

Degree of the offspring's challenging behaviour was not considered in the analysis by most studies. This is a notable omission, as the literature demonstrates a relationship between challenging behaviour and parental mental health (Baker et al, 2005; Gallagher, et al 2013; Griffith et al., 2011; MacDonald et al., 2010; McIntyre et al, 2002; Meppelder et al, 2015). Due to the lack of information on challenging behaviour it was not possible to take this factor into consideration in the meta-analysis.

The majority of the studies included in this systematic review and meta-analysis recruited parents exclusively through services provided for families of children with disabilities or organisations which supported such families. As a result, the majority of parents in the studies were known to services and so the results of our study may only be applicable to parents who exhibit help seeking behaviour to these organisations. Fathers who instead chose to rely on informal support networks may not be represented in these results.

4.4.5 Future Research

Only one paper included older father carers (Upadhyaya & Havalappanavar, 2008). However, this study reported an age range of less than 35 to 71 years of age with no reported mean age or distribution, and so there may be a limited number of carers in the sample aged 60 and above. This is important as the impact on parents caring for a son/daughter with intellectual disabilities over time is a topic which has received little attention from researchers within the field. Of the research that does exist on older parent carers, a focus has been on mothers as they have traditionally been viewed as the main caregiver in the family unit. However, as discussed in the introductory chapter, a number of factors make it prudent to include fathers. As fathers enter retirement they are more available to assist their partner in caregiving activities, and their partner's deteriorating health or death may make this alteration necessary. At this time of life, the factors which may account for differences between mother and father mental health at an earlier point in their caring journey may no longer be relevant. For example, as fathers were often the parent who continued working while the mother acted as the main caregiver, they may not have spent as much time with their child or taken on as much responsibility for day-to-day tasks and advocacy for their child. Therefore, it is important for future research to explore the mental health and well-being of older fathers of people with intellectual disabilities. This gap in the existing research literature is addressed in the second phase of this PhD project by undertaking a qualitative study with fathers aged 60 years and above, the methodology of which is discussed in the following chapter.

Chapter 5: The Qualitative Study Methodology (Study 2)

5.1 Introduction

The results from the systematic review discussed in the previous chapter have contributed to a greater understanding of current research into the mental health of fathers caring for a son/daughter with intellectual disabilities. However, very few of the studies which met the inclusion criteria contained older fathers (aged 60 years and above) in their sample (Griffith et al., 2011; Rowbotham et al., 2011; Upadhyaya & Havalappanavar, 2008), and the number of older fathers within these samples was limited. This indicates a gap in our understanding about the mental health and well-being of older fathers. Given that older fathers of a son/daughter with intellectual disabilities are a growing cohort within society, the dearth of information around their experiences and well-being is particularly concerning. It was considered important to compliment and elaborate on the findings of the systematic review by conducting a qualitative study with older fathers, in order to better understand the experiences of this type of carer. Conducting a qualitative study was deemed an appropriate means of increasing our understanding of their experiences as it allows fathers to share their story in their own words, in a way which would not be possible with a quantitative study.

The aim of this chapter is to discuss the methodological approach selected for the qualitative study. The chapter begins with the overall research objective, then describes the various qualitative methodologies available to the researcher, before discussing the qualitative paradigm which was selected and the reasons behind this selection. The methods used for data generation, data analysis, ethical considerations and research rigour are also detailed.

5.2 Research objective

The overarching objective of this study was to better understand the caregiving experience of older fathers of a son/daughter with intellectual disabilities, and how caregiving impacts their mental health and well-being.

Aims

- To explore older fathers’ experience of caring, and how this has changed as they age
- To understand how caring impacts older fathers’ mental health and well-being
- To identify factors which impact the mental health and well-being of older fathers

5.3 Rationale for a qualitative study

Qualitative research allows the collection of rich descriptions of social life, social processes and the generation of theory which provides a comprehensive conceptual understanding of a complex phenomenon (Hesse-Biber, 2004). This type of research also enables the researcher to explore areas which are revealed to be important to the participants under study. Guba and Lincoln note that qualitative research reflects the meaning that people attach to events and actions (Guba & Lincoln, 2004). As little is currently known about the experiences of fathers it was deemed important to explore the meaning which they attach to their caring role and the events in their lives. Qualitative research enabled the researcher to explore these meanings with fathers by asking questions about experience, meaning and perspective.

5.4 Finding a perspective

The philosophical approach adopted by the researcher guides the way that data is collected and interpreted, making the choice of a philosophical stance an important step in qualitative research. The philosophical stance and the accompanying methods used in a study are commonly referred to as a paradigm. The approach dictates how the inquiry is carried out in practice. Over the years there has been a significant degree of overlap between paradigms, with the frequent relabelling of similar constructs and approaches. However, the most commonly referred to paradigms in current research include positivism, post positivism, critical theory, participatory and constructivist. Paradigms are based on three philosophical concepts that directed the nature of a study: epistemology (which determines the nature of the relationship between the researcher and participant and how we learn about our world), ontology (which refers to beliefs about the form and nature of reality), and methodology (which addresses the techniques used by the researcher to acquire knowledge about the topic under investigation) (Guba & Lincoln, 2004). The five major paradigms are described detail below.

5.5 Choice of Methodology

5.5.1 Positivist & post-positivist paradigms

The aim of both positivist and post-positivist paradigms is explanation (Lincoln et al, 2011). Science and the scientific method are given precedence in these paradigms. According to this perspective, the study of the social world can occur in much the same way as the natural world. Therefore, this study of the social world can produce causal explanations. Positivist approaches treat each fact collected from the data as a building block which all add to the knowledge base (Guba & Lincoln, 2004). This knowledge base can then be used to predict and control phenomenon. According to these paradigms, generalisations may be made from findings in a study to a population setting. The researcher is the expert in the topic, rather than the participant. Through the process of data collection, the researcher increases his ability to predict and control the phenomenon which is under investigation.

Since the aim of positivist research is explanation, while the aim of the qualitative study was one of exploration, these paradigms would not have enabled an in-depth exploration of fathers experiences and constructions of reality. Fathers were also considered to be the experts of their own experiences, rather than the researcher, as little research has previously been conducted with this group. However, a positivist approach was taken for the later quantitative phase of the project. As detailed in Chapter Three, using qualitative data in order to identify a research question that is best tested with quantitative data is a common approach in mixed methods research designs. The quantitative element of the study will be discussed in further detail in Chapter Seven, and was informed by the data captured in the qualitative phase. In this way, a positivist approach supported the collection and analysis of data to explore one of the themes developed from the qualitative results.

5.5.2 Critical Theory

The aim of critical theory is to challenge and change social or cultural structures (Guba & Lincoln, 2004). Advocacy and activism are key concepts in this paradigm. The interviewer is an investigator and facilitator: the 'transformative intellectual' (Giroux, 1988). This implies that the investigator is already in possession of knowledge and understanding as to what transformations are required. This paradigm acknowledges the influence that the interviewer and interviewee have upon one another, and that this inevitably influences the inquiry. Unlike the positivist paradigms, critical theory does not view knowledge as accumulating in a linear fashion. Instead knowledge is acquired by the interaction between interviewer and interviewee, with further interactions leading to fewer misunderstandings on the part of the interviewer, and more informed insights being formed as a result (Guba & Lincoln, 1994). Unlike positivism, the importance of values is stressed in both this method of inquiry and constructivism (see below). In critical theory, values contribute towards shaping the findings of research and are used as a means of stimulating action to alter existing structures.

However, as little is known of older fathers' experiences, how these experiences could influence theoretical and practical frameworks was also unknown. Unlike critical theory, the researcher also did not aim to directly make changes but to explore participants' experiences and expand our understanding of these experiences, making this paradigm a poor fit for the present study.

5.5.3 Participatory

A fundamental quality of the participative worldview is that it is self-reflective (Heron & Reason, 1997). Co-researchers are invited to participate in the inquiry process through data collection and analysis, as the aim is to conduct research with, rather than on, the group under study. A participatory worldview emphasises the importance of every research project containing an action plan for reform which will effect change in the social world. This change can be in the lives of participants, institutions and organisations which impact their lives, or the lives of researchers. Some similarities do exist between the participatory and constructivist perspectives, described below, in that they both advocate for the existence of multiple realities from an ontological perspective (Lincoln & Guba, 1985), and both adopt a subjectivist epistemology (Lincoln et al., 2011). However, the participatory approach was not chosen for the current study as conducting a participatory enquiry would have required involving participants in the study design phase as well as creating an action plan for reform, and this was not thought practical, due to the time constraints of a PhD project.

5.5.4 Constructivism

A constructivist approach to qualitative research emphasises the pluralistic and changing nature or reality. Constructivist researchers believe that there is no one reality or truth, and the researcher aims to understand a phenomenon from the participants point of view (Denzin et al, 2007). The researcher and participant construct meanings together during their interaction. The researcher is not a neutral observer in this type of inquiry and their preconceptions may shape the direction of the inquiry (Charmaz, 2014). This approach recognises the fact that researchers begin the interview process with pre-existing ideas and knowledge about the topic under investigation, as was the case in the current study. Constructivist researchers use a number of tools, such as research diaries, to record such preconceptions in an attempt to make researchers aware of these ideas and biases. Further details of the constructivist method of inquiry is provided in section 5.6 of this thesis.

5.5.5 Thematic Analysis

Thematic analysis is a method for identifying and analysing paterns of meaning in data (Braun & Clarke, 2017). Patterns are identified through a process of familiarisation with data, coding, theme development and theme revision. Braun and Clarke (2014) describe thematic analysis as a useful tool for health research. There are a number of different approaches to thematic analysis, in terms of the way themes are identified, data is coded and interpreted (Terry et al, 2017). Researchers engaging in thematic analysis must decide how they will approach these elements of analysis. The first decision involves choosing either a deductive or inductive approach. A deductive method to coding involves analysis moving from theory, to predication of themes, to gathering evidence through coding for these themes. Themes are usually at least partly determined in advance of analysis and guide the interview questions. In the second version of thematic analysis, an inductive approach is taken to coding and theme development. Themes are developed through immersion in the data, rather than using pre-existing codes. Such theme development is considered to be subjective and themes are created by the researcher, rather than discovered in the data (Braun & Clarke, 2006).

A further division within thematic analysis is the choice of a (critical) realist/essentialist and constructivist approach. A (critical) realist or essentialist way of conducting thematic analysis involves reporting an assumed reality that exists within the data. Constructivist thematic analysis takes a different approach, focussing on how a particular reality is created by the data collected from participants.

Approaches to thematic analysis also differ in terms of whether a semantic or latent approach is taken to coding and theme development. Semantic coding and theme development reflect the explicit content of the data and this is more of a ‘surface level’ interpretation of meaning. Latent coding and theme development go deeper in their analysis and attempt to report underlying concepts and assumptions that underpin the data. However, these are still interpretations by the researcher, rather than one underlying truth to be mined or discovered. Generally, inductive, semantic and (critical) realist elements of thematic analysis usually occur together. This is also true of deductive, latent and constructivist elements, although this is not always the case.

Braun and Clarke (2006) claim that thematic analysis is the essential foundation of qualitative analysis and the first method that researchers should learn. It is particularly suitable for researchers with no previous experiences of qualitative research due to its accessibility, few prescriptions and procedures. Given that this was the principle researcher's first experience of qualitative work, this was a key element in the decision to use thematic analysis for the current project. Thematic analysis was also chosen as the method of qualitative analysis for the current project, as it provides a theoretically flexible approach to analysing qualitative data. Due to the flexibility that this approach provides, it can be used across a range of ontological frameworks and epistemological approaches to data (Braun & Clarke, 2006). Therefore, it is important that researchers select a clear theoretical approach to thematic analysis.

5.6 Thematic Analysis: the method of choice

As discussed above, thematic analysis can be approached in a number of different ways. The current study followed an inductive, latent, constructivist approach to thematic analysis. This was deemed most appropriate as this involves examining the ways in which events, realities, meanings, and experiences are the effects of a range of discourses operating within society. This interpretation of thematic analysis is drawn directly from data and aims to offer insight into a participants' world. Therefore, it is a means of capturing a complex reality or phenomenon such as a father carer's experience.

This approach to thematic analysis was selected as there are three key elements of constructivist inquiry that match the aims of the current study: its relativist ontology, subjective epistemology and naturalistic methodology. A number of assumptions underpin this philosophical approach: values in research, constructed realities, the inquirer/participant relationship, generalisation, and causality (Rodwell, 1998). An overview of the methodology and constructivist approach to thematic analysis followed in the current study is outlined below.

5.6.1 Values in research

In constructivist inquiry, it is assumed that values guide inquiry, and so involving participants directly in the research process adds credibility to the study and affirms the values they hold. Charmaz (2006) suggests that this can be done by providing a summary of the interview to participants, so that they may check for accuracy and make suggestions for additions and subtractions in order to better represent their experiences and perceptions of the phenomena under study. Researchers who follow a constructivist approach also advocates for researchers to document their opinions, values and assumptions about the topic under study, prior to the commencement of data collection. Such researchers make regular notes on their thoughts and perspectives as the research progresses, to help them become more aware of their own values and potential biases, as well as to make the researcher's decision making and analysis process more transparent (Braun & Clarke, 2006; Charmaz, 2014). These techniques were used in the current study to mitigate against the findings being directed by values held by the researcher, rather than the participant.

5.6.2 Constructed realities

The relativist ontology in constructivist thematic analysis accepts that there are multiple, socially constructed realities (Guba & Lincoln, 2004). This position acknowledges that individuals attach multiple meanings to a single phenomenon and that there are multiple ways of interpreting the data produced from interviews (Ponterotto, 2005). Braun and Clarke (2006; 2014) are clear that themes do not simply 'emerge' from the data, and that such themes are self-evident. Constructed realities refer to the process of creating a reality that reflects someone's view of the world and who they think they are in relation to it. Constructivism aims to move towards a consensus with the participant, while remaining open to new interpretations of a construction as the discussion continues and as new interviews are held with other participants. In this way, researchers are not a neutral part of the process but construct meaning with the participant (Braun & Clarke, 2006). In the current study, the interviewer regularly checked their interpretation of each father carer's constructions by repeating key ideas to ensure that the father's meaning was understood, as well as by asking for clarification. Interpretation during this process is also dependent on an understanding of the particular context in which events occur. Participants' understanding of their world is influenced by previous events in their lives, and interviewers must gain a sense of the background of the people and events which impact how individuals interpret the world around them. By asking fathers about their family life at the beginning of the interview, and then guiding fathers to relate their experiences from the birth of their child to the present day, the researcher in the current study aimed to gain an understanding of the key people and events in the fathers' lives. This enhanced the researcher's grasp of the context in which fathers constructed realities were developed. In order to acknowledge the impact of the researcher on the inquiry and challenge any preconceptions held, the researcher engaged in constant reflection in the form of a research diary.

5.6.3 Inquirer/Participant relationship

The subjectivist epistemology in constructivism enables the researcher and participant to jointly create constructions and reach a consensus (Guba & Lincoln, 2004). Therefore, the interviewer and the interviewee influence one another as the data for the research project is collated, and the interviewer is not simply a neutral observer (Braun & Clarke, 2006; Charmaz, 2006; Rodwell, 1998). By engaging in lengthy and in-depth interaction, both participant and researcher can gain deeper insights into the phenomenon under study (Ponterotto, 2005). Co-creation of data through an interactive relationship between participant and interviewer was also adhered to in the current study.

5.6.4 Generalisation

According to the constructivist perspective, constructions which emerge from qualitative research are unique, and the exact conditions may never reoccur (Guba & Lincoln, 2004). The knowledge gained is impacted by, for example, the gender, ethnicity and socioeconomic status of both the interviewee and the interviewer. Therefore, there is no single truth which can be discovered (Braun & Clarke, 2006). It was assumed that fathers participating in the qualitative study would hold multiple perspectives and realities as individuals, and attribute different meanings to similar experiences (Crotty, 2003; Grbich, 2007). As a result, the findings are not intended to be viewed as generalisable to all older fathers of a son/daughter with intellectual disabilities (Grbich, 2007).

5.6.5 Causality

Causality is also not viewed as relevant by constructivists, who see reality and individuals as in a constant state of flux and mutual shaping, making cause and effect impossible to determine (Lincoln & Guba, 1985). As individuals can rethink and re-evaluate their situations, the course of action which they choose to follow can also alter depending on circumstances (Charmaz, 2017). Causality, in this setting, has also been described as simplistic and misleading (Appleton & King, 2002).

5.7 Operationalisation of Thematic Analysis

Having decided upon the general approach to the qualitative study, it was important to determine how thematic analysis would be operationalised in order to answer the study's questions. While flexibility is key within this methodology, various phases are involved in a constructivist approach to thematic analysis. These include an emergent design, entry, research design, data collection, data analysis, rigour, and inquiry product (Rodwell, 1998). These elements are discussed below, along with the methods of addressing each component within the current study.

5.7.1 Emergent design

Constructivist inquiry requires that the focus of the study is shaped by the researcher, participants, and themes identified through data collection and analysis (Rodwell, 1998). Themes or patterns within data are identified in a 'bottom up' or inductive manner in a constructivist driven thematic analysis and are considered to be 'data driven' (Patton, 1990). They should not therefore, be guided by the researcher's theoretical interest in the topic under study (Braun & Clarke, 2006). It is important to examine the fit of initial ideas with the data to ensure that the developed themes represent participant's experiences, rather than preconceptions of the researcher (Braun & Clarke, 2015). As a researcher brings a particular perspective to the study it is not possible to do this completely. Therefore, keeping notes about decision making brings greater transparency to the process and enables the researcher to reflect on the role they are playing in shaping themes. This advice was adhered to in the current study by recording initial thoughts and assumptions about the interviewer's research interests in a research diary, but continually comparing them to the data and dispensing with those which did not fit the data. Participants were also allowed to shape the inquiry in the current study through the use of semi-structured interviews, as the interviewer followed up on interesting and unexpected remarks that participants made, as well as engaging in topics or ideas that participants chose to discuss in depth. This afforded participants the opportunity to impact the direction of the interview, although the interviewer continued to act as the guide.

5.7.2 Entry

The methodological requirements of a constructivist inquiry include a natural setting, as a participant's reality cannot be separated from its context (Rodwell, 1998). This can be achieved by the researcher gaining some prior knowledge of the topic under study in order to determine what a natural setting would consist of in the particular situation (McMillan & Schumacher, 1993). Charmaz (2014) also advocates attempting to enter participants' settings and situations in order to gain a further understanding of their world. This requirement was accounted for in the current study by offering participants the choice of being interviewed in their own home or the University of Glasgow, depending on what was more convenient. Five fathers chose to be interviewed at home and two fathers chose to be interviewed at the University of Glasgow. The researcher prepared for the interview by reading guidance on conducting qualitative interviews and had informal discussions with supervisors and colleagues to assist with the design of the study and data collection, as recommended by Appleton and King (2002).

5.7.3 Data collection and analysis

Braun and Clarke (2006) identified six phases to a thematic analysis process. Familiarisation with the data is an essential first step in thematic analysis. This is achieved by constantly reading and rereading data collected from participants. Moving back and forth between data collection and analysis allows further familiarisation, and so these phases of inquiry are not linear as in some other interpretations of constructivism.

Coding in constructivist thematic analysis involves asking analytical questions of the collected data and writing down thoughts and ideas throughout the coding process. As well as providing a means of learning about participants' experiences, this also helps guide subsequent data collection. After reading an interview transcript, generating initial codes is the second phase in thematic analysis. This involves analysing the data in search of the participants' meaning and grouping pieces of the data into codes which identify a feature of the data that appears interesting to the analyst. Once all data has been initially coded and collated, the researcher begins the third phase of the process by constructing themes. During this stage of analysis, the initial codes are sorted into groups by considering how different codes may combine to form an overarching theme. This process forms an essential element of thematic analysis (Braun & Clarke, 2006; Alhojilan, 2012). Themes should be supported with adequate evidence, as Braun and Clarke (2006) suggest, such as quotations from participants to illustrate the meaning of each theme. A core idea or concept that underpins each theme must be identified, and this helps researchers to determine whether or not individual codes fit within a given theme. The potential relationship between different codes and themes is assessed during this process and results in a visual aid such as a 'thematic map' which illustrates these relationships. Some initial codes may become main themes, others may become sub-themes, while still others may be discarded or recoded. At the end of this phase, a number of candidate themes have been identified.

In phase four, candidate themes are reviewed to ensure that data within themes cohere together meaningfully and that there are clear distinctions between themes. Level one of this process requires that all coded data extracts within a theme be reviewed and assessed as to whether they form a coherent pattern. If they do not, further revisions of this theme are required. For level two, a similar process is adopted for the entire data set. In phase five, themes are defined and named. The validity of candidate themes in relation to the whole data set must be considered, as well as the accuracy of the meanings of these candidate themes (Patton, 1990). This process results in the creation of a thematic map, which illustrates the relationship between candidate themes (Bruan & Clark, 2006). Sub-themes within each theme are next identified, which provide structure to large and/or complex themes, as well as producing a hierarchy of meaning within the data.

Constant comparison is a method of analysis used throughout the coding process that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with code, code with code, code with category, category with category, and category with concept. Data units which do not appear to fit into an identified category are set to one side for later consideration, rather than discarded. Writing informal analytic notes, is another ongoing activity during this thematic analysis approach. This process encourages researchers to increase the level of abstraction of their codes and theories by taking time to stop and consider what data means and how it relates to other data and codes in the transcript. In the final phase a report is produced, offering a final opportunity to adjust the analysis and communicate the story of the data.

5.7.4 Rigour in thematic analysis

The issue of how to judge the quality of a thematic analysis has not yet been fully resolved. However, Braun and Clarke (2006) make various suggestions for how to protect against a poor-quality inquiry product. In theory, thematic saturation must be reached before recruitment of participants ends. Saturation in thematic analysis refers to the point when data collection can stop as there are no new instances of a category identified in the data (Braun & Clarke). As will be discussed later in this chapter, recruitment for this project was a very challenging process and the final sample consisted of seven fathers. Therefore, saturation was not achieved. However, multiple observations per father were included for most categories.

Braun and Clarke (2006) provide a 15-point checklist for a high-quality thematic analysis. These are divided into criteria related to transcription, coding, analysis, the written report, as well as the overall process. The first criteria is that the data has been transcribed to an appropriate level of detail and checked against the tapes for accuracy. This was achieved in the current study by transcribing interviews verbatim from the recordings and checking through the transcripts by listening to the tapes after the first draft had been produced.

Braun and Clarke’s criteria for coding were met as each data item was given equal attention in the coding process, themes were not generated by an anecdotal approach but by the researcher familiarising themselves with the data and considering all aspects of the data, all relevant extracts for all themes were collated, themes were checked against one another and against the original data set, and themes were also checked for internal consistency and distinctiveness. Discussions between the primary researcher and supervisors about the codes and themes in the data facilitated these checks.

Such discussions were also used to ensure that the necessary criteria were met for the analysis part of the process. Discussions were conducted about whether the data had merely been described or interpreted at a deeper level, the extracts for each theme illustrated the analytic claims, the analysis told a well-organised story about father carers experiences, and there was a good balance between analytic narrative and illustrative extracts for each theme.

Criteria for the written report were met in the current study by ensuring that the approach to thematic analysis was clearly explained. The researcher regularly checked Braun and Clarke’s six steps to analysis so that the process was appropriately followed, and remained aware that they were an active participant in the research process. Keeping a research diary increased the transparency of the research process and aided the researcher in avoiding the use of pre-existing categories by documenting ideas and themes as they developed and using interview data to keep these themes grounded in the data.

5.7.5 Inquiry product

The final methodological element of a constructivist approach to thematic analysis is the inquiry product. According to Charmaz, interviews are negotiated and contextual (Charmaz, 2006). Through an interview format the interviewer and interviewee can exchange and negotiate meanings so that the interviewer can build an understanding of the interviewee's world. Interviews are not neutral as they are influenced by the relationship formed between the interviewer and interviewee, and impressions brought to the interview. The interactive nature of a constructivist approach informs the inquiry product (Braun & Clarke, 2006). Researchers ask critical questions of the data from the first interview, and this informs their interpretation of the data and directs questions asked in later interviews. Researchers seek confirmation of their interpretations and adjust them as necessary, following further discussion and interpretation with participants. In this way, the researcher works with the participants to accurately interpret their meanings and perspectives.

5.8 Developing a tool

Interviews were seen as the most appropriate method of data collection for the current study, in order to obtain an in-depth understanding of fathers' experiences. There are a number of different styles of interview which can be utilised including unstructured, semi-structured and structured interviews. These differ in terms of how much control the interviewer has over the content and flow of the interview, with unstructured interviews providing the least amount of control for the interviewer and the largest amount of control for the participant.

5.8.1 Unstructured Interviews

Unstructured interviews are generally conducted without a pre-planned set of questions or a priori parameters that restrict the topics which can be investigated. Such an interview style resembles a free-flowing conversation more than an interview, except that the conversation is skewed to cover the interests of the interviewer (Grey, 2009). This allows participants to set the pace and extent to which they are comfortable talking about an issue. Unstructured interviews are often recommended for long-term fieldwork as it places limited restrictions on participants (Corbin & Morse, 2003). However, this style of interview may limit the interviewer's ability to gather specific information. An unstructured interview format was not selected for the current study as it would have restricted the interviewer's ability to explore all stages of the caregiving journey or to follow up on interesting points raised by participants in previous interviews.

5.8.2 Structured Interviews

Structured interviews involve the interviewer asking a series of standardised questions, with pre-determined follow-up questions. This style of interview is often used in clinical diagnostic interviews. Interviewers do not deviate from the order of questions or their wording, with the aim of increasing reliability and replicability of diagnosis (Mueller & Segal, 2014). Such a style of interview helps to keep the interviewee on topic. However, it lacks the richness of data which could be obtained from other forms of interviewing and restricts the interviewee's opportunity to elaborate on their answers and to create a shared meaning with the interviewer (Alsaawi, 2014). This interview format was therefore deemed unsuitable for use in the current project, as constructivist thematic analysis interviewing requires the topic guide to develop over time as new themes are identified in the data from previous interviews.

5.8.3 Semi-structured interviews

Semi-structured interviews were selected for the current study as it would allow an investigation of the topics of interest using an interview guide, and yet provide enough flexibility to pursue areas of inquiry which emerge during the interview and appear important to the participant. With this style of interview, an interview guide is often used to keep the interviewee focussed on the line of inquiry (DiCicco-Bloom & Crabtree, 2006). This style of interviewing fits with the constructivist approach to research as it allows the initial questions to develop into working hypothesis throughout the study. Constructivist inquiry places the researcher in the role of a learner and believes that it is not possible to approach a participant's constructed reality with a set of predetermined questions. As Guba and Lincoln assert: 'what is needed under these circumstances is a highly adaptable instrument that can enter a context without prior programming, but that can, after a short period, begin to discern what is salient and then focus on that' (Guba & Lincoln, 1989). Charmaz further supports the use of this method of qualitative research as the flexibility and level of control of the interviewer provide an excellent method of data collection (Charmaz, 2014).

Interviews which follow the constructivist thematic analysis method use flexible and emergent techniques. This allows for researchers to follow-up on ideas raised by interviewees. Emergent phenomenon must be investigated and their properties defined. For example, when the participant mentions a topic or an issue the researcher could ask what that topic or issue means to them. This method also emphasises the importance of language chosen by the participant and aims to understand both meaning and actions, and how people construct them (Charmaz, 2000). The constructivist focus of the interviews centres on eliciting participants' interpretations, assumptions, and implicit meanings. Therefore, the questions for the current study were broad and continued to develop with each interview.

5.8.4 Ethics

In-depth interviews, particularly on sensitive topics such as mental health, can stir up powerful emotions in the participant (Morse et al., 2002). Therefore, it is of vital importance that the researcher considers how to protect the well-being of the participants. In the current study this was done by debriefing fathers after the interview and sign posting them to organisations, such as Enable Scotland, which could offer them further support if required. Prior to the commencement of the interview, fathers were informed that they could stop the interview at any time or chose not to answer any questions with which they were uncomfortable. When fathers became upset during an interview, they were asked if they would like to terminate the interview or if they would like to take a break before continuing. However, no father chose to end the interview and all fathers wanted to continue even after becoming upset.

5.8.5 Consent

Each participant was informed of the aims and objectives of the study, as well as the reasons why they had been selected to take part. They were issued with a Participant Information Sheet (Appendix D), Consent Form (Appendix E) and a stamped and addressed envelope for returning the Consent Form. Participants were instructed to return the signed consent form in the pre-addressed envelope if they wished to participate in the study, or to contact the researcher using the email address provided in the Participant Information Sheet. They were informed that they could withdraw consent to participate at any time during the interview and were provided with contact details of the researchers should they wish to ask any questions about the study prior to giving their consent.

5.8.6 Confidentiality and anonymity

Confidentiality and anonymity are ‘primary safeguards against unwanted exposure’ (Christians, 2013). Participants were informed that their information would be treated as strictly confidential and stored anonymously. The participant information sheet made clear that while direct quotes would be used, the participants name or any other names given in the interview would be changed and that only members of the research team would be able to access this information. Each participant was assigned a pseudonym for the interview transcripts and in the writing of the final report. They were also informed that data collected during the study would be entered into a database and access, confidentiality and security would be maintained according to the regulations outlined under the University of Glasgow regulations and the Data Protection Act (1998). Data was stored on a University of Glasgow laptop, encrypted to NHS standards. Paper copies of anonymous data was stored in a locked filing cabinet at the Psychology Department, Administration Office, Gartnavel Hospital. Transcriptions will be kept for 10 years before being destroyed, in line with University of Glasgow policy. Recordings were deleted as soon as they had been transcribed.

5.9 The Qualitative Study

The qualitative study involved conducting in-depth interviews with the intention of gaining a greater understanding of the experiences of older fathers’ caregiving journey and its impact on their mental health. A further aim was to capture the meanings and interpretations of older fathers’ experiences of caring for their son/daughter with intellectual disabilities.

The inclusion criteria for the study were as follows:

o Fathers must provide care for their son/daughter with intellectual disabilities.

o Fathers must be at least 60 years of age.

o Fathers must be able to provide informed consent.

o Fathers must be fluent in English.

5.10 Procedure

5.10.1 Locating and recruiting participants

Participants were identified through relevant charitable organisation's records of their service users and their families (Enable Scotland, PAMIS, Turning Point Scotland, Capability Scotland, Share Scotland, Glasgow Disability Alliance, Carers Scotland, Carers Trust, Age Scotland, Independent Age, Talking Matts, Down Syndrome Scotland, Inclusion Glasgow, Garvald Edinburgh, Thistle Foundation, Sense Scotland, Quarriers, Father Network Scotland, Edinburgh Carers Council, Home Start Scotland, and Cross Reach). The research team had pre-existing links with some of these charities and the project was discussed with staff at these organisations. Information was provided about the study and the inclusion criteria, and the participant information sheet and consent form were discussed. Potential participants were identified and provided with a participant information sheet, cover letter, consent form and a stamp addressed envelope. The participant information sheet instructed participants to complete and return the consent form to the research team if they were interested in taking part. If participants preferred, staff indicated that they could contact the researcher by email, using the email address provided in the information pack. Participants were also located through social media channels of relevant charitable organisations. The tweet which was posted was as follows:

We are looking for #fathers of a son/daughter with #learningdisabilities aged 60+ to take part in our exciting new project. Check out our website https://www.sldo.ac.uk/projects/carers-and-families/carers/ or email k.dunn.1@research.gla.ac.uk to find out more

In accordance with a constructivist thematic approach, participant recruitment in the current study used purposive sampling, where any interested fathers who met the inclusion criteria was accepted into the study. As will later be discussed in this chapter, recruitment for the study was challenging and only 7 fathers were identified who met the inclusion criteria. It has also been noted in the literature that fathers are a notoriously challenging group to recruit for research (Carpenter & Towers, 2008; May & Fletcher, 2013). It has been suggested that this is partly due to fathers' inaccessibility during working hours, a lack of visibility to services, and beliefs that mothers are best able to answer questions about their children (Carpenter & Towers, 2008).

5.10.2 Interview Schedule

An interview schedule was designed for the semi-structured interviews (Appendix F) to investigate the experience of caring for a family member with intellectual disabilities over time, and the impact on their mental health and well-being. A historical approach was taken to questions, with the interviewer guiding the participant through their child's early years up to the present day. This style of interview was chosen to put participants at ease and allow them to tell the story in their own words. An initial interview guide was developed which began with the question 'Can you tell me a bit about your son/daughter and your family life'. This was designed to provide participants with a familiar topic and to gain information about their background and personal circumstances. If they did not volunteer demographic information such as their own age and age of the child who they cared-for when answering this question, they were asked for it more directly. The first question was also designed to focus the participants' attention on the topic at hand and to encourage them to open up and talk about their experiences.

From this point on, the interview schedule consisted of a number of experience questions which covered the course of their caring journey. For example, fathers were asked 'what were the early years like caring for your son/daughter?' This question was chosen to encourage fathers to reflect back on the beginning of their caring journey, and to make comparisons between their experiences then and now. As fathers had been caring for a number of decades, whether fathers felt that their role and experience of caring had altered over time was of interest to the researcher. Opinion questions such as ‘what things have helped you in your caring role?’ were asked to form an understanding of the sources of support that fathers found useful, which could better inform policy makers and practitioners on how to support fathers of a son/daughter with intellectual disabilities.

The constructivist thematic analysis approach (Braun & Clarke, 2017) adopted for analysis emphasises the importance of theory emerging through inquiry and being grounded in the data, rather than being developed prior to data collection. It is therefore important that interviewers are not guilty of fitting data into preconceived categories identified in the existing literature. Some of the questions on the interview schedule did cover issues which have been reported in the literature. For example, one of the first questions asked in the interviews was ‘what was it like when your child was born?’ This could have resulted in parents touching on the experience of receiving a diagnosis for their child, which is well documented in the literature. However, this was not due to forcing the data into this category, but rather a desire to have fathers reflect back upon their whole caring journey to gain an understanding over the entire caregiving trajectory. As a result, interview questions touched on issues such as their child’s birth, entering and leaving the school system, current experiences, and looking into the future. The study’s themes were not, therefore, directly influenced by previous research. Various steps have been identified to protect against forcing data into preconceived categories in constructivist thematic analysis. One such step which was taken in the current study was to revisit the interview schedule after each interview and alter questions to reflect any new ideas or concerns raised in previous interviews. This helped to prevent the researcher continuing along a line of inquiry which was not relevant for the interview participants (Charmaz & Belgrave, 2012). A further step taken was to create memos for each developed category, using raw data from interviews to support points made within these memos. By following this strategy, participants’ voices and meanings, rather than preconceptions of the researcher, guide the theoretical development of categories (Charmaz, 2000).

5.10.3 Conducting interviews

Once participants had contacted the research team to indicate their consent, an interview was arranged at a date, time and location of the participants choosing. Interviews took place either in participants' homes or at the University of Glasgow, whichever was most convenient for the father. Arrangements were made via telephone or email and the details of the interview were then confirmed prior to interview. Contact details for the research team were made available to the participants to allow them to ask any further questions or change/cancel the interview.

The interviewer arrived promptly for each interview, to ensure that fathers felt that their time was valued and their contribution to the study was appreciated. Prior to commencing the interview, fathers were once again shown the participant information sheet, encouraged to ask any questions that they had and asked to sign the consent form. Fathers were asked for their permission to tape record the interviews and reminded that they could stop the interview at any time. The interviewer had familiarised themselves with the interview schedule prior to the interview, ensuring that questions could be asked in a relaxed and conversational manner. When fathers gave a vague response to a question, the interviewer repeated their statement as a question or asked for clarification.

Two fathers became visibly upset during the interview and were asked if they would like to stop the interview or take a break. However, in both instances they wanted to continue and just took a few moments to compose themselves. The interview was brought to a close when no further new information was being produced or when the participant appeared tired. At the end of each interview the interviewer summarised the topics that had been covered and participants were asked if there was something else which they would like to mention which had not been discussed. All participants were sent a £20 Marks and Spencer voucher and a letter thanking them for giving up their time in order to be interviewed for the study. However, the voucher was not used as an incentive for fathers to take part in the study and participants were unaware that they would receive this upon completing the interview.

5.10.4 Verifying accounts

A field journal was kept during the course of the qualitative study. An entry was made within 24 hours of each interview in order to avoid the interviewers' memory of the interaction altering through the passage of time. A further reason for the importance of the field journal is the acknowledgement of the researchers influence as recognised by constructivist thematic analysis (Braun & Clarke, 2006). Researchers pursuing this methodology should enter the analysis stage with as few preconceptions as possible, and field journals help the researcher to become aware of their preconception as well as to gain insights from the interviews. Each entry contained details such as the context of the interview, discussion with supervisors, insights gained from the literature or through contact with other carers.

A written summary of each interview was produced and sent to the participant for review. Participants were invited to make any corrections where their meaning had been misinterpreted and to add any further information. This summary was provided along with a pre-stamped and addressed envelope in order to allow participants to return the summary to the research team. All fathers responded and were largely happy with the account of the interview, with only one father asking that a quote from the bible be included to summarise his experiences.

5.10.5 Data analysis

A large volume of rich data was derived from the interviews. Each interview was transcribed and imported into NVIVO software which was used for data management. The analysis was conducted manually in order to allow immersion in the data, in keeping with the constructivist approach. As previously noted, data analysis proceeded in parallel with data collection. In accordance with constructivist thematic data analysis, a bottom-up approach was used to identify categories and themes rather than forcing data into predetermined categories.

Reviewing themes is the next stage of the data analysis process (Braun & Clarke, 2006). This took place in the current study by comparing sections of data with the same code within each interview. The researcher assessed if the same underlying meaning was present in both sections of data. When this was the case, both sections of data retained the same code, and the data was recoded with a more appropriate label when this was not the case. This procedure was applied across, as well as within, interviews. The researcher spent long periods of time familiarising themselves with the data in order to apply this process of constant comparison. Later interviews often resulted in previously coded data being recoded and the theoretical framework adjusted, as the researcher gradually immersed themselves in the data and gained a greater understanding of the participants' worlds.

This chapter has provided an account of the methods, and their rational, used to inform the qualitative study. The results of the qualitative study will be discussed in detail in the following chapter.

Chapter 6: Results of the Qualitative Study (Study Two)

6.1 Introduction

This chapter presents findings from in-depth analysis of data from seven interviews with fathers who had a son/daughter with intellectual disabilities. As outlined in the previous chapter, interview data was collected and analysed using Braun and Clarke's (2006) approach to constructivist thematic analysis. The overall purpose of the qualitative component of this project was to increase our understanding of the experience of older fathers who have been caring over a prolonged period of time. This knowledge will provide a clearer understanding of the needs of this population for practitioners and policy makers, enabling them to cater the provision of supports and services appropriately for fathers.

Participants provided rich and detailed descriptions of their life with their son/daughter with intellectual disabilities. All fathers were at or approaching retirement and had been caring for their son/daughter for a number of decades. Fathers had experienced a variety of challenges and rewards as part of their caring role over the years and discussed their journey from the offspring's birth and diagnosis, up until the present day, as well as speculating about what the future may hold for themselves and their son/daughter. While this was not part of the study's inclusion criteria, all fathers who participated in the study were married and living with their wife. Demographic information for the included fathers is presented in Table 9, and a profile of each father is included in Appendix G.

While fathers' experiences differed, their accounts revealed a number of common themes. Fathers reflected back upon their caring journey and felt that their lives had been forever changed by parenting a son/daughter with intellectual disabilities. This experience had led them to view their lives and the world around them in an entirely different manner, as if through a different lens. A narrative summary is provided below, detailing the themes and subthemes.

Themes are also represented in Figure 15, which provides a means of organising the themes. Quotations from fathers are presented to provide support for interpretation of themes. Fathers quotations throughout this chapter have been adjusted to remove hesitations such as ‘eh’ or ‘hmm’ when this does not alter meaning, and colloquialisms have also been changed to plain English to facilitate understanding of the reader.

Table 9- Participant demographic information

Father pseudonym	Age of father	Father employment status	Number of offspring in family	Age of child	Gender of offspring	Severity of offspring’s ID*
Mr Walker	64	Retired	1	28	Female	Moderate
Mr McKay	68	Retired	2	37	Female	Profound
Mr Thomson	64	Full-time employment	3	28	Female	Moderate
Mr Hughes	64	Unemployed	3	29	Male	Severe
Mr Murphy	60	Full-time employment	3	34	Male	Mild
Mr Kendall	61	Unemployed	1	28	Male	Mild
Mr Lampton	66	Semi-retired	3	33	Female	Profound

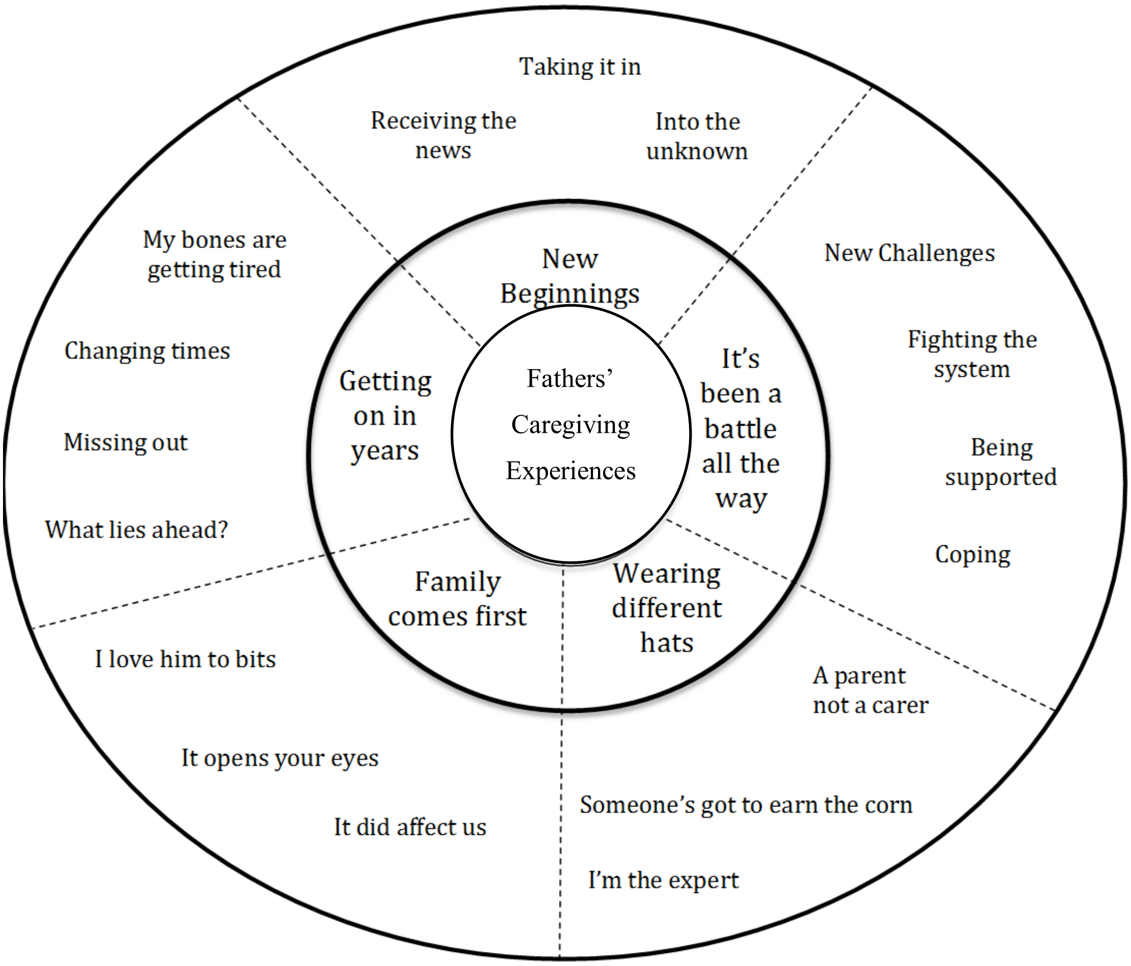
*intellectual disabilities

The study’s themes are as follows:

1. New beginnings: Fathers discussed their initial experiences of becoming not only a parent but a parent of a son/daughter with intellectual disabilities.
2. It’s been a battle all the way: Fathers came to accept their offspring’s intellectual disabilities, became acquainted with their son/daughter’s needs and fought to fulfil these.
3. Wearing different hats: Fathers perceived themselves to have various identities in addition to that of father– such as main breadwinner or expert.
4. Family comes first: Family was highly valued and prioritised by fathers, who saw both the benefits and challenges of having a son/daughter with intellectual disabilities for the family unit.

5. Getting on in years: Fathers reflected back on their caring journey, how their caring role has changed as they have aged, and what the future might hold for themselves and their offspring.

Figure 15: Thematic analysis themes and sub-themes



6.2 New Beginnings

6.2.1 Overview of 'New beginnings'

Fathers discussed their experiences of becoming a father of a son/daughter with intellectual disabilities. None of the fathers interviewed knew that their offspring would have intellectual disabilities prior to birth, and so this had been a new journey down an alternative path for them. Fathers had been unsure what this diagnosis would mean for their son/daughter or themselves going forward, and remembered feeling that they were entering unchartered territory or a ‘new beginning’. ‘New beginnings’ is now discussed within the context of three subthemes associated with this first analytical category. While not every father touched on all of these subthemes, they provide a general representation of the fathers’ experiences. These subthemes are outlined below:

- How they told me still matters: how medical professionals informed fathers of their offspring’s condition, and the impact that this had upon them.
- Taking it in: the early days after their son/daughter’s birth or diagnosis, when fathers were trying to take in the news and adjust to the unexpected situation.
- Into the unknown: After receiving a diagnosis or indication that their son/daughter will experience difficulties, fathers were unsure of what to expect for their offspring.

6.2.2 ‘How they told me still matters’

The way that fathers received the news that their son/daughter had intellectual disabilities varied but most recalled the incident vividly. This was an event in their lives that had affected them deeply and fathers remarked on the manner with which this news had been delivered. Medical professionals often gave parents hope and a much-needed life raft to cling to in these early days when they received the unexpected news:

> “*And I have to say the one person’s words that I have never forgotten, and often repeated, was the consultant paediatrician who said to us the day he was born, and I quote ‘Stimulate this child as much as you can and you will be amazed at what he will achieve’.*”
> (David Murphy: Interview 5)

Equally, early negative interactions with medical professionals had stayed with fathers. Fathers felt particularly angry or resentful towards medical professionals who had informed them of their son/daughter’s condition in an unthoughtful or tactless way. These encounters were described heatedly by fathers who could quote exactly what had been said to them decades later:

"*Those words burned into the side of my head 'She'll never walk, talk, see or hear. Your daughter's a vegetable' will never go away... The American doctor I'll never forgive. Never! I thought her attitude was absolutely abysmal*".
(Neil Walker: Interview 1)

Regardless of how the news had been delivered, fathers began to gradually take in their son/daughter's diagnosis and come to terms with what it might mean for them. This will now be discussed in the sub-theme 'taking it in'.

6.6.3 'Taking it in'

A diagnosis of intellectual disabilities was given to their offspring at or soon after birth for four fathers. Most described this as being a great shock to them, and something that they had not foreseen. Three other participating fathers had suspected that something was wrong but didn't receive an official diagnosis until years later. Fathers described how they began to take in this unexpected information after they had received the diagnosis. Processing the news had taken some time and coming to terms with the diagnosis had been one of gradual acceptance:

"*Very, very sad prognosis, but once you learn a wee bit more about it and you settle down, becomes a bit more bearable and you get a wee bit more hope.*"
(Neil Walker: Interview 1)

Part of 'taking it in' had also involved coming to terms with the different expectations that fathers had for their offspring, and how some of these expectations had to change post-diagnosis. This was a form of grieving for the son/daughter they had expected to have and fathers admitted that they had struggled with the implications of their offspring's condition:

"*One of the things when I first got told, and it's stupid and you've probably heard it before, 'It means he'll never be able to sit his driving test'. And I actually broke down in tears that day when I heard that. And I thought 'How stupid is that?' I mean it's another 18, well 17 years away. Why are you getting upset about that now? But it was just when you heard that, that's when you realise you've got a disabled kid.*"
(Larry Kendal: Interview 6)

Coming to terms with the idea that their offspring had intellectual disabilities and may be restricted in what they could achieve in life had been a difficult transition for fathers. This was especially challenging as most fathers were not initially given a clear idea of what specific restrictions or additional difficulties their son/daughter might face. They remembered having a feeling that they were entering a new stage in their lives, but what that stage would look like was relatively unknown. This will now be discussed in the sub-theme 'into the unknown'.

6.2.4 'Into the unknown'

Even when fathers had been made aware early on that their son/daughter had intellectual disabilities or slow progress, the majority did not have a clear idea of the extent of the disability or what this would mean for their offspring's development or future prospects:

"*You're told 'disabled' and you think 'Oh she might not be able to walk very well, might be in a wheelchair, might have a problem with her arm'. They didn't know exactly what they were talking about.*"
(James McKay: Interview 2)

Fathers felt that they had often been given worst case scenarios by medical professionals, and had been unsure how closely their own son/daughter would fit this pattern. Happily, in most instances, fathers felt that their offspring had overcome the odds and had exceeded doctors' initial predictions. Fathers expressed relief that their son/daughter was able to do more than had been initially suggested. One father felt it was not helpful to have been given the worst-case scenario in the beginning:

"*I mean, we were told that Rachel was never going to sit up. We were told she would never walk or talk. And you see her out there, you know? She'll have a conversation with you, and sometimes it's more meaningful than others. But she can express her needs, her desires and stuff like that. She can let you know when she's not happy, things she enjoys, things she doesn't like, which is a vast, vast difference from what we were told to expect. And I think we were probably…. I don't think it was a good thing to be told all that.*"
(Greg Thomson: Interview 3)

While some fathers were relieved that the worst-case scenario had not occurred, others confessed that things had been harder than they had initially anticipated:

"*I remember one time going back home from the hospital, driving the car and praying to God saying 'You know I'll do anything if you just make sure she's ok. You know? I don't mind her being in a wheelchair or something like that'. Because we didn't realise exactly how Jessica was going to turn out. I just wanted her to live, but it was harder than we thought it was going to be.*"
(James McKay: Interview 2)

6.2.5 Summary of 'New beginnings'

This analysis revealed that the early days, when a father's son/daughter had received a diagnosis or when they themselves had suspected that something was wrong, were characterised by the realisation that this was a new beginning for them. Fathers remembered feeling despair and panic when they realised that their offspring would have a life-long disability. However, over time they began to process the information and to come to terms with what this would mean for them and their offspring. At the same time, many had experienced stress and worry as they had not anticipated or planned for this new beginning. Most had not fully understood what this new beginning would involve and had felt that they were heading into the unknown. This had been a frightening prospect for fathers who had just wanted the best for their son/daughter.

Once fathers had come to terms with their offspring's condition, they had begun to realise how their son/daughter's life would be impacted by the diagnosis. They had learned what they could do to ensure their son/daughter had the best possible quality of life and had fought to secure these necessary services and supports. This experience was captured in 'it's been a battle all the way'.

6.3 It's been a battle all the way

6.3.1 Overview of 'It's been a battle all the way'

'It's been a battle all the way' captures the process of a father facing the unanticipated situation of being a father to a son/daughter with intellectual disabilities and taking on the responsibility to provide their offspring with the best life possible. Taking up this challenge had involved 'fighting the system' in order to obtain necessary services and supports. Through this advocacy role they had encountered, what they had perceived to be, flaws in the system which they had to navigate round or overcome. They had been helped in part by the people and organisations which had supported them in their role or they had felt hindered by those who were seen to create further difficulties in their lives. 'It's been a battle all the way' is now discussed within the context of the four subthemes associated with this second category. Every father touched on all of the subthemes in this category and their experiences built a picture of what their caregiving role had involved over the years. These subthemes are outlined below:

- Taking on new challenges: Fathers faced numerous new and unforeseen challenges in caring for their offspring.
- Fighting the system: Numerous aspects of the system were described as obstacles to obtaining necessary supports and services for their son/daughter. Fathers felt that to gain necessary supports and services for their offspring it had been necessary to fight for them.

- You do need the help: The individuals and/or organisations which had served as a source of support for them during their caring journey, and how this helped to protect their well-being were discussed.
- Coping strategies: Fathers had employed various coping strategies, either consciously or unconsciously, to deal with the day-to-day stressors and demands of their caring role.

6.3.2 Taking on new challenges

Taking on the role of carer had presented fathers with a series of new and unforeseen challenges. These had included financial strain, challenging behaviour, their offspring's health issues, and many more. In the early years of their son/daughter's life, many fathers experienced a number of difficulties associated with their offspring's sleep and health problems. In many cases these issues had a seriously detrimental effect on the father's well-being:

"*Not only did she not sleep, she would stand at her door and scream at the height of her voice all night long. We never ever got to the back of it. We were at sleep clinics, we had specialists in. It was absolutely horrendous! Then you thought your world was coming to an end.*"
(Greg Thomson: Interview 3)

Having a son/daughter with intellectual disabilities had also put a financial strain on fathers. One father had been on a very high income prior to leaving work to care for his son. He had struggled with the disparity between what they had previously been able to afford, and what was possible now on a significantly reduced income:

"*But financially it's been, it's not been a struggle, but obviously when you've been used to a certain income… you've sort of given up on all your pension rights as well. It was a bit of a struggle to begin with.*"
(Larry Kendall: Interview 6)

Three fathers also described the challenging behaviour that their son/daughter displayed. Mr Hughes had found that his son's challenging behaviour had become worse when his son reached puberty:

"*It's a big strain because you don't know what's going to happen next. A situation can develop in seconds, not minutes, seconds. And I mean seconds*."
(Martin Hughes: Interview 4)

Perhaps the most significant challenge which all fathers had faced was in obtaining appropriate and much needed services and supports for their son/daughter. The struggle that fathers had faced while trying to achieve this will now be discussed in the sub-theme 'fighting the system'.

6.3.3 Fighting the system

Feeling that the only way to obtain the necessary supports and services for their son/daughter was by 'fighting the system' was expressed by all fathers. The language that they used to describe this aspect of their caring role such as, 'battle', 'fight' and 'struggle' indicated that obtaining the necessary services had never been an easy task and instead had been a constant challenge. This was something which fathers were deeply frustrated by and which had taken a significant toll on their well-being.

"*.. but it's been a battle all the way. And that's probably had more of an effect on my mental health than actually having to deal with a son with learning disabilities, if I'm honest about it.*"
(Larry Kendall: Interview 6)

Fathers identified numerous flaws in the system which had seemed to operate as barriers to accessing services. As a result, fathers had taken on the role of advocating for their son/daughter in order to ensure that they received necessary supports and services. 'Fighting the system' is now discussed under two sub-headings associated with this category: 'there were so many barriers in the way', and 'beating the drum'.

There were so many barriers in the way
Fathers identified a number of barriers which had prevented their son/daughter from accessing services or had resulted in low quality services. For example, cuts to services and a lack of funds had regularly impacted fathers. Mr Walker spoke of a time when his daughter had had all of her benefits cut following a medical assessment which he felt was a totally inaccurate representation of his daughter, her health and her abilities:

"*.. according to this chap Michelle could have been in line for the Olympics, probably the marathon. Because when I read his report, it certainly wasn't about Michelle. And I tried to take that further, with the result we went through an extremely stressful time.*"
(Neil Walker: Interview 1)

Issues with respite was another common complaint. Obtaining respite was a difficulty that many parents had experienced:

"*We relied on respite, but again, it was a real struggle getting the council to agree to appropriate respite.*"
(Martin Hughes: Interview 4)

This had caused a lot of stress and had interfered with fathers' abilities to participate in support groups and other activities that they valued. Even when fathers had been able to obtain respite or other necessary services, they were often faced with further difficulties and felt that they could not always rely on receiving high quality services. One father had often spent time in hospital to care for his son as he had not been confident that hospital staff had the necessary knowledge and training to look after him:

"*I mean I've lost count of the number of times I've slept on hospital floors. And you know the nurses will say 'Why do you stay? We're here?' and I went 'Well do you know anything about Cerebral Palsy?' 'Eh no' says 'Well see with cerebral palsy, if Jack is sick he throws his head back and inhales his vomit and*

is dead in 30 seconds that's why I stay with him'. 'Oh, but we're here' I says 'So you're going to have somebody sitting with him 24 hours a day, I don't think so'."
(Larry Kendall: Interview 6)

The transition between child and adult services was another area where fathers identified flaws in the system. There had often been difficulties obtaining a placement for their offspring after leaving school and this had caused a great deal of anxiety and worry. Fathers relayed that it had been necessary to begin planning for transition far ahead of the age when their son/daughter had been expected to leave school. This was seen as the only way to ensure children could transition seamlessly between school and their next destination:

"*Hectic! It wasn't easy, there were so many barriers in the way. The only thing I can say is, because we started early, she was ready when she left school.*"
(Nigel Lampton: Interview 7)

Beating the drum

The various flaws in the system which had served as barriers for their offspring obtaining high quality services had led to fathers taking on the task of advocating for their son/daughter:

"*I saw it as this as a battle I have to fight on his behalf, an advocacy kind of role for the chap who can't speak for himself.*"
(David Murphy: Interview 5)

Fathers had developed different strategies for accessing what they needed from the system and to advocate for their son/daughter. While the tactics that fathers had developed differed, the need to constantly push for services was expressed by everyone:

"*So, we've always been quite lucky in that we've always had respite. Some people aren't getting respite at all. How they cope… I've no idea. But, only because of, you know, beating the drum so to speak.*"
(Larry Kendall: Interview 6)

Fathers found that challenging decisions made by social work or the council had often been successful in obtaining more or better-quality help. This had been particularly true when they found evidence of another family receiving the help that they themselves were seeking:

"*And oh, they said 'Oh no, you can't do that. You've got to go away to (city), transport and all that'. And we said 'Well there's transport from this area, other people from this area go, and we can name them.*"
(James McKay: Interview 2)

At times fathers had felt that the system was set against them and that they were constantly fighting to meet basic needs. However, there were various individuals and organisations where fathers had turned to for support during their caring journey, and these will now be discussed under the sub-theme 'you do need the help'.

6.3.4 You do need the help

Support for fathers had been offered, sought and received in many forms from formal and informal sources. For example, assistance with physical caregiving tasks, financial assistance, emotional support, advice, and time away from their caring role in the form of respite. Many fathers spoke of family members, their local church community, and other parents as having been essential for supporting them in their caring role. More formal sources of support were also discussed such as social workers, teachers in their children's school, and health care professionals. 'You do need the help' will now be considered under two sub-headings: informal support and formal support.

Informal Support

Fathers identified numerous informal sources of support and the positive impact that this had had on themselves and their son/daughter. Each father had a unique set of family circumstances, yet six of the seven fathers attributed at least one family member as having been an important source of support for him in his caring role. Only one father directly identified his relationship with his wife as a source of support:

"*I've seen so many marriage break ups because of it. They've not been able to cope with the situation and, you know? The relationship between the mother and the father becomes fragmented and they end up going their separate ways just because of that. I've been lucky. I've always had a strong marriage and we've always been able to kind of support each other.*"
(Nigel Lampton: Interview 7)

The fathers' existing circle of friends were also often referred to as being supportive. Where this was the case, fathers described themselves as having primarily drawn their support from this source:

"*And I've got so many friends. There's a big circle. We didn't need anybody else.*"
(Neil Walker: Interview 1)

Other parents were identified as having been another valuable source of support by many fathers. Parents had been able to give advice on where to access services or how to best approach social work on different topics. Fathers often felt that information obtained from parents had not been offered from more official channels such as social work or the council:

"*I think without the information you get from other parents and other carers and what have you, you would be lost, you know? Because it's other people's experiences ... it's only people that have been there and done it who can tell you that. The same way, various services, charities, volunteers and all sorts of stuff.*

It's word of mouth. 'Oh, I've heard they can do this for you, they can do that'. It's invaluable information you get from other parents."
(Greg Thomson: Interview 3)

Many of the fathers were, or had been at some point in their lives, involved with their local church. For some, being part of their church had served as an important source of support and they felt that their son/daughter had been included in the church community:

"*So, we've not thrown ourselves into the (Down Syndrome charitable organisation), as some people do. That just …. I think part of that is because our big involvement was with another community, it was the church community. And that community fulfilled not just some of our needs and interests, but also the family's.*"
(David Murphy: Interview 5)

Most fathers spoke enthusiastically about their experiences with charities that support individuals with intellectual disabilities. Mr Walker's daughter was heavily involved with a charitable organisation which runs various clubs and training sessions. The majority of her social life had stemmed from this charity and Mr Walker was full of their praises:

"*So (charitable organisation) is a God send.*"
(Neil Walker: Interview 1)

Formal Support

Fathers' attitudes to formal sources of support reflected their experiences with individuals from those organisations. Many fathers had had very positive experiences while others had been less fortunate and had become very sceptical of any formal supports.

Most fathers had anticipated that their son/daughter would attend a similar type of school to themselves and had experienced initial disappointment at the thought of them going to a ‘special school’. However, fathers were universal in their appreciation for the attention and help that these schools had provided their son/daughter:

“*When you went in it was wonderful! The atmosphere, the teachers just the oh, it was lovely, just brilliant. You felt right at home when you went in.*”
(Larry Kendall: Interview 6)

Fathers had often received support from personal assistants (PAs) and paid carers who were generally highly spoken of. This had provided a much-needed break for the family. In some instances, the same carers had been working for the family for many years and had become more like family than formal carers:

“*So, probably them more than anything have been sort of a life saver ... They’re like family, I mean they really are, they’re like family.*”
(Larry Kendall: Interview 6)

Respite was another commonly discussed source of support. This had provided not only a much-needed break for fathers, but also an opportunity for their offspring to socialise and take part in different activities. According to most fathers, their son/daughter loved attending respite services:

“*She loves it! And we enjoy it too. We know she’s being well looked after, she’s happy. When she comes back she’s always happy.*”
(Nigel Lampton: Interview 7)

While fathers could turn to a number of sources of support to help them through challenging times, it had often been necessary to adopt coping strategies of their own to navigate their caring journey. These will now be discussed under the sub-theme ‘coping strategies.’

6.3.5 Coping strategies

In order to deal with the challenges and strains of caring, fathers had employed a number of coping strategies over the years. These ranged from finding humour in difficult situations, to focussing on the positives, to taking things one day at a time. The exact strategy or strategies that fathers had relied upon varied, but all fathers discussed or implied using them.

Comparison was a common topic throughout the interviews. Fathers had looked to others in similar circumstances to compare how well they were doing or what services were being provided for them. This appeared to have been used as a coping method by some fathers who were able to say ‘it could have been worse’:

“*All in all, it could have been a lot worse. He could have been a wee boy who just wasn’t happy with his life and just constantly down. He has his moments but on the whole, he’s quite enjoyable to be around. And that’s sort of made it a lot easier for me*”.
(Larry Kendall: Interview 6)

Similarly, fathers had compared their son/daughter to other individuals around them, such as those in their family. This had sometimes been upsetting as fathers saw other people’s offspring making strides towards independence or engaging in activities that their son/daughter could not participate in:

“*We both get upset. When the two girls got married there I thought ‘that’s the last one’ because Sophie will not be. I find that quite hard. I wasn’t bitter, I just find it disappointing. I’ve got three girls, only two of them getting married. You know, that was the last one.*”
(Nigel Lampton: Interview 7)

The use of humour and focussing on the positives were other common coping mechanisms. As there was nothing they could do about their son/daughter’s condition it was considered unhelpful to wallow in the negatives:

"*As I say you wouldn't meet a nicer person. And it's a great comfort to know that she'll never do any harm. Not many parents can say that. That's it, I always look at that as the bright side*."
(Neil Walker: Interview 1)

"*See when you're from a certain generation, probably you're picking it up from your parents who went through the war, and you know adversity. This is what it's like. You just need to get on with it, just need to grit your teeth and do it.*"
(Larry Kendall: Interview 6)

One father acknowledged that, while he always tried to focus on the positives, there were times when he had wished things could be different. However, he had found admitting this to himself to be a helpful way to work through this feeling:

"*I think it's ok for anybody to have moments when they wish things were otherwise but ... and I think it's healthy to admit to that. And in being able to talk about it gets rid of it in a way, gets it in the right perspective*."
(David Murphy: Interview 5)

6.3.6 Summary of 'It's been a battle all the way'

Fathers had faced various new challenges throughout their caring journey which they had initially felt unprepared for. They had gradually made adjustments in their lives in order to accommodate their offspring and to deal with the new challenges they faced. Various aspects of the social and care system had often increased fathers' stress and anxiety. These issues within the system had resulted in a cynical outlook for many fathers, who had felt that the system was designed to prevent their son/daughter accessing services. By taking on the position of advocate for their offspring, fathers had fought for services and supports to help their son/daughter. Being well supported and adopting coping strategies had helped parents to navigate their caring journey and to successfully take on the role of a carer for their son/daughter.

While the role of father was evident throughout the interviews, fathers also emphasised that they had identified with a number of different roles during their caring journey. These roles will now be discussed under the sub-theme ‘wearing different hats’.

6.4 Wearing different hats

6.4.1 Overview of ‘Wearing different hats’

‘Wearing different hats’ captures how the caring journey had impacted fathers’ sense of identity. A father’s perception of their own identity came up regularly throughout the interviews and included that of parent, expert in their offspring’s care, and main breadwinner. Switching between these identities as the situation demanded, or ‘changing hats’ as one father described it, had been a common experience for fathers. ‘Wearing different hats’ is now discussed within the context of the three subthemes associated with this category. Not every father touched on all of subthemes in this category, as not every identity applied to each father, but their individual experiences built a picture of how they perceived their caregiving role and their other identities. These subthemes are outlined below:

- A parent not a carer: Fathers considered themselves to be parents of their son/daughter with intellectual disabilities in the same way that they were parents of their other offspring, and that ‘carer’ was an inaccurate label.
- Someone’s got to earn the corn: Fathers considered themselves to be the main breadwinner for the family, while their wife cared for their son/daughter full-time.
- I’m the expert: Fathers described being experts in their offspring’s care as they had learned how best to support and care for them.

6.4.2 A parent not a carer

The role of parent to their son/daughter with intellectual disabilities had clearly been a very important part of their identity. As a father, they had taken on various tasks such as physical caregiving activities, fighting for services, advocating and generally trying to improve their offspring’s quality of life. Fathers emphasised that their role had been one of a parent, rather than a carer, and that all caregiving tasks and activities that they had been involved with were due to them being their son/daughter's father. As is discussed later in this chapter, fathers felt that they had a strong bond with their offspring and so the term 'carer' may have been seen as underrepresenting the importance of their relationship, and implying that they were not close:

"*I would say we don't see it as being carers. Carers are somebody else. That's not us, you know? We're just her parents*."
(Neil Walker: Interview 1)

On the other hand, the role of parent was one that was taken very seriously. It was clearly important to these men that they were viewed as a good father and they were determined to do all they could for their son/daughter:

"*I mean, one of the things we've always said is 'she's our daughter, same as her elder sister. We do our best for her elder sister and we're doing our best for Jessica'*."
(James McKay: Interview 2)

6.4.3 Someone's got to earn the corn

Providing for their family financially had been another important part of fathers' identities, particularly when their wife had had to stay home to look after son/daughter child full-time. Being able to support their family under difficult circumstances appeared to have been a source of pride for many fathers. Those who identified as main breadwinners admitted that they often had not known the ins and outs of their wife's daily tasks and challenges. As they had worked during the day they were not around when things were happening and sometimes were unable to give a clear account of why certain decisions had been made with regards to their offspring such as moving schools:

"*And as I said, I wasn't involved in this cos I didn't know half the things that were going on, because I'm at my work during the day*".

(James McKay: Interview 2)

As fathers were usually the main breadwinner within their family, most acknowledged that their wives had been the main caregiver for their son/daughter. This was highlighted by the language which fathers used to describe their contribution, such as ‘filling in’ and ‘allowing her (their wife) to take a break’. This suggests that they did not consider caregiving to be their main task and that they had engaged in caregiving activities on a temporary basis to assist their wife. This was even true of fathers who had retired and were just as available as their retired wife. The acknowledgment that their wife had been most involved was often followed by a justification that this division of tasks was common among families:

“*I’m more of an aide de camp for Amy. I think most husbands are*.”
(James Mr McKay: Interview 2)

Fathers who had worked full-time while their wives looked after their son/daughter were quick to justify their time away from the home. The justifications that fathers made for having been less involved in their son/daughter’s care suggests that many appeared to experience some guilt about not having been as available for their wife or their offspring. They were usually quick to stress that their absence had been necessary and that they had still been involved in their son/daughter’s life:

“*... and whilst I was there as much as I could be for Laura, somebody’s got to go out and earn the corn*.”
(Greg Thomson: Interview 3)

The idea of traditional gender roles being enforced was evident throughout the interviews. When asked for details of how they had cared for their son/daughter, most identified more physical tasks as having been their domain, while others had been completed by their wife.

"*My wife does the primary care and then I do the fetching and so on, and help at the end*." (Mr Lampton: Interview 7)

A different pattern emerged for two fathers who had originally been high earners but had had to give up their jobs and this aspect of their identity in order to assist their wife with their son/daughter's care. In both cases, this change in their circumstances was not described as a choice but as a necessary alteration in order to prevent their offspring being moved into residential care. These fathers appeared to have struggled with letting go of this part of their identity:

"*And when you become a carer I think you're seen as a bit of a second-class citizen sometimes, 'you're sponging off the state'. I mean I've been … had people shout at me 'Oh you and your mobility car, you've got it easy' and things like that. And I say 'Oh really, you like to have him for a week and see how easy it is pal?*'"
(Larry Kendall: Interview 6)

Whether fathers remained the main breadwinner or gave up work to care for their son/daughter, they had all acquired in-depth knowledge of their offspring's needs. This identity was captured under the sub-theme 'I'm the expert'.

6.4.4 I'm the expert

While navigating the social care system was often a challenge, many fathers felt that they had become an expert in both the system and how to care for their son/daughter. Various examples were given of times when the fathers had spoken up to medical professionals to safeguard their offspring, using their expertise to ensure that their son/daughter received appropriate care. On one occasion, Mr Walker's daughter had been admitted to hospital after a fall and was about to be discharged without a proper examination. Mr Walker challenged this decision and ensured that his daughter received further medical attention:

"*And I said 'Her eyes were rolling, absolutely rolling'. I says 'Knocked to the head and she's just been sick' I says 'Don't call me a doctor but to me that's concussion.' 'Oh, maybe we should go and have another look' Hmm.....*"
(Neil Walker: Interview 1)

This 'hat' was discussed in particular detail by fathers who had given up work to look after their son/daughter, suggesting that having more time available to them had enabled these fathers to become more involved in the advocacy element of parenting a son/daughter with intellectual disabilities. This identity may also have provided such fathers with status or purpose they felt they had lost after leaving employment. One father had become an advocate for other people with intellectual disabilities and took great pride in being a source of advice and information for other parents. In some ways, taking on this role of expert seemed to counteract the loss of status and identity that occurred from leaving employment:

"*So, I'm actually getting phone calls from other families who ...'My son's just leaving school Larry, what would you advise?' I'm saying well 'don't do this, don't do that, don't do this, don't do that'. And I get a great deal of, sort of satisfaction from doing that, because what I've learned the hard way...hopefully I can divulge to other people and they won't find it quite as hard going forward, you know?*"
(Larry Kendall: Interview 6)

6.4.5 Summary of 'Wearing different hats'

The majority of fathers had tended to be less involved in caregiving tasks than their wives, as they had been at work during the day. However, this pattern did not appear to have altered much even when fathers had retired. Fathers continued to look on their wife as the main provider of care for their offspring, and to view particular tasks as being in her domain. For those who had given up work to become a full-time carer, there was a feeling that they had lost some of their identity and value as a member of the workforce. However involved fathers had been in performing caregiving tasks, they took pride in being an expert in their offspring’s needs. Fathers also gained satisfaction from being able to share their knowledge and assist other parents who were newer to their caring role.

As a father, the family unit was of vital importance to them. They highly valued the relationship that they had formed with their son/daughter, and how this relationship had helped them to grow as a person. Fathers were also aware of the impact that caring had on the rest of the family, both negatively and positively. This experience is captured in ‘family comes first’.

6.5 Family comes first

6.5.1 Overview of ‘Family comes first’

For all interviewed fathers, family was a central part of their life and something which they had always sought to put first. The majority of fathers had had more than one offspring, and fathers had been determined to treat their son/daughter with intellectual disabilities the same as their other offspring and to do their best for him or her. Fathers spoke of the bond that they had formed with their son/daughter and how this relationship had developed over time. They felt that they themselves had grown as a person over their caring journey, and often credited their son/daughter with teaching them what is important in life. Their son/daughter with intellectual disabilities held a central role within the family unit and fathers described how highly their offspring was valued by themselves and their family. The high value which fathers placed on their family, their relationship with their son/daughter, and the way caring for their offspring with intellectual disabilities had impacted the whole family is captured in ‘family comes first’.

‘Family comes first’ is now discussed within the context of three subthemes associated with this final analytical category. Not every sub-theme was touched on by every father, yet they provide a general representation of the high importance which fathers placed on the family unit, and the relationships within this unit. These subthemes are outlined below:

- I love him to bits: The love and affection that fathers felt for their son/daughter, and how their bond had developed over time.
- It opens your eyes: Fathers outlook on life and how their values were impacted by their caring journey, with many describing it as a learning experience.
- It did affect us: The father, their wife and any other offspring had been affected by their son/daughter's intellectual disability, with both negatives and positives of their family situation being recognised by fathers.

6.5.2 I love him to bits

Fathers clearly enjoyed talking about their son/daughter, and did so with enthusiasm. Their offsprings' achievements were a source of great pride for fathers. Mr Murphy's son recently competed in the Special Olympics and won a bronze medal. His entire family, and a number of their neighbours, had come to support his son during the race. This was an incredible experience and Mr Murphy was extremely proud:

"*It was amazing, it was amazing! For him too of course. We were just over the moon because they don't give away medals at that level for nothing. And to see his name come up on the electronic scoreboard was brilliant. It was lovely.*"
(David Murphy: Interview 5)

Fathers were often very protective of their son/daughter and aware that they required extra help with daily tasks. They stressed how important it was to help and support them as much as possible. This was most notably the case when the father had a daughter, rather than a son:

"*You want to help, you want to be… and they need the help. You know, silly little things like helping her up on a chair, whatever. She's still a little girl.*"
(Greg Thomson: Interview 3)

In many instances, humour was an important part of the relationship between fathers and their son/daughter with intellectual disabilities. Fathers spoke about the in-jokes they had with their offspring and how laughing and joking together formed a key part of their daily interactions:

"*The relationship I've had with Mark has always been, there's always been an element of teasing and fun. And you know, we'll be walking along the road and I'll just put my foot out like that (gestures) and trip him up. Poor boy must be peeved to death with this but he rises to it every time. And the only reason I do it is because it makes him laugh.*"
(David Murphy: Interview 4)

For some fathers, the relationship that they described with their son/daughter had not changed much over time. This was either because their offspring had continued to need a similar level of support over the years and so the father still viewed them as a young child that he must protect and care for, or because the relationship had always been and remains strong:

"*I don't see that it's changed in any way. Michelle's my pal.*"
(Neil Walker: Interview 1)

"*Has it changed? I'd probably still treat her a wee bit infantile, if you like. Sometimes I'm guilty of that. She's a 27/28-year-old girl. Ok, she's got the mental age ...not really increased much. But I treat her as my wee girl, whereas I don't do that with the other two.*"
(Greg Thomson: Interview 3)

In addition to forming a strong bond with their offspring, fathers felt that they had gained additional benefits from having a son/daughter with intellectual disabilities. This is captured by the sub-theme 'it opens your eyes'.

6.5.3 It opens your eyes

Caring for their son/daughter has had a significant impact on father's lives, and many also identified their caring role as a source of personal development.

Fathers felt that they had grown as a person, and that they were forever changed by the experience.

One father described the birth of his son as something of a reality check. For him, caring for his son had made him revaluate what is really important in life:

"*Sharing your life with somebody who has specific additional needs, I think gives you an insight into what's important in life. I think ... makes you think of ... the values in life that are important, and I think you adjust your perspective. I think it, it stops you in your tracks*."
(David Murphy: Interview 5)

Fathers attributed their relationship with their offspring to making them a better and more caring person. One father described himself as now being more knowledgeable of disabilities and more aware of the challenges that people with disabilities face.

"*It's affected me mainly in the fact that when I'm out and about and I see other people with disabilities, you know, I think, 'I hope they're getting it ok'. In the past, before Jessica, you see people with disabilities and you just (shrug) 'It's just a disability' but now when I see somebody with a disability I wonder how they're getting on*."
(James McKay: Interview 2)

Fathers had also been very aware of and, at times, concerned by the consequences of having a son/daughter with intellectual disabilities on other members of the family unit. These feelings are captured by the sub-theme 'it did affect us'.

6.5.4 It did affect us

While fathers emphasised their personal growth, they also recognised that having a son/daughter with intellectual disabilities had impacted the family unit, both negatively and positively. All fathers had felt a profound impact on themselves and their lives from taking on their caregiving role:

"*But definitely a huge impact on my life, massive impact. It changes, changes everything, absolutely everything*!"
(Greg Thomson: Interview 3)

Despite the impact that fathers had experienced, many commented that their wife had been more affected by caring than they were. Fathers often felt that this was due to their wife having taken a more active role in caring, while they had served as the main breadwinner and participated less frequently in caregiving activities. This gender divide was seen as to be expected and normal:

"*I think that generally having a disabled child has a far greater effect on the mother. You know? Because you know the mother is with the child, a lot more*."
(Greg Thomson: Interview 3)

Some fathers struggled with the idea that they had somehow let their family down by being unable to provide for them in the way that they would have liked to, had they not had to make the choice to leave or reduce their working hours to care for their son/daughter. This was particularly apparent for fathers who were from a higher income bracket:

"*.. the fact that giving up work meant that she's had to, you know .... When other people are going out and decorating the house we've had to make do with what we've had. Her pal's… 'She's got a brand-new three-piece suite, I wish I could get one.*'"
(Larry Kendall: Interview 6)

Yet, it was not just a financial concern. Fathers also worried about whether they had been a good father to their other offspring, in terms of the childhood that they had been able to provide for them. Many related that there had been activities they could not afford, or events they could not attend due to their caring role:

"*You feel guilty about the girls, you feel 'Have we been ignoring them while they've been growing up*?"
(Larry Kendall: Interview 6)

While fathers felt that they and the rest of their family had experienced certain challenges and stresses due to their son/daughter with intellectual disabilities, they also identified numerous ways in which the family had benefited from their offspring's presence:

"*Mark is Mark, and Mark has enriched our family in a way that would never have happened had he not been Mark. So, it's not a .... It can never be... I suppose is what I'm saying (is) it can never be a regret, it can never be a regret.*"
(David Murphy: Interview 5)

Other sons/daughters in the family had often grown as a result of having a sibling with intellectual disabilities. Fathers felt that their other offspring had become more mature or more caring through the experience:

"*I think that the other two kids, maybe they're just a lot more mature than I was at their age, I don't know, but they're a lot, they're better people if you like. They know through experiences that there are other people less fortunate. They're more tolerant of people.*"
(Greg Thomson: Interview 3)

A number of the fathers who participated in these interviews had a daughter whose career path had been influenced by their sibling with intellectual disabilities. For example, Mr Kendall's daughter became an educational psychologist and was able to use her experiences with her brother to relate to other families who have offspring with intellectual disabilities:

"*She always said that's why she went into psychology, because of Jack she felt this affinity and she wanted to help other people in the same position. And it has helped her really because a lot of the time she'll go and visit parents and they'll*

say 'You don't know what it's like' and she'll say 'Well actually I do, I do know what it's like. I know exactly what you're going through'."
(Larry Kendall: Interview 6)

6.5.5 Summary of 'Family comes first'

The analysis of this theme revealed that the family unit was incredibly important to fathers. The majority of fathers had a strong relationship with their son/daughter with intellectual disabilities and was proud of all that they had achieved. Fathers took on much of the responsibility for any stress or challenges which their wives or other offspring had faced over their caring journey. They acknowledged that this had had a negative effect at times. However, fathers felt that their family had gained so much from their son/daughter with intellectual disabilities and highly valued their contribution to the family.

Thinking about how they and their family had been impacted by caring, caused fathers to reflect back on their entire caring journey. They felt that their lives had dramatically changed over the years, especially in comparison to other parents, and began to consider what the future would hold for themselves and their son/daughter. This experience was captured in 'getting on in years'.

6.6 Getting on in years

6.6.1 Overview of 'Getting on in years'

The prolonged nature of their caring role was felt by all fathers, particularly now that they were getting older and some were beginning to experience a change in their health. After so many years caring and watching societal attitudes and service provision change over time, fathers could reflect back on their own early experiences and compare them to those of younger parents nowadays. Comparing themselves to other parents had often led fathers to feel that they had missed out on a number of opportunities in their lives, and that they were restricted in what they could do in retirement. Fathers reported facing a future where they must address the question of what happens to their son/daughter when they are no longer able to continue caring. 'Getting on in years' is now discussed within the context of the four subthemes associated with this category. Not every father touched on all of subthemes in this category but the themes summarised the overall experience of life as an ageing carer. These subthemes are outlined below:

- My bones are getting tired: Fathers continued to care for their offspring as they themselves grew older and frailer, and so encountered difficulties performing certain tasks.
- Changing times: Reflecting back upon their caring journey, fathers noted how their caring role had changed over time and how their experiences differed from parent carers nowadays.
- Missing out: Certain aspects of a father's life had been sacrificed in order to care for their son/daughter, and they were now adjusting to the idea that their retirement would likely be quite different from other parents as they continued to care.
- What lies ahead?: The time has now come for fathers to plan for a time when they are no longer here or no longer able to care. They discussed various hopes and fears associated with their offspring's future.

6.6.2 My bones are getting tired

Fathers discussed the prolonged nature of their caregiving role and how certain caring tasks and responsibilities, which would typically be expected of parents of young children, have extended into their offspring's adulthood. Some fathers foresaw that, while they were managing relatively well at the moment, they would need extra support or services to continue caring in the future. These fathers realised that their ability to perform certain tasks and keep up with all the demands of a caregiving role was starting to change:

"*One of these days we're going to end up needing them at night or over the weekend. We'll see. We're doing ok at the moment.*"
(Nigel Lampton: Interview 7)

Some fathers admitted that they had initially been resistant to the idea that they were ageing and that they would have to make adjustments to their lifestyle, as well as the way they care for their offspring. Facing the fact that getting older has limited their ability to do physical caregiving tasks that they used to do was particularly difficult for fathers, as this was the aspect of caring that they had always been most involved with. However, most fathers were now at a point where they realised that these changes were necessary due to their own health problems or age:

"*As she got older I refused to consider myself getting older and it took me a long while to start using the hoist etc. and things that were provided. But I realised, after a few problems with health wise, that meant I better start using the hoist.*"
(James McKay: Interview 2)

While many fathers wanted to continue caring for as long as possible, and certainly for the time being, it was unclear how much choice fathers felt that they had in this matter. Fathers spoke of carrying on despite health problems and/or fatigue:

"*Oh, well I'm getting older and my bones are getting more tired. That's what I keep saying to social work but they say 'well, you're coping. As long as you're doing it. The minute you say you can't do it anymore we'll deal with that when it happens*".
(Larry Kendall: Interview 6)

Fathers commented on how their caring journey, lasting over two or three decades, had changed as they aged. The ways in which their caring role altered over time is discussed under the sub-theme 'changing times'.

6.6.3 Changing times

Fathers remarked that times have changed in terms of the support that is necessary or available to them, with many needing to, and being able to, get more respite and assistance in their caring role. Despite initial resistance to accepting more help, several fathers noted that they were now gaining more freedom with extra assistance. This was very important for fathers, both because of their health and because it allowed them more freedom and time to themselves or with their wives. Some of the fathers felt guilty for having time off and experiencing more freedom. However, they rationalised that everyone needs time off:

"*I hate to say it but all the time we were away I think I thought about Jack once. And I felt really guilty about that because…. and Grace said 'I think you've deserved it after 20 odd years, you know?' I suppose I do*."
(Larry Kendall: Interview 6)

However, some fathers did not feel they had obtained enough freedom and talked about the fact that their social lives were still restricted, or that their son/daughter had become more physically dependent on them as they became older:

"*Because, you know I'm 64 in a few weeks' time and if I want to go out on a Friday night I need to get a baby sitter. You know, it's, that's when it brings it home to you*."
(Greg Thomson: Interview 3)

Fathers discussed the fact that they were originally told their son/daughter would have a reduced lifespan and would not live into their 20s, and so they had not expected to be in a caring role at this point in their lives:

"*We were told that we'd be lucky if Jessica reached 20. Because at that age, at that period of time, because of the health system shall we say, and also social system for care, that's what they tended to do, die off*."
(James McKay: Interview 2)

Fathers felt that some of their experiences were not representative of parents from younger generations, as many aspects of caring has changed over time. Changes in degree and type of support provided for parents was raised. There was a feeling that in the past parents were expected to 'just get on with it' whereas younger parents nowadays are expecting and demanding more from professionals and services:

“*.. but that’s what it was like in those days. Well that’s it, just get on with it. No support, no nothing*.”
(Larry Kendall: Interview 6)

By comparing themselves with younger parents, fathers began to compare themselves with other parents or people their own age. They reflected that in some ways they feel that they have been restricted in their lives and have missed out due to their caring role. This will be discussed under the theme of ‘missing out’.

6.6.4 Missing out

Fathers were aware that their life was different from many parents their age. They felt that their lives, both now and in the future, was more restricted:

“*So, I think it’s not overstating it to say that that’s that loss of not being able to be completely free in the way that other people are, always having to make sure that Mark is safe, and that the right things are in place for him. That’s a lifelong commitment because we are his parents. Nothing can change that. Therefore, you have to adjust and not feel bitter and not feel resentful*.”
(David Murphy: Interview 5)

Reflecting back on their lives, most fathers felt that they had missed out on various social opportunities due to their caring responsibilities. While none of the fathers regretted caring for their son/daughter, many fathers felt that they had made significant sacrifices in their personal lives in order to continue caring:

“*I’ve had my moments where I’ve said ‘Why me?’ When my mates are all off to a golf weekend and I can’t go. Or off to a stag weekend and I can’t go on a stag weekend. It’s moments like that that really hit home and I think ‘If Ross wasn’t here I could have done this and done that, done this and done that’*.”
(Larry Kendall: Interview 6)

Many fathers were starting to realise that their retirement will probably be quite different from their peers, or from what they had initially anticipated for themselves, due to their continued caring role. One father spoke about the fact that he was about to retire and realised that he would not be able to do the kind of things that other retired people do, such as travel with his wife as a couple:

"*What do most couples do when they retire? They see themselves having the freedom to do the things they would like to do. Now I'm not saying Carolyn and I won't be able to do that, but with certain things we won't be able to do it unless we make provision for Mark. So, someone else has got to look after him or whatever. Or Mark's got to come with us so we can't do it on our own*."
(David Murphy: Interview 5)

Approaching or reaching retirement encouraged fathers to think about what future they would like to build for their son/daughter. The realisation that they must make provision for their offspring, and their associated concerns with such a plan, is captured under the sub-theme 'what lies ahead?'

6.6.5 What lies ahead?

Fathers were starting to look ahead and think about what the future might hold for themselves and their son/daughter. Fathers realised that there would eventually come a time when they were no longer able to continue caring:

"*There may be a day when we cannot look after him or we're not here to do it*."
(David Murphy: Interview 5)

Despite the additional difficulties they had experienced in recent years from caring into old age, many fathers were committed to continue caring as long as possible:

"*At the moment, we're still able to do a lot of things, but as I say I've had two heart operations over the past few years and eh my wife's not the best. And she's …. her arthritis is starting to bother her, and a few other things. And that's going*

to be a problem in a few years' time. And I can't see us being able to cope, we'd want to as long as we can but we've got to get a place set up for Jessica."
(James McKay: Interview 2)

Concern or despair over what might lie ahead for their offspring was expressed by most fathers. At this point in their lives, fathers were often trying to imagine a life for their son/daughter and themselves in the future. The realisation that they could not continue caring indefinitely brought with it a number of concerns about the quality of support and care their offspring would receive. Due to negative experiences with the care and social system, many fathers were concerned that their son/daughter would not be well looked after when they themselves were no longer caring for him or her. Being unable to rely on or guarantee high quality support for their offspring was a source of great worry for fathers:

"*We're always scared she'll get her own place and they'll bring people in …. You hear horror stories*."
(Nigel Lampton: Interview 7)

Two fathers felt that they were best placed to support their sons and expressed a lack of faith that the system could ever adequately take care of him. They did not believe that their sons would have the same quality of life and the same support to be active and participate in the social activities they currently enjoy:

"*When you hear all the horror stories you think 'No, you don't want to take a chance.' I wouldn't trust anyone else to do it.*"
(Larry Kendall: Interview 6)

Fathers also expressed concern over relying on family members to care for their offspring, either because they doubted whether the family member would follow through or because they didn't think it would be fair to expect that of their family:

"*There are people within the family who've said we'll do this, we'll do that. My experience of friends and family is they're full of good intentions but at the end of the day they walk away. There's the famous one when someone's babysitting 'nice to give them back'. And I do believe that would be the case. So that's quite worrying.*"
(Neil Walker: Interview 1)

The uncertainty over what might lie ahead induced fathers to begin planning for their offspring's future to ensure they were adequately supported and would have a good quality of life. Most fathers had taken some steps to secure their son/daughter's future once they are too old to continue their caring role or are no longer around to care. Some fathers already had a plan in place or underway while for some this still seemed far enough off for no set plan to be established yet. As their offspring's desire for independence increased some fathers felt more comfortable with the idea of them moving out of the family home. The belief that this was a move their son/daughter also wanted seemed to help them come to terms with the idea:

"*And Jack is 27 now and he's saying 'When am I getting my own house?' Which is only natural, you know*?"
(Nigel Lampton: Interview 6)

Speaking to other parents who had achieved this transition also made some fathers feel more comfortable with the idea of their son/daughter moving on:

"*Most of them will tell you that it's a very positive experience for the child, to move away from home, as it is with any youngster, you know*?"
(Greg Thomson: Interview 3)

6.6.6 Summary of 'Getting on in years'

Fathers felt some resentment about the things that they had missed out on, or would likely miss out on in retirement, due to their caring role. This resentment was directed, not at their offspring, but at flaws in the system which had prevented them from having more freedom in the past. There was some hope that they would now be able to enjoy more time to themselves and with their wives, as services stepped in to support them more in their old age.

The fathers who participated in these interviews had been caring for their son/daughter over a prolonged period of time. They were beginning to notice a difference in their physical health, as well as the caregiving tasks that they could undertake. This had led them to begin the process of seriously considering future alternatives for their offspring's care, once they were no longer able to continue. While there was some concern about the quality of care that their son/daughter would receive, fathers were not yet panicking about this. It was felt that there was still time to organise their offspring's next steps and so most fathers did not yet have a definite plan in place.

6.7 Discussion

It was noteworthy that the fathers in this study rejected the label of 'carer' and instead wished to be described as fathers during the interviews. Fathers may have responded in this manner because the term 'carer', which usually refers to individuals who are paid to look after someone, did not apply to them. This reaction is also documented by a review of the literature around carers who look after a family member. This review suggests that 'carers' continue to view their relationship with the cared-for person in terms of the pre-existing relationship e.g. husband-wife, father-daughter (Molyneaux et al, 2011). A study of husbands who cared for their wives with physical health conditions found that men viewed themselves as having a number of roles such as worker, husband etc, but not carers. They primarily identified themselves as husbands and related that all caregiving tasks done for their wives were due to their role as husband (Gollins, 2001). While fathers in the current sample did not have a pre-existing relationship with their offspring, in the way that carers in the above referenced studies did, it was evident that fathers considered caregiving activities to be a natural element of their relationship. They felt that it was their duty to look after their son/daughter and that these caregiving actions were due to being a good parent, not a carer. That caring was perceived as a normal aspect of their role within the family unit has also been documented in studies of individuals caring for a range of family members (Carduff et al., 2014; Robinson & Williams, 2002; Smyth et al., 2011).

Fathers in the current study also appeared to feel that the use of the term 'carer' devalued their son/daughter's worth. It was very important to fathers that their son/daughter be valued by the people around them, and not only seen as an individual with intellectual disabilities who needed additional support with every-day tasks. This is connected to the subtheme 'I love him to bits', where fathers emphasised the importance that they placed on their relationship with their offspring, and how much they loved their son/daughter. There is some evidence of this theme emerging in the existing literature. A meta-synthesis of qualitative work on the experience of carers of individuals with intellectual disabilities and challenging behaviour (Griffith & Hastings, 2014), identified only one study which explicitly identified love as a theme. However, the researchers asserted that, it was actually an underlying component of all themes in the included studies.

Fathers admitted that having a child with intellectual disabilities can be extremely stressful at times and that there was sometimes a negative impact on their family, yet most emphasised that the positives gained had far outweighed the negatives. This supports previous research, which has found that having a child with intellectual disabilities caused many parents to re-evaluate their lives and perceive benefits for the entire family unit (Beighton & Wills, 2017; Chadwick et al., 2013). These findings demonstrate that focussing on stress and coping models to understand fathers' experiences paint an incomplete picture of life with a son/daughter with intellectual disabilities. That fathers in this study experienced both positive and negative outcomes from parenting a son/daughter with intellectual disabilities provides support for the Two Factor Model of Psychological Well-being (Lawton et al., 1991) discussed in Chapter Two. The Two Factor Model of Psychological Well-being proposes that both positive and negative outcomes may be experienced simultaneously from caring, and that this is due to the operation of two different appraisal processes operating in parallel. In the context of this study, fighting social services for sufficient supports was associated with negative outcomes, while the rewarding relationship with their son/daughter was associated with positive outcomes for fathers.

While the majority of fathers did emphasise the positive aspects of life with a son/daughter with intellectual disabilities, this was not true of two fathers. These fathers appeared to be worn down by their caring role and spoke of life as a constant battle to get their needs met. These were fathers whose son/daughter had severe or profound intellectual disabilities, and one whose son regularly exhibited challenging behaviour. These fathers had experienced particular difficulty obtaining appropriate services for their child and described the type of care that they needed to provide as more physically demanding than the other fathers in the study. In both cases, their child was more dependent on them and did not appear to have gained much independence. However, the only other father who had a son/daughter with more significant support needs did not describe his experience in this way. This father received a high degree of formal and informal support and his description of life with his daughter was full of joy. This demonstrates the importance of providing fathers with adequate support to continue their caring role for as long as they wish.

‘Fighting the system’ was identified as the most stressful aspect of caring by multiple fathers. This finding also highlights the need to supply fathers with high quality services and supports, in order to protect against poor mental health outcomes. Leaving fathers to struggle without such support until they hit a crisis point would also be more expensive for the health and social care system than providing assistance throughout their caring journey. Fathers’ accounts of fighting the system in order to obtain necessary support is also consistent with findings from a meta-synthesis on the experience of family caregivers of individuals with an intellectual disability (Griffith & Hastings, 2014). It is interesting that some of the fathers in this study felt that they had achieved more access to services or had figured out how to work the system as they aged. This perceived change may be due to improved services or it may be the result of a better understanding of how to obtain them. Alternatively, after so many years caring, fathers may simply feel grateful for any services that they receive.

Due to the difficulties of obtaining formal supports, many fathers in this study were more likely to rely on informal sources of support such as family, friends, and other parent carers. While these sources of support were greatly appreciated by fathers, as fathers age it becomes particularly important that they also receive support from more formal channels. This is vital for parents who are attempting to secure a plan for their offspring's future, as the majority of fathers in this study felt it was either not possible or inappropriate to rely on family. Receiving appropriate support and feeling that the social, care, or council workers were on their side was very clearly very important for fathers. This suggests that providing fathers with appropriate support can protect against poor mental health for this population, and therefore better able to perform their caring role and to make plans for their offspring's future.

Fathers described becoming an expert in the social care system as positively impacting their well-being and giving unemployed fathers a new sense of purpose. This suggests that fathers derive benefits from services include them in discussions about their offspring's care and helping them to navigate the social care system. Some fathers felt that service providers did not acknowledge their important role in their son/daughter's life, and would tend to direct all correspondence to their wife. This suggests that services continue to reinforce traditional gender roles, which can leave fathers feeling disengaged and excluded (Mueller & Buckely, 2014a; Mueller & Buckley, 2014b; Rivard & Mastel-Smith, 2014).

From the interviews in this study it is apparent that older fathers are involved in and concerned about their child's life. However, the majority of fathers described themselves as being the main breadwinner with only a limited involvement in their child's care, while their wives performed the bulk of caregiving tasks. The language that fathers used to describe their contribution to caring, such as 'filling in', highlights this gender split. This was also true of fathers who had retired, suggesting that they still viewed caregiving as their wife’s domain. These results challenge the applicability of recent research, discussed in Chapter One, which has documented a shift in traditional gender roles within the household. However, the fathers who participated in this study were aged 60 years old and over and this pattern may not be demonstrated among younger fathers who have not grown up with the same traditional gender roles. The two fathers who had been caring full-time for many years also described a higher degree of participation in day-to-day caregiving than the other fathers in the sample.

The love that fathers felt for their child motivated them to begin the process of making plans for the future. However, the extent to which fathers had taken concrete steps to put plans in place varied widely between fathers. Fear of the future has been identified as an important theme in other qualitative work with older parents, as is evidenced by a systematic review which included studies on the views of older carers (Innes et al, 2012). While fathers in this study mentioned concerns about the future, it was not a dominant theme and many fathers were far away from the panic described in many other studies with older carers. In fact, there was a total lack of urgency in making plans for all but one father. This may be a reflection of the fact that the previous studies have mostly interviewed mothers rather than fathers. Interestingly, in the case of the one father who was deeply concerned about what would happen after he was gone, his son did not have the most severe intellectual disabilities in the sample and would likely not need as much support as some of the other fathers’ offspring. However, he did experience mental health problems and his father was very aware of how easily his mood could be affected by external factors. It is understandable then that his father would be concerned that there was a possibility of him being placed in a poor-quality residential facility, or not having carers who would keep an eye on him, due to the impact that this could have on his mental health.

6.7.1 Strengths and limitations

This is the first known study of the experiences of older fathers of a son/daughter with intellectual disabilities and the results have added to the evidence base by focussing on a population who have been largely excluded from the debate around the experiences of family carers. Conducting in-depth interviews enabled the researcher to gain rich detail about the experiences of fathers across their caring journey, form the birth of their son/daughter with intellectual disabilities, up until the present day.

While this study provided new insights into older fathers' experiences, a number of limitations were identified which require the results to be interpreted with caution. Upon reviewing the transcripts of initial interviews from the qualitative phase, it appeared that the interviewer had not always gone as deeply into participant accounts as may have been possible with a more experienced interviewer. In later interviewers, deeper questions were employed wherever possible although it was challenging to investigate every element of the fathers' stories in as much depth as would have been desirable due to time pressures and the difficulty of attempting to cover the whole caring journey in one interview. Some fathers were also particularly interested in giving detailed accounts of specific parts of their experience, which did not allow as much time for investigating other elements of their caring experience. However, as the semi-structured interviews were designed to be partially guided by participants, it would have been inappropriate not to respect issues of particular concern to individual fathers. The constructivist nature of the qualitative analysis also called into question whether the interviewer was truly making shared constructions with participants, or whether the themes identified in the data were more guided by the interviewer's ideas and preconceptions. Every effort was made to avoid this by taking measures such as keeping a research diary to record thoughts on the interview before and after analysis, and by checking that themes were grounded in the data through the process of constant comparison.

All participants in the current study were married white Scottish fathers which may reduce the relevance of the emerging themes for fathers from ethnic minority groups or those who are unmarried. This reflects a difficulty in recruiting fathers for the study, which has been noted in previous research and discussed in Chapter Five. Two fathers who participated in the current study initially referred the research team to their wife’s email address and phone number. When these fathers understood that it was their views and experiences that the research team was interested in, they explained that they had assumed their wife would be the best person to talk to as she was most involved in their child’s care. After the study a number of fathers also confided to the researcher that it had been a relief to talk about their experiences as no one had ever asked them about their caring journey. A future challenge for researchers is to determine means of identifying fathers and encouraging them to participate in research in order to have their views and experiences more represented. Further implications of the findings from this study for theory, policy and practice will be discussed in Chapter Nine.

Chapter 7: Quantitative Methodology Chapter (Study 3)

7.1 A Change of Direction

The original aim of the quantitative element of the current project was to investigate the prevalence and determinants of mental ill-health in fathers of a son/daughter with intellectual disabilities, compared to fathers in the general population. In order to achieve this, the intention was to conduct analysis on data from the Scotland Census 2011 which would be linked to data from the Prescribing Information System (PIS). The Census would have enabled the researcher to identify the population under study (fathers of a son/daughter with an intellectual disability), fathers of individuals with intellectual disabilities and matched control groups (based on age, gender and Scottish Index of Multiple Deprivation). The PIS would have enabled the researcher to identify current and previous mental health conditions of fathers and controls. National Records of Scotland (NRS) had agreed to generate the father cohorts and send indexing keys to the data controller of the health data; payload data would then be sent to the Scottish National Safe Haven for data linkage.

Approval for the project was sought from the Administrative Data Research Network (ADRN) panel and obtained on 01/08/2017. Ethical approval was also obtained from the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee on 10/10/2017. A Public Benefit and Privacy Panel (PBPP) for Health and Social Care was submitted on 10/11/17 and subsequently approved on 10/01/2018. Unfortunately, during this time (04/12/2017) ADRN informed the research team that while the project had been approved, there would be delays in accessing the linked data due to a high volume of other pre-approved projects awaiting linkage from the ADRN statistics team. After numerous communications with ADRN, the researcher was informed of further significant delays to accessing the linked data. On the 01/09/2018 the decision was made to plan a separate study as there was only one year left for the

PhD scholarship attached to the project. The ADRN team also confirmed that it was unlikely that the data would be available in time to be included in the project.

Once it had been established that the original data source would not be available in time for the project, an alternative focus was selected for the study. This was informed by results of the earlier qualitative study which collected data on the experiences of fathers of a son/daughter with intellectual disabilities. This is in keeping with an exploratory sequential mixed methods design, as outlined in Chapter Three of this thesis. A key theme in the qualitative data was 'Family comes first', where fathers emphasised the importance of their family and their relationship with their offspring with an intellectual disability. Based on the importance that fathers in the qualitative study attached to their relationship with their son/daughter with intellectual disabilities, father-child closeness was selected as the focus of the quantitative study.

The UK Millennium Cohort Study, which is a longitudinal cohort study including families from across the UK, was chosen as an appropriate data set which would enable the exploration of father-child closeness. Further details of the Millennium Cohort Study are outlined below. Father-child closeness was addressed with analysis of data from waves 3-5 (when the child with an intellectual disability was aged 5-11) of the UK Millennium Cohort Study. These data waves were selected as they included all variables of interest and used consistent wording of these measures for each variable, over the different waves. The following research questions were formed:

1) Does father-child closeness of fathers with a child who has intellectual disabilities remain stable over time?
2) Does the trajectory of father-child closeness differ between fathers with and without a child with intellectual disabilities?
3) Is father-child closeness of fathers with a child with intellectual disabilities over time associated with father-mother relationship psychological distress, general health, paternal life satisfaction, paternal work-family balance, or challenging behaviour?

4) Is father-child closeness associated with the same factors for both fathers of children with and without intellectual disabilities?

7.2 The Millennium Cohort Study (MCS)

Data was extracted from the UK Millennium Cohort Study (MCS), which is a longitudinal cohort study of children in England and Wales born between September 2000 and January 2002 (and children in Scotland and Northern Ireland born between 24 November 2000 and 11 January 2002). This difference in birth dates for those included in Scotland and Ireland was designed to avoid substantial overlap with a Department of Health survey of infant feeding practices, which was sampling children born between September and November 2000. The MCS is the first British birth cohort to include all four countries in the UK.

To be included in the study, children had to be living in the UK at age nine months and be eligible to receive Child Benefit at this age. Child Benefit is a universal benefit for families whose residency in the UK is permanent (e.g. asylum seekers and members of the armed forces living temporarily in the UK are not eligible). Children who were living in ‘non-household situations’ such as hospitals, women’s refuges, prisons at age nine months were included, as well as children not born in the UK but resident in the UK at age nine months. The study excluded children who died before age 9 months, emigrated from the UK before age 9 months, and were not resident in the UK at age 9 months. To date there have been seven surveys: the first (MCS1) when children were aged 9 months old, the second (MCS2) when they were aged 3, the third (MCS3) when they were aged 5, the fourth (MCS4) when they were aged 7, the fifth (MCS5) when they were aged 11, the sixth (MCS6) when they were 14, and the most recent (MCS7) when they were aged 17.

7.2.1 Sampling design

Stratifying involves dividing the population of interest into separate groups, known as strata, and drawing a probability sample from each of these groups. The aim is to identify a sample that is representative of each of the subgroups. Disproportionate stratified sampling was used for the MCS to ensure that all four

UK countries, ethnic minorities and families from areas of high socioeconomic deprivation were well represented. The population was stratified by country (Scotland, England, Northern Ireland and Wales). Stratification was conducted by electoral wards as they were defined on 1st April 1998 (1984 for Northern Ireland). In England, three strata were created:

1) Ethnic minority stratum: children living in wards where at least 30% of the population were from ‘black’ or ‘Asian’ ethnicities according to the UK 1991 Census of Population. The categories 'Black' and 'Asian' were defined as a) 'Black’: Black Caribbean, Black African and Black Other as reported on the Census form, or b) 'Asian': Indian, Pakistani and Bangladeshi as reported on the UK 1991 Census form.
2) ‘Disadvantaged’ stratum: children living in wards within the upper quartile of the ward-based Child Poverty Index (CPI) for England and Wales. This constituted the poorest 25% of wards with a CPI of at least 38.4%. Children were not included if they fitted into stratum one.
3) ‘Advantaged’ stratum: children living in wards which were not in the top CPI quartile, and who were not included in stratum one.

No ethnic minority stratum was created for Scotland, Northern Ireland or Wales as population estimates for these countries were lower than 1.5% in 1999, compared to 7.2% in England (Schuman, 1999). For Wales, Scotland, Northern Ireland two strata were created:
1) ‘Disadvantaged’ stratum: children living in wards within the upper quartile of the ward-based Child Poverty Index (CPI) for England and Wales, with a CPI of at least 38.4%.
2) ‘Advantaged’ stratum: children living in wards what were not in the top CPI quartile.

The Child Poverty Index used for stratification is defined as the percentage of children under 16 in an electoral ward living in families that were receiving at least one of the following in 1998: Benefits paid to unemployed adults (Income Support and/or Jobseekers Allowance) and/or benefits paid to employed individuals on low incomes (Family Credit and/or Disability Working Allowance). The CPI is one component of the Index of Deprivation or ID2000 and was selected as the stratifying factor for disadvantage in the MCS, because its focus on child poverty is more closely related to the concerns of MCS than the full ID2000. This data was also available for all four UK countries at the time of sampling, whereas ID2000 was unavailable at the time of sampling for Scotland and Northern Ireland.

Clustering is a technique which involves identifying groups (or clusters) of participants that represent the population of interest. The MCS sample was clustered by characteristics of electoral wards. Clustering was used as it was more cost effective than sampling the entire UK population and enabled interviewers conducting fieldwork to focus on particular areas and keep costs low. As the MCS used characteristics of electoral wards as a method of stratification, wards rather than postcode areas were also used to implement clustering. After the sample wards were selected, a list of eligible children was generated from the Child Benefit register provided by the Department of Work and Pensions. Systematic sampling from ward lists also resulted in stratification by region and ward size. The MCS sample was randomly selected within each stratum in each country. As this means the sample is not self-weighting, weighted estimates of means, variances etc. were needed (Plewis et al, 2007). The stratified cluster sample design described above resulted in an unequal probability of families being selected from the UK population. For example, families living in low socioeconomic areas are more likely to be selected for participation in the study than families in high socioeconomic areas (Hansen, 2012). In order to correct for this, sample design weights and probability weights were calculated for the MCS database. In the current study, the overall sample design weight (including non-response adjustment) for the whole UK from wave 5 of the MCS was used for analysis (Plewis et al, 2007).

7.2.2 Achieved sample

In the first wave of the study 18,552 families were interviewed and the cohort included 18,818 children, representing a response rate of 72% of all the families with eligible children living at nine months in the sampled wards (Hansen, 2012). At the second wave of the study families who should have been in the first wave, but had been missed because they had only recently moved to an eligible address, were included. This group of ‘new families’ brought the sample size of total families interviewed to 19,243 (and the number of children to 19,517). Data from waves three (n=15,246 families), four (n= 13,857 families) and five (n= 13,287 families) were used for the current study. In these waves, the children in the sample were aged five, seven and eleven respectively. Baseline data was also included for a number of variables from wave one, when children were aged nine months. These include parent gender, child gender, child date of birth, child birth weight in kilos, gestation time of child, mother age at birth of child, and father age at birth of child.

7.2.3 Measures

The questionnaire for the MCS was developed by the Centre for Longitudinal Studies team (based at the University College London) with input from a team of external collaborators, and piloted with families. Interviews were conducted with a main carer and partner of the main carer. At sweep one the main carer was usually the child’s mother as questions on pregnancy and delivery were included in MCS1. In later sweeps the same person who was the main carer at sweep one was encouraged to complete the main carer component of the interview. As a result, the main carer in each wave was overwhelmingly female. Measures from the MCS which were used in the current study are listed below:

Identification of intellectual disabilities: In order to identify fathers of children with intellectual disabilities, data from MCS3-5 were used in a four-step process designed by Totsika and colleagues (Totsika, et al, 2019). Trained interviewers administered standardised cognitive assessments to child participants at age 7. These assessments examined children’s word reading and pattern construction skills, two scales from the British Ability Scales (BAS-II; Elliott et al. 1996) along with mathematics ability (NFER Progress in Maths). A factor analysis was conducted of the age standardized scores of these measures, which provided a total cognitive ability index (g) that accounted for 63% of the total variance across these measures. An overall cognitive factor (g) that was two standard deviations below the mean of the total cognitive ability index was used to identify children with intellectual disability. The decision to examine child cognitive scores at age seven was made as children had been in formal education in the UK for around two years by this age, and this is an appropriate age to identify intellectual disability (Maulik et al, 2011). When cognitive assessment information was unavailable at age seven, standardised cognitive assessments given at earlier time points (ages 3 and 5) were used. Parent and teacher reports at age seven were used to indicate whether the child had special educational needs. Teacher reports that the cohort child was performing significantly below average on five academic outcomes associated with reading, writing and maths were also incorporated. A derived variable was then created to identify children with an intellectual disability based on the standardised cognitive assessments, parent/teacher reports of special educational needs, and teacher-rated performance progress for the small percentage of children without cognitive assessments. The presence of intellectual disabilities was coded as 1 and the absence of this diagnosis was coded as 0.

Child age: Child age was coded in months and centred at age 5 (i.e. time 0 ≈ 0 months, measured around 5 years) with subsequent time points at age 7 (time 1 ≈ 48 months), and age 11 (time 2 ≈ 96 months). Centring involves transforming a variable into deviations around a fixed point. In the current study, this was done for the variable ‘child age’ by subtracting the value of 5 from each child’s age.

Autism: Main respondents indicated whether any doctor or health professional had ever diagnosed their child with autism or Asperger’s syndrome by aged seven with a yes/no answer.

Challenging behaviour: The Strengths and Difficulties Questionnaire (SDQ; Goodman & Scott, 1999) measures behaviour problems in children aged 2 to 17 years of age. The main respondent provided SDQ scores for their child in each wave. The SDQ contains 25 items which are measured on a 3-point scale from not true to certainly true. Emerson and colleagues (2014) identified items contained in the SDQ which could be considered indicators of behaviours that challenge: ‘often has temper tantrums’ and ‘often fights with other children or bullies them’. These were scored as 1 point for an item being ‘somewhat true’ and 2 points for it being ‘certainly true’, which resulted in each child being assigned a score in the range 0-4. The authors identified children as showing behaviours that challenge if they scored 3 or 4 on this short scale (Emerson et al, 2014). This measure of challenging behaviour was utilised in the current study.

Paternal mental health: The Kessler (K6) scale (Kessler et al, 2002) is a brief mental health screening measure used in the general population. At each included MCS wave, fathers rated the frequency with which they had experienced six symptoms (depressed, hopeless, restless, fidgety, worthless, or that everything was an effort) over the previous 30 days. High scores indicate poorer mental health on this measure.

Paternal general health: Fathers were asked how they would describe their health generally (rated on a scale of 1= excellent to 5= poor).

Paternal life satisfaction: At each wave, fathers were asked how satisfied or dissatisfied they were with how their life had turned out so far (rated on a scale of 1= completely dissatisfied to 10= completely satisfied).

Paternal work life balance: Fathers rated how satisfied or dissatisfied they were with the balance between the amount of time they spent with their family and the amount of time they spent at work (rated on a scale of 1= very satisfied to 5= very dissatisfied).

Closeness to child: Fathers were asked how close they would say they were to their child (rated on a scale of 1= not very close to 4= extremely close).

Father-mother relationship: A father’s relationship with his partner was measured by asking how happy or unhappy they were with their relationship, all things considered (rated on a scale of 1= very unhappy to 7= very happy).

Family deprivation: A four-item composite measure was created to assess family deprivation in each wave: neighbourhood deprivation (living in an area ranked in the bottom decile for the UK population, according to the Index of Multiple Deprivation), parental unemployment (no parent in the household was working vs at least one parent was working), income poverty (OECD<60% of median UK income), and subjective poverty (main respondent's report of finding it quite/very difficult to manage financially vs managing well financially). The overall family deprivation score ranged from 0 to 4, with higher scores for higher levels of deprivation.

7.3 Growth curve modelling

7.3.1 Measuring inter-individual differences in intra-individual change

As the aim of the current study was to examine father-child closeness over time, a method of analysis to measure inter-individual differences in intra-individual changes over time was required. The current study utilised hierarchical data, which refers to variables which are nested or clustered within other variables, such as children nested within classrooms. For example, when measuring outcomes such as academic attainment or behaviour in the classroom, the classroom to which students belong can impact such outcomes. Children are nested or clustered within classrooms in this example. Therefore, it is desirable to create a research design which takes classroom placement into account when examining these outcomes. Longitudinal data, where outcomes are measured repeatedly over time, as in the current study, are another form of hierarchical data. In this instance, measurements of father-child closeness over multiple waves of data is nested within fathers. The father is a contextual variable which impacts rating of father-child closeness over waves of the MCS. The analysis must therefore take into account the fact that father-child closeness is impacted by the particular father from whom the rating came, and so observations are not independent.

Traditionally, generalised linear models would have been used for such a project e.g. analysis of variance (ANOVA) or analysis of covariance (ANCOVA). However, this is only possible where equal sample sizes exist in each of the repeated measures of a study. In reality, this criterion can be challenging to meet and using an ANOVA or ANCOVA with unbalanced samples can increase type II errors (Hox, 2002; Singer & Willet, 2003). The assumption of independent observations, which is key to general linear models, is also not usually met when dealing with a repeated measures design and this was the case in the current study. Data which is hierarchical introduces dependency in the data, and so residuals will be correlated. A further drawback of using a repeated measures ANOVA is that this method of analysis requires equal spacing between time points and there are problems working with missing values in datasets.

An alternative approach to dealing with longitudinal data which overcomes the problems outlined above, is to use growth curve modelling. Growth models allow for the analysis of observations (father-child closeness) nested within groups (fathers) and is a broad term that has come to define a set of analytical procedures that allow for the estimation of between-person differences in within-person change over time (Curran et al, 2010). Growth models were selected as the most appropriate method of analysis for the current study for a number of reasons. Firstly, growth models do not require balanced data across the different waves of a longitudinal study which results in a more flexible and powerful approach to analysing unbalanced data. Analysis can be run on data where the number and spacing of measurement occasions vary. In the MCS dataset used in the current study, measurements were taken from families at different intervals and some data points were missing. Second, growth models enable the study of both intra-individual and inter-individual differences in growth parameters. Most other statistics for repeated-measures designs allow only the study of group differences in patterns of change, while growth curve modelling also focus on change at the individual level. This enables a more comprehensive understanding of developmental changes of father-child closeness across time in the data set. Third, change parameters are estimated with greater precision with increasing waves of data, and so reduces the standard errors of within-subject change in growth parameter estimates (Willet, 1998; Speer & Greenbaum, 1995). Fourth, the effects of predictors at a higher level in hierarchical data (e.g. fathers) can be added to the growth curve models (Bryk & Raudenbush, 1992). Finally, these models allow for discrete or continuous predictors, as well as time invariant or time variant predictors. Time variant variables change over time (e.g. child behaviour, father age etc.) while time invariant variables do not alter over time (e.g. age of father at birth of child). As variables of interest in the current study are both time variant and time invariant, this is a benefit of growth models.

There are two levels in growth models: level 1 models refer to the within-person change in the model (i.e. repeated measurements over time), level 2 models refer to the rate of change which varies across individuals. For observations over time in a longitudinal design, level-1 is the repeated measure and level-2 is the variable nested within person. In the current study, reports of father-child closeness (level-1) were nested within fathers (level-2), which is a level up in the data hierarchy. It is possible to have further levels in a complicated data hierarchy although the current study requires only two levels. The level-1 component of the multi-level model represents the change fathers will experience during the time period under study, while the level-2 component represents differences between fathers.

7.3.2 Growth curve model trajectories

Within-person patterns of change measured using growth models are referred to as growth curves or trajectories, and these patterns can be flat, linear or curvilinear in form. Flat trajectory models (random intercept-only models) represent no change over time. As the trajectory slope increases, this indicates more rapid growth across time points. Random intercept linear growth models imply that an outcome (father-child closeness) is changing over time but that all individuals (fathers) change at exactly the same rate. This linear trend is represented graphically by a straight line. Fully random linear growth models imply that the outcome (father-child closeness) is changing over time but that the amount of change varies randomly across individuals (fathers). A quadratic trend is represented graphically by a curve in the line which implies that there is either an initial increase in the outcome variable followed by a decrease over time, or an initial decrease in the outcome variable followed by an increase over time. For example, a drug initially increases performance but the effect of this drug wears off over time. At least three time points are required in the data to find a quadratic trend, as with only two time points the means of the dependent variable can only be connected to a straight line. Cubic trends (two changes in the direction of the trend) and quartic trends (three changes in the direction of the trend) also exist in some data sets, although these can only be measured with more than three time points. Therefore, the current study will only examine flat, linear and quadratic trajectories. In order to test the various trends using the MCS dataset, a series of models were run and evaluated. Linear trends were tested by including the predictor variable alone in the model (child age in the current study). A quadratic trend was tested by adding a predictor that is age^2 in the model.

Basic growth models involve fixed and random effects that capture the collection of individual trajectories over time. In a growth model, the fixed effects represent the mean of the trajectory for all individuals in the sample such as mean father-child closeness, as a function of covariates. The random effect represents the random probability distribution around that fixed effect, such as the population variance of father child closeness, as a function of covariates. In a linear trajectory, the fixed effects are estimates of the mean intercept (e.g. starting point) and mean slope (e.g. rate of change) that define the trajectory pooling of the entire sample. The random effects are estimates of the between-person variability in the individual intercepts and slopes. Smaller variation suggests that the parameters defining the trajectory are more similar across the sample. Larger variation suggests that there are greater individual differences in the magnitude of the trajectory parameters around the mean values. Fixed and random effects capture the characteristics of growth for both the sample as a whole, and the individuals within the group.

7.3.3 Multilevel models

There are two approaches to fitting growth models to data. The first approach is to fit the growth model within the structural equation modelling (SEM) framework (Bollen & Curran, 2006; Duncan et al, 2006; Meredith & Tisak, 1990). The SEM incorporates the observed repeated measures as multiple indicators on one or more latent factors to characterize the unobserved growth trajectories. The second approach is to fit the growth model within the multilevel modelling framework (Bryk & Raudenbush,1987; Raudenbush & Bryk, 2002; Singer & Willett, 2003). Multilevel models involve taking data hierarchy, or dependency of observations, into account in the analysis and so allows for the nesting of multiple individuals within a group. However, the model can also be applied to multiple repeated measures nested within each individual e.g. multiple measures of father-child closeness over time. Multilevel analysis with a continuous outcome variable can be seen as an extension of linear regression analysis, while multilevel analysis with a dichotomous outcome variable is an extension of logistic regression analysis (Twisk, 2006). However, conducting multiple regression analysis on one sample would be a waste of statistical power and very time consuming, and so multilevel models are used in this instance. Multilevel modelling and SEM often yield similar results and share the same rationale for modelling growth (Wu et al, 2009). Multilevel modelling was selected as the most appropriate method of fitting growth curves to the MCS data to allow multiple repeated measures (in different MCS waves) nested within an individual (fathers). Multilevel modelling proves more intuitive output as it describes the relationships in the model as a series of regression equations. It enables researchers to estimate and test model parameters and graphically represent growth trajectories.

The overall fit of a multilevel model is tested with a chi-square likelihood ratio test, such as AIC in SPSS. It is recommended that multilevel models are built up from a basic model in which all parameters are fixed, by adding random coefficients and confounding variables. To compare models the log-likelihood of the new model is subtracted from the value of the old model. In the current study, multilevel models were used to examine the best fitting shape of trajectories for father-child closeness in fathers of children with an intellectual disability between the ages of 5 and 11 in the MCS. A baseline growth model can be expanded to include one or more predictors of growth. This second phase of growth modelling is known as a conditional growth model as the fixed and random effects are now ‘conditioned on’ the predictors. There are two types of predictors in growth models: time-invariant covariates (TIC’s) which are constant over time e.g. age of father at birth of child, biological sex, and time-variant covariates (TVC’s) which change as a function of time e.g. child’s behaviour, quality of father-mother relationship. Time-variant predictors are introduced in the level one equation, and time-invariant predictors are introduced in the level two equations.

7.3.4 Assumptions

The usual linear model assumptions also apply in multilevel modelling. Firstly, there must be a linear or quadratic relationship between the outcome and independent variables, which can be assessed using scatterplots. Secondly, the residuals should be normally distributed and this can be investigated using normal plots. The residuals should be uncorrelated, which is usually not the case in multilevel analysis as this analysis involves correlated observations. Thirdly, independent variables are not highly correlated with each other, which can be tested using Variance Inflation Factor Values. Multicollinearity can be an issue in multilevel models if interactions cross levels in the data hierarchy. Centring the model’s predictors is one way to address this issue. As previously mentioned, centring is a method of reducing multicollinearity issues between predictor variables. The fourth assumption of linear models is that of homoscedasticity. In designs which contain several groups of participants, it is assumed that these groups come from populations with the same variance. This can be checked by plotting the values of the residuals against the values of the outcome predicted by the model. Additional assumptions related to random coefficients must be considered for multilevel modelling. It is assumed that these coefficients are normally distributed around the overall model. This means that a random intercepts model would have intercepts in the different contexts that are normally distributed around the overall model. In a random slopes model, the slopes of the models in different contexts are also assumed to be normally distributed.

7.4 The current study

The relevant MCS waves (MCS3-5) were downloaded from the UCL Centre for Longitudinal Studies website for analysis in the current study. A confidentiality agreement was signed with the UK Data Service to agree to the conditions of use of the MCS. A new dataset was created from the variables of interest (detailed earlier in this chapter) across all three waves and the data was then converted from wide to long format in SPSS to facilitate the multilevel model analysis. The derived variables described earlier in this chapter (intellectual disability, challenging behaviour, and family deprivation) were created using syntax in SPSS. Cases (fathers) were deleted from the dataset if the data was missing from the ‘presence/absence of intellectual disability’ variable. This left a sample of 50,574 families for inclusion in the analysis.

The first aim of the current study was to understand the shape of the trajectory that best describes change in father-child closeness from wave 3-5 of the MCS. Unconditional means models were fitted to examine between and within variance of father-child closeness. This model had one fixed effect that estimated the grand mean of the responses across time points and individuals. A one-way ANOVA model with a random effect was run to serve as a baseline model to examine individual variation in the outcome variable (father-child closeness) without regard to time. This model assessed the mean of father-child closeness and the amount of father-child closeness that exists in intra-individual and inter-individual levels. In this model, linear slopes were allowed to randomly vary across individuals. Child age was entered as level 1 and allowed to randomly vary across level 2 units (i.e. fathers). Quadratic effects for father age were fixed and random predictors. These models captured the incremental within-person variance explained by the respective age trajectories. Age terms were added into the model sequentially (age, age2), with the optimal trajectory (for these and subsequent models) identified by a significant change in the AIC (Raudenbush & Bryk, 2002) when compared to the previous model. The models were then expanded, by adding a between- person predictor for the presence of autism (coded 1 for co-occurring ASD and 0 for those without ASD, as per the measure available within the MCS), and a cross-level interaction with this variable and the within-person predictor age. These models allowed for the examination of the age-related trajectory of father-child closeness accounting for the presence of autism.

The second aim of the study was to examine how father-child closeness trajectories differed between children with intellectual disabilities and children without intellectual disabilities. A comparison group of children without intellectual disabilities was added to the model in order to make this comparison, accounting for baseline covariates which included mother age at child birth, father age at child birth, gestation time, and child weight at birth. Challenging behaviour of the child was also entered into the model at this time. The third research question addressed whether paternal variables (specifically, psychological distress, general health, life satisfaction, work-life balance, marital satisfaction) and child variables (gender, autism and challenging behaviour) co-varied with the trajectories of father-child closeness. These paternal and child variables were entered into the model as covariates. The fourth study aim was met by adding the control group of fathers of children without intellectual disabilities into the model. All models utilised the combined (longitudinal) sampling and attrition weight provided within MCS.

The following chapter will report the results of the analysis conducted on waves three to five of the MCS data set to meet the study aims and address the research questions outlined at the beginning of this chapter.

Chapter 8: Results of Quantitative Study (Study 3)

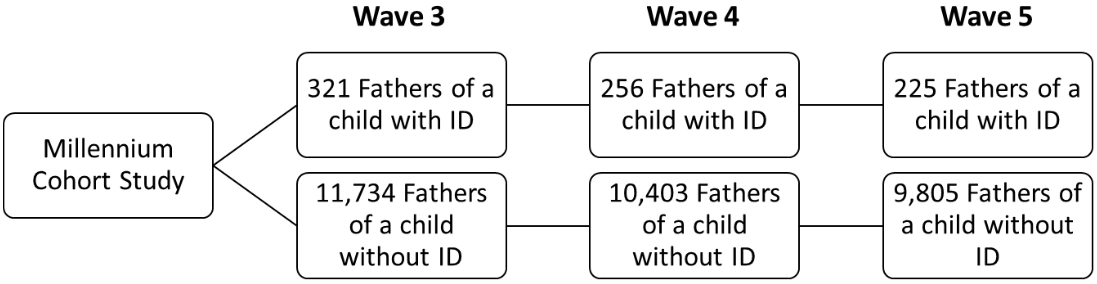
This chapter reports the results of statistical analysis on data from waves 3 to 5 (children aged 5-11 years old) of the Millennium Cohort Study, as detailed in the previous chapter. Demographics of fathers and their children included in the sample, and growth models applied to reported father-child closeness over time are reported below.

8.1 The Sample

8.1.1 Sample demographics

The total sample size of the dataset containing father data and reporting the presence or absence of intellectual disabilities in the child from MCS wave 3 was 12,055. Of these cases, 321 fathers of a child with intellectual disabilities and 11,734 fathers of a child without intellectual disabilities were identified in the sample. As illustrated by figure 17, the number of these fathers who participated in the study dropped slightly at wave 4 and again at wave 5.

Figure 16: Flowchart of sample over waves 3-5 of the MCS



Further demographic information for fathers and their children with or without intellectual disabilities is displayed in table 10. At wave 3 missing data for fathers of a child with an intellectual disability ranged from 44.2% (satisfaction with work/family balance) to 0% (child gender) and increased over time for all variables.

Table 10: Means and standard deviations for time-varying predictors and outcomes for each measurement occasion

Demographic Variable	**Children with intellectual disabilities (N at wave 3= 321)**	**Children without intellectual disabilities (N at wave 3= 11,734)**
Child age at data wave 3	Mean 5.2 (SD 0.3)	Mean 5.2 (SD 0.2)
4	Mean 7.2 (SD 0.2)	Mean 7.2 (SD 0.2)
5	Mean 11.2 (SD 0.3)	Mean 11.2 (SD 0.3)
Male	60.7% (N= 195)	50.8% (N= 5,958)
Autism	3.1% (N=10)	1.2% (N= 115)
Father completed the questionnaire as a main respondent	5.9% (N= 19)	3.2% (N= 375)
Main respondent age at child birth	28.35 (SD 6.8)	29.35 (SD 5.5)
Partner respondent age at child birth	31.53 (SD 6.0)	32.35 (SD 6.0)
Living in households with <60% of the median income of all families in the MCS	55.9% (N= 175)	23.4% (N= 2,730)

8.2 Research Questions

The research questions addressed by the current analysis are:

1) Does closeness of fathers with a child who has intellectual disabilities remain stable over time?
2) Does the trajectory of father-child closeness differ between fathers with and without a child with intellectual disabilities?
3) Is father-child closeness of fathers with a child with intellectual disabilities over time associated with child (autism, gender, challenging behaviour) or

family (socioeconomic status, father-mother relationship, psychological distress, general health, paternal work-family balance) variables?

4) Is father-child closeness associated with the same factors for both fathers of children with and without intellectual disabilities?

8.3 Time-varying predictors

Means and standard deviations were calculated for time-varying predictors and outcomes at each wave of data collection and these are displayed in table 11. On average, both fathers of a child with and without intellectual disabilities reported feeling close to their child at each wave of data collection. Fathers of a child with intellectual disabilities were more likely to report that their child displayed challenging behaviour at all three time points. These fathers also reported higher rates of psychological distress than fathers of a child without intellectual disabilities. However, their psychological distress scores were still at the lower end of the distress scale. Mean scores for the other measured variables appear very similar between groups of fathers.

Table 11: Means and standard deviations for time-varying predictors and outcomes for each measurement occasion

	Time 1 (child age 5)	**Time 2 (child age 7)**	**Time 3 (child age 11)**
	Mean (SD)	Mean (SD)	Mean (SD)
Father-child closeness (1= "Not very close", 4= "Extremely Close")			
Child with ID	3.28 (0.75)	3.24 (0.89)	3.28 (0.76)
Child without ID	3.38 (0.67)	3.37 (0.71)	3.30 (0.75)
Marital satisfaction (1= "Very unhappy", 7= "Very happy")			
Child with ID	5.71 (1.69)	5.79 (1.47)	5.68 (1.52)
Child without ID	5.86 (1.40)	5.92 (1.40)	5.80 (1.37)
Work-life balance (1= "Very satisfied", 5= "Very dissatisfied")			
Child with ID	3.07 (1.39)	2.20 (1.10)	2.22 (1.08)
Child without ID	2.91 (1.17)	2.67 (1.18)	2.51 (1.11)
Psychological distress (0-24 with higher scores representing more distress)			
Child with ID	4.20 (4.31)	4.01 (3.95)	3.16 (5.98)
Child without ID	2.94 (3.33)	2.93 (3.40)	3.20 (4.34)
General health (1= "Excellent", 5= "Poor")			
Child with ID	2.61 (1.11)	2.68 (1.13)	2.55 (1.20)
Child without ID	2.28 (0.98)	2.28 (1.01)	2.25 (1.03)
Child challenging behaviour (0/1/2= No challenging behaviour, 3/4= Challenging behaviour)			
Child with ID	3.29 (1.27)	3.34 (1.19)	3.17 (1.10)
Child without ID	2.71 (0.91)	2.64 (0.89)	2.66 (0.87)

8.4 Research Question One: Does closeness of fathers with a child who has intellectual disabilities remain stable over time?

The first aim of the study was to understand the shape of the trajectory that best described change in father-child closeness over time from MCS waves 3-5 for fathers with a child who has intellectual disabilities. After running a null model, a linear term was added to the model as a fixed and random effect. The linear model 1 assumes the trend over time for each father is a straight line, but the slope of this line is different from one father to the next. The linear term was not significant in the model (*p*= 0.797). As the coefficient is close to zero, the average slope of father-child closeness is relatively flat, which suggests that there is not much variation with time. However, the AIC is slightly lower than the null model, which suggests that there is variation between fathers in the slope of father-child closeness. For some fathers, father-child closeness increases with time, while for others it decreases.

A quadratic term was then added to the model as a fixed and random effect. The quadratic model 2 assumes the trend over time for each father is a curve, with variability between fathers in terms of slope and curvature. Both linear and quadratic trajectories were close to significance ([Age-5]: p=0.073, [Age-5]^2: p= 0.100) in this model, and the AIC was lower (AIC 952.5) than the model without the quadratic effect (AIC 1018.6). Models with age and age^2 as fixed effects only (and not random effects a well) resulted in a higher AIC than the model with the age terms as both fixed and random. Models with age terms as random effects only also had a higher AIC. This demonstrates that the shape of the trajectory is best represented by a quadratic curve. As the AIC has improved from the linear model, this suggests that there is variation between fathers beyond simply varying linear trends. Each father has their own trajectory which is fairly flat on average, but there is variation with many different shapes to the trajectories.

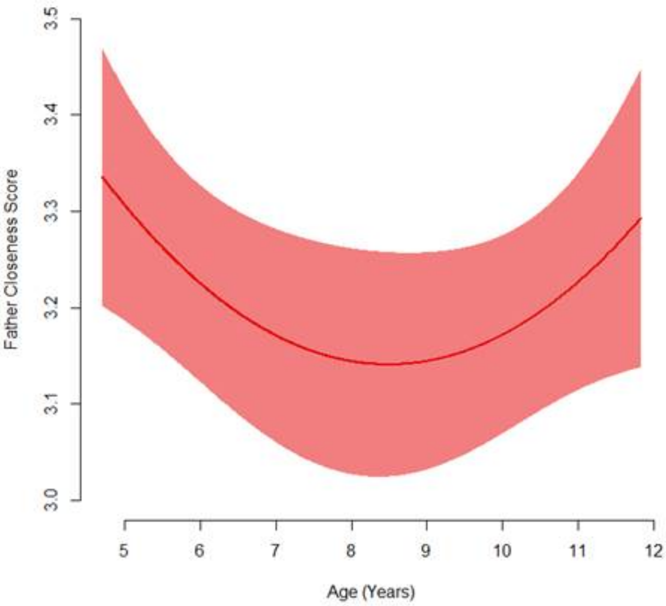
Mean father-child closeness at age 5 was 3.24, out of a total possible score of 4.0 on the father-child closeness measure. The negative coefficient for the linear term is -0.12, indicating a decrease in father-child closeness between age 5 and 7 years. The positive coefficient for the quadratic term is 0.02, indicating an increase in father-child closeness between ages 7 and 11. Results are displayed in table 12 and figure 18.

Table 12: Association between age and father-child closeness, for children with ID

Model 0 is the null model. Model 1 is a linear model, with [Age-5] as a fixed and random effect. Model 2 is a quadratic model, including [Age-5] and [Age-5]^2 as fixed and random effects. All models include a constant term, and random intercepts for each father-child pair.

Model	Coefficient	Estimate	95% CI	p-value	AIC
0: Null	Constant	3.24	(3.15, 3.34)		1019.277
1: Linear	Constant	3.25	(3.13, 3.37)		1018.624
	[Age-5]	-0.00	(-0.03, 0.03)	0.797	
2: Quadratic	Constant	3.32	(3.20, 3.44)		952.460
	[Age-5]	-0.12	(-0.24, 0.01)	0.073	
	[Age-5]^2	0.02	(-0.00, 0.04)	0.100	

Figure 16: Father-child closeness trajectory



8.5 Research Question Two: Does the trajectory of father-child closeness differ between fathers with and without a child with intellectual disabilities?

The difference in shape of the trajectory that best described change in father-child closeness for fathers with and without a child with intellectual disabilities was next investigated. Intellectual disability was included as a binary term, with intellectual disabilities= 1 and no intellectual disabilities= 0. Age modelling was done using linear and quadratic terms, which were added to the model as fixed and random effects. Interactions were used to assess whether the age trajectory differs between fathers of a child with and without intellectual disabilities.

When interaction terms were added to model 3b, the interaction term linear age by intellectual disabilities was not significant ($p= 0.064$), while quadratic age by intellectual disabilities was significant ($p=0.045$). However, the model was not improved when interaction terms (AIC 48025.8) were added to the quadratic model 3b, compared with the quadratic model 3a without (AIC 48015.1) interaction terms, as the model without interaction terms had a lower AIC. Model 3a also had a lower AIC value than model 2a, and so model 3a is a better fit for the data than model 2a. Therefore, the quadratic model without interaction terms (model 3a) was the best fit. This suggests that there is no difference in trajectory with age between fathers of children with intellectual disabilities and other fathers.

In the model of best fit, mean father-child closeness at age 5 was 3.38, and fathers of a child with intellectual disabilities reported lower levels of closeness ($\beta= -0.11$) than fathers of children without intellectual disabilities. These results also appear to fit with the raw data presented in table 1. As the coefficients for linear and quadratic trends in this model were close to zero ([Age-5]: $\beta= -0.01$, $[Age-5]^2$: $\beta= -0.00$), the slope of father-child closeness is relatively flat. However, when a quadratic model was run where aged terms were fixed and not random, model 3a was a better fit (AIC model 3a: 48015.11 vs fixed age term model: 51372.296). This implies that there is variation in trajectories between fathers. Results are displayed in table 13.

Table 13: Association between age and father-child closeness, for children with and without ID

Model 0 is the null model. Models 1, 2a and 2b are linear models, with [Age-5] as fixed and random effects. Models 3a and 3b are quadratic models, including [Age-5] and [Age-5]^2 as fixed and random effects. All models include a constant term, and random intercepts for each father-child pair.

Model	Coefficient	Estimate	95% CI	p-value	AIC
0: Null	Constant	3.34	(3.33, 3.36)		51484.068
1: Linear	Constant	3.35	(3.33, 3.36)		51483.327
	ID	-0.10	(-0.20, -0.01)	0.025	
2a: Linear	Constant	3.39	(3.37, 3.40)		50399.293
	ID	-0.11	(-0.20, -0.02)	0.014	
	[Age-5]	-0.02	(-0.02, -0.01)	<0.001	
2b: Linear	Constant	3.39	(3.37, 3.40)		50405.195
	ID	-0.14	(-0.25, -0.03)	0.010	
	[Age-5]	-0.02	(-0.02, -0.01)	<0.001	
	ID*[Age-5]	0.01	(-0.01, 0.04)	0.323	
3a: Quadratic	Constant	3.38	(3.37, 3.40)		48015.111
	ID	-0.11	(-0.20, -0.02)	0.012	
	[Age-5]	-0.01	(-0.02, 0.01)	0.302	
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.147	
3b: Quadratic	Constant	3.38	(3.37, 3.40)		48025.767
	ID	-0.07	(-0.19, 0.04)	0.223	
	[Age-5]	-0.01	(-0.02, 0.01)	0.421	
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.092	
	ID*[Age-5]	-0.10	(-0.20, 0.01)	0.064	
	ID*[Age-5]^2	0.02	(0.00, 0.03)	0.045	

8.6 Research Question Three: Is father-child closeness of fathers with a child with intellectual disabilities over time associated with child (autism, gender, challenging behaviour) or family (socioeconomic status, father-mother relationship, psychological distress, general health, paternal work-family balance) variables?

A further aim of the study was to examine whether child (autism, gender, challenging behaviour) and family variables (socioeconomic status, psychological distress, general health, work-life balance, and marital relationship) co-varied with the trajectories of father-child closeness.

The quadratic model 2 was used to investigate further variables associated with the trajectory of father-child closeness as this was the best model fit (see table 12). When variables were added separately to the model, an increase in father-child closeness was associated with higher marital satisfaction (β= 0.08, p<0.001), and lower psychological distress (β= -0.03, p<0.001). All other variables in the model were not significantly associated with father-child closeness when added separately to the model. When all variables were added to the model (3i), an increase in father-child closeness was associated with higher marital satisfaction (β= 0.08, p=0.008), and lower psychological distress (β= -0.04, p=0.012). Results are displayed in table 14.

Table 14: Association between age and father-child closeness for children with ID, including predictors

Model 3l is the full model which includes all child and family variables, including [Age-5] and [Age-5]2 as fixed and random effects. Each subsequent model subtracts one variable at a time. All models include a constant term, and random intercepts for each father-child pair.

Model	Coefficient	Estimate	95% CI	p-value
2: Quadratic	Constant	3.32	(3.20, 3.44)	
	[Age-5]	-0.12	(-0.24, 0.01)	0.073
	[Age-5]^2	0.02	(-0.00, 0.04)	0.100

3a: Autism	Constant	3.37	(2.6, 4.15)	
	[Age-5]	-0.13	(-0.26, 0.01)	0.071
	[Age-5]^2	0.02	(-0.00, 0.04)	0.100
	Autism	-0.03	(-0.43, 0.37)	0.883
3b: Gender	Constant	3.31	(3.02, 3.60)	
	[Age-5]	-0.12	(-0.24, 0.01)	0.074
	[Age-5]^2	0.02	(-0.00, 0.04)	0.101
	Gender	0.01	(-0.18, 0.20)	0.932
3c: Challenging behaviour	Constant	3.29	(3.09, 3.49)	
	[Age-5]	-0.08	(-0.21, 0.05)	0.220
	[Age-5]^2	0.01	(-0.01, 0.03)	0.360
	Challenging behaviour	0.01	(-0.01, 0.02)	0.415
3d: Socioeconomic status	Constant	3.37	(3.23, 3.51)	
	[Age-5]	-0.12	(-0.25, 0.01)	0.069
	[Age-5]^2	0.02	(-0.00, 0.04)	0.100
	Socioeconomic status	-0.08	(-0.24, 0.08)	0.302
3e: Work/family balance	Constant	3.26	(3.00, 3.52)	
	[Age-5]	-0.07	(-0.20, 0.07)	0.321
	[Age-5]^2	0.01	(-0.01, 0.03)	0.297
	Work/family balance	0.02	(-0.05, 0.09)	0.569
3f: Marital satisfaction	Constant	2.87	(2.57, 3.17)	
	[Age-5]	-0.12	(-0.24, 0.00)	0.058
	[Age-5]^2	0.02	(-0.00, 0.04)	0.088
	Marital satisfaction	0.08	(0.03, 0.13)	0.001
3g: General health	Constant	3.49	(3.27, 3.70)	
	[Age-5]	-0.12	(-0.25, 0.01)	0.074
	[Age-5]^2	0.02	(-0.00, 0.04)	0.100
	General health	-0.06	(-0.13, 0.01)	0.071

3h: Psychological distress	Constant	3.46	(3.32, 3.61)	
	[Age-5]	-0.13	(-0.25, 0.00)	0.52
	[Age-5]^2	0.02	(-0.00, 0.04)	0.056
	Psychological distress	-0.03	(-0.05, -0.02)	<0.001
3i: All variables	Constant	3.14	(2.01, 4.27)	
	[Age-5]	-0.05	(-0.21, 0.10)	0.518
	[Age-5]^2	0.01	(-0.02, 0.03)	0.617
	Autism	-0.14	(-0.59, 0.32)	0.545
	Gender	0.09	(-0.13, 0.31)	0.401
	Challenging behaviour	-0.01	(-0.02, 0.01)	0.546
	Socioeconomic status	0.09	(-0.12, 0.29)	0.420
	Work/family balance	0.05	(-0.03, 0.12)	0.254
	Marital satisfaction	0.08	(0.02, 0.14)	0.008
	General health	-0.03	(-0.12, 0.07)	0.579
	Psychological distress	-0.04	(-0.06, -0.01)	0.012

A backwards selection procedure was then used to discard the least significant variables from model 3i, one at a time, until all included variables reach statistical significance. The results are displayed in table 15. In the final model 7, an increase in father-child closeness was associated with higher marital satisfaction (β= 0.06, p=0.013) and lower psychological distress (β= -0.03, p=0.003) for fathers of a child with intellectual disabilities.

Table 15: Association between age and father-child closeness, for children with ID, including predictors

Model 1 is the full model which includes all variables, including [Age-5] and [Age-5]2 as fixed and random effects. Each subsequent model subtracts one variable at a time. The final model which includes only statistically significant variables is Model 7. All models include a constant term, and random intercepts for each father-child pair.

Predictor	p-values under each model (Model 1 = Full Model, Model 7 = Final Model)						
	1	2	3	4	5	6	7
General health	0.579						
Challenging behaviour	0.546	0.563					
Gender	0.401	0.382	0.761				
Socioeconomic status	0.420	0.467	0.749	0.742			
Autism	0.545	0.535	0.432	0.416	0.433		
Work/family balance	0.254	0.256	0.111	0.104	0.126	0.222	
Psychological distress	0.012	0.005	0.008	0.009	0.002	<0.001	0.003
Marital satisfaction	0.008	0.008	0.004	0.004	0.006	0.002	0.013

8.7 Research Question Four: Is father-child closeness associated with the same factors for both fathers of children with and without intellectual disabilities?

As the quadratic model (model 3a) was the best fitting model when including fathers of children with and without intellectual disabilities (see table 4), this was used as the base model for adding covariates to a model to compare fathers of children with and without intellectual disabilities. All results of this analysis are reported in table 16. When variables were added separately to the model, an increase in father-child closeness was associated with autism (β= 0.22, p<0.001), lower levels of challenging behaviour (β= -0.01, p<0.001), lower poverty levels (β= -0.06, p<0.001), higher satisfaction with work/life balance (β= -0.02, p<0.001), higher marital satisfaction (β= 0.05, p<0.001), better general health (β= -0.05, p<0.001), and lower psychological distress (β= -0.02, p<0.001).

For most variables, their addition to the base model did not alter the estimated association between intellectual disabilities and father-child closeness. However, the coefficient for intellectual disabilities was reduced by almost half (from -0.11 to -0.06, p=0.244) when satisfaction with work/family balance was accounted for, and when accounting for challenging behaviour, the coefficient for intellectual disabilities became very close to zero (+0.01, p=0.820).

When all variables were added to the model (5l), an increase in father-child closeness was associated with lower challenging behaviour (β= -0.01, p<0.001), lower poverty levels (β= -0.06, p<0.001), more satisfaction with work/life balance (β= -0.01, p=0.022), higher marital satisfaction (β= 0.03, p<0.001), better general health (β= -0.04, p<0.001), and lower psychological distress (β= -0.01, p<0.001).

Table 16: Association between age and father-child closeness, for children with and without ID

Model 0 is the null model. Model 1 is a linear model, with [Age-5] as a fixed and random effect. Model 2 is a quadratic model, including [Age-5] as a fixed and random effects, and $[Age-5]^2$ as a fixed effect. All models include a constant term, and random intercepts for each father-child pair.

Model	Coefficient	Estimate	95% CI	p-value
3a: Quadratic	Constant	3.38	(3.37, 3.40)	
	ID	-0.11	(-0.20, -0.02)	0.012
	[Age-5]	-0.01	(-0.02, 0.01)	0.302
	$[Age-5]^2$	-0.00	(-0.00, 0.00)	0.147
5a: Autism	Constant	2.95	(2.74, 3.15)	
	ID	-0.12	(-0.21, -0.03)	0.012
	[Age-5]	-0.01	(-0.02, 0.01)	0.385
	$[Age-5]^2$	-0.00	(-0.00, 0.00)	0.104
	Autism	0.22	(0.12, 0.32)	<0.001
5b: Gender	Constant	3.38	(3.35, 3.42)	
	ID	-0.11	(-0.20, -0.02)	0.012
	[Age-5]	-0.01	(-0.02, 0.01)	0.302
	$[Age-5]^2$	-0.00	(-0.00, 0.00)	0.147
	Gender	-0.00	(-0.02, 0.02)	0.990
5c: Challenging behaviour	Constant	3.49	(3.46, 3.51)	
	ID	-0.02	(-0.12, 0.07)	0.594
	[Age-5]	-0.01	(-0.02, 0.01)	0.356
	$[Age-5]^2$	-0.00	(-0.00, 0.00)	0.107
	Challenging behaviour	-0.01	(-0.01, -0.01)	<0.001
5d: Socioeconomic status	Constant	3.40	(3.38, 3.41)	
	ID	-0.09	(-0.18, -0.00)	0.041
	[Age-5]	-0.01	(-0.02, 0.00)	0.227
	$[Age-5]^2$	-0.00	(-0.00, 0.00)	0.166
	Socioeconomic status	-0.06	(-0.08, -0.03)	<0.001

5e: Work/family balance	Constant	3.45	(3.42, 3.48)	
	ID	-0.06	(-0.16, 0.04)	0.244
	[Age-5]	-0.01	(-0.02, 0.00)	0.212
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.187
	Work/family balance	-0.02	(-0.03, -0.02)	<0.001
5f: Marital satisfaction	Constant	3.10	(3.07, 3.15)	
	ID	-0.10	(-0.19, -0.01)	0.026
	[Age-5]	-0.01	(-0.02, 0.00)	0.183
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.298
	Marital satisfaction	0.05	(0.04, 0.05)	<0.001
5g: General health	Constant	3.50	(3.48, 3.53)	
	ID	-0.09	(-0.18, -0.00)	0.039
	[Age-5]	-0.01	(-0.02, 0.01)	0.378
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.098
	General health	-0.05	(-0.06, -0.04)	<0.001
5h: Psychological distress	Constant	3.44	(3.42, 3.45)	
	ID	-0.09	(-0.18, -0.00)	0.050
	[Age-5]	-0.01	(-0.02, 0.00)	0.216
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.440
	Psychological distress	-0.02	(-0.02, -0.02)	<0.001
5i: All variables	Constant	3.16	(2.93, 3.39)	
	ID	0.04	(-0.07, 0.14)	0.518
	[Age-5]	-0.01	(-0.00, 0.01)	0.280
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.211
	Autism	0.13	(0.02, 0.24)	0.021
	Gender	-0.01	(-0.03, 0.01)	0.422
	Challenging behaviour	-0.01	(-0.01, -0.01)	<0.001
	Socioeconomic status	-0.06	(-0.09, -0.02)	<0.000

	Work/family balance	-0.01	(-0.02, -0.01)	0.001
	Marital satisfaction	0.03	(0.03, 0.04)	<0.001
	General health	-0.04	(-0.05, -0.03)	<0.001
	Psychological distress	-0.01	(-0.01, -0.01)	<0.001

A backwards selection procedure was then used to discard the least significant variables from model 5i, one at a time, and the results are displayed in table 17. The final model suggests that in the sample with both groups, father-child closeness is increased by 0.01 units with a one unit increase in work/life balance, 0.03 units with a one unit increase in marital satisfaction, 0.04 units with a one unit increase in general health, 0.13 units with the presence of autism, and 0.01 units with a one unit decrease in psychological distress. Father-child closeness is reduced by 0.01 units with the presence of challenging behaviour, and 0.06 units with higher rates of poverty.

In the full model, the intellectual disabilities coefficient was close to zero (β= .04) but in the base model it was -0.11. Therefore, a factor which has been added to the full model explains the association between intellectual disabilities and father-child closeness. From models 5a-5i, challenging behaviour appears to be largely responsible for the change in coefficient and so explains the majority of the difference in father-child closeness between fathers with and without intellectual disabilities.

Table 17: Backwards selection model of covariates and the association between age and father-child closeness, for children with and without ID, including predictors

Model 1 is the full model which includes all variables, including [Age-5] and [Age-5]^2 as fixed and random effects. Each subsequent model subtracts one variable at a time. The final model which includes only statistically significant variables is Model 2. All models include a constant term, and random intercepts for each father-child pair.

Predictor	p-values under each model (Model 1 = Full Model, Model 2 = Final Model)	
	1	2
Gender	0.422	
Autism	0.021	0.023
Challenging behaviour	<0.001	<0.001
Socioeconomic status	<0.001	<0.001
Work/family balance	0.001	0.001
Marital satisfaction	<0.001	<0.001
General health	<0.001	<0.001
Psychological distress	<0.001	<0.001

Interaction tests were carried out in order to determine if the associations between the predictors in Table 18 and father-child closeness were different between fathers of children with and without intellectual disabilities. When interaction terms were added to the model with only significant variables (model 5) one by one, no interactions were statistically significant. When all variables and interaction terms were added to the final model (7h), there were no statistically significant interaction in the model. The AIC of the final model (7h) was 40541.6, compared to 48015.1 in model 3, suggesting that the model which includes interaction terms is a better fit of the data.

Table 18: Association between age and father-child closeness, for children with and without ID

Model 3 is the full model with all significant variables included, with [Age-5] and [Age-5]^2 as fixed *and random effects. Models 7-7 included all significant variables but only ID, relevant variable, and relevant interaction terms are reported for each subsequent model. Model 7k is the model with all interactions. All models include a constant term, and random intercepts for each father-child pair.*

Model	Coefficient	Estimate	95% CI	p-value
5: All significant variables	Constant	3.15	(2.92, 3.38)	
	ID	0.04	(-0.07, 0.14)	0.513
	[Age-5]	-0.01	(-0.02, 0.01)	0.280
	[Age-5]^2	-0.00	(-0.00, -0.00)	0.210
	Autism	0.13	(0.02, 0.24)	0.023
	Challenging behaviour	-0.01	(-0.01, -0.01)	<0.001
	Socioeconomic status	-0.06	(-0.09, -0.03)	<0.001
	Work/family balance	-0.01	(-0.02, -0.00)	<0.001
	Marital satisfaction			
	General health	0.03	(0.03, 0.04)	<0.001
	Psychological distress	-0.04	(-0.05, -0.03)	<0.001
		-0.01	(-0.01, -0.01)	<0.001
7a: ID* Challenging behaviour	Constant	3.15	(3.23, 3.38)	
	ID	-0.00	(-0.20, 0.20)	0.968
	[Age-5]	-0.01	(-0.02, 0.01)	0.278
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.212
	Challenging behaviour	-0.01	(-0.01, -0.01)	<0.001
	ID*Challenging behaviour	0.00	(-0.01, 0.02)	0.640
7b: ID* socioeconomic	Constant	3.15	(2.92, 3.38)	
	ID	0.00	(-0.12, 0.13)	0.944
	[Age-5]	-0.01	(-0.02, 0.01)	0.281
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.208
		-0.06	(-0.09, -0.03)	<0.001

	Socioeconomic status	0.11	(-0.08, 0.30)	0.265
	ID*socioeconomic			
7c: ID* work/family balance	Constant	3.15	(2.92, 3.38)	
	ID	-0.12	(-0.34, 0.11)	0.304
	[Age-5]	-0.01	(-0.02, 0.01)	0.283
	$[\text{Age-5}]^2$	-0.00	(-0.00, 0.00)	0.210
	Work/family balance	-0.01	(-0.02, -0.01)	0.001
	ID*work/family balance	0.05	(-0.02, 0.12)	0.124
7d: ID* marital satisfaction	Constant	3.15	(2.92, 3.38)	
	ID	-0.24	(-0.58, 0.09)	0.151
	[Age-5]	-0.01	(-0.02, 0.01)	0.273
	$[\text{Age-5}]^2$	-0.00	(-0.00, -0.00)	0.216
	Marital satisfaction			
	ID*marital satisfaction	0.03	(0.03, 0.04)	<0.001
		0.05	(-0.01, 0.10)	0.081
7e: ID* general health	Constant	3.15	(2.92, 3.38)	
	ID	0.05	(-0.19 0.28)	0.702
	[Age-5]	-0.01	(-0.02, 0.01)	0.280
	$[\text{Age-5}]^2$	-0.00	(-0.00, -0.00)	0.210
	General health	-0.04	(-0.05, -0.03)	<0.001
	ID*general health	-0.00	(-0.09, 0.08)	0.930
7f: ID* psychological distress	Constant	3.15	(2.92, 3.37)	
	ID	0.11	(-0.03, 0.26)	0.125
	[Age-5]	-0.01	(-0.02, 0.01)	0.276
	$[\text{Age-5}]^2$	-0.00	(-0.00, -0.00)	0.212
	Psychological distress	-0.01	(-0.01, -0.01)	<0.001
	ID*psychological distress	-0.02	(-0.05, 0.00)	0.114

7g: ID*Autism	Constant	3.11	(2.87, 3.34)	
	ID	0.76	(-0.15, 1.67)	0.101
	[Age-5]	-0.01	(-0.02, 0.01)	0.281
	[Age-5]2	-0.00	(-0.00, 0.00)	0.209
	Autism	0.15	(0.04, 0.26)	0.010
	ID*autism	-0.37	(-0.83, 0.09)	0.116
7h: All interactions	Constant	3.11	(2.88, 3.34)	
	ID	0.28	(-0.76, 1.32)	0.596
	[Age-5]	-0.01	(-0.02, 0.01)	0.277
	[Age-5]^2	-0.00	(-0.00, 0.00)	0.213
	Autism	0.15	(0.04, 0.26)	0.010
	Challenging behaviour	-0.01	(-0.01, -0.01)	<0.001
	Socioeconomic status	-0.06	(-0.10, -0.03)	<0.001
	Work/family balance	-0.01	(-0.02, -0.01)	0.001
	Marital satisfaction	0.03	(0.03, 0.04)	<0.001
	General health	-0.04	(-0.05, -0.03)	<0.001
	Psychological distress	-0.01	(-0.01, -0.01)	<0.001
	ID*Autism	-0.36	(-0.83, 0.11)	0.129
	ID*Challenging behaviour	0.00	(-0.01, 0.02)	0.915
	ID*socioeconomic status	0.16	(-0.04, 0.36)	0.118
	ID*work/family balance	0.07	(-0.00, 0.14)	0.061
	ID*marital satisfaction	0.05	(-0.01, 0.10)	0.111
	ID*general health	0.01	(-0.08, 0.10)	0.863
	ID*psychological distress	-0.02	(-0.05, 0.01)	0.191

A backwards selection model was then used to discard the least significant interactions from model 7h, one at a time, and the results are displayed in table 19. The model suggests that there is no significant difference on the effect of socioeconomic status, work/family balance, marital satisfaction, autism, challenging behaviour, general health or psychological distress on father-child closeness for fathers with or without a child with intellectual disabilities. The AIC of the final model was 40523.2, making this a better fit of the data than model 3 (AIC 48015.11).

Table 19: Backwards selection model of covariates and the association between age and father-child closeness, for children with and without ID, including predictors

Model 1 is the full model which includes all interactions, including [Age-5] and [Age-5]^2 as fixed and random effects. Each subsequent model subtracts one interaction at a time. Model 7 is the full model with only significant interactions. All models include a constant term, and random intercepts for each father-child pair.

Predictor	p-values under each model (Model 1 = Full Model, Model 7 = Final Model)						
	1	2	3	4	5	6	7
ID*Challenging behaviour	0.915						
ID*General health	0.863	0.868					
ID*Psychological distress	0.191	0.190	0.190				
ID*Socioeconomic status	0.118	0.119	0.110	0.127			
ID*Autism	0.129	0.122	0.124	0.103	0.123		
ID*Work/family balance	0.061	0.060	0.058	0.067	0.094	0.100	
ID*Marital satisfaction	0.111	0.108	0.109	0.058	0.074	0.066	0.081

8.8 Discussion

8.8.1 Research Question One: Does closeness of fathers with a child who has intellectual disabilities remain stable over time?

The quadratic model, which was the best fit for the data, suggested that on average, father-child closeness did not remain stable over time but decreased between the ages of 5 and 7, only to increase between the ages of 7 and 11 years old. There is variation in father-child closeness for fathers who have a child with intellectual disabilities over time, in terms of slope and curvature of the trajectory. Each father has their own trajectory which is fairly flat on average with a slight curve, but there is variation with many different shapes to the trajectories. These results support the fact that both children with intellectual disabilities and their fathers are unique individuals with differing skills and support needs, and therefore their relationship and the degree of closeness felt will be different for each father.

8.8.2 Research Question Two: Does the trajectory of father-child closeness differ between fathers with and without a child with intellectual disabilities?

The quadratic model was also found to be the best fit of the data for fathers with a child without intellectual disabilities. This assumes that the trend of father-child closeness over time for each father is a curve, with variability between fathers in terms of slope and curvature. While the slope of father-child closeness is relatively flat, which suggests that there is not much variation with time, the trajectory did show a slight curve. Similarly to fathers of a child with intellectual disabilities, father-child closeness fell slightly between the age of 5 and 7 years old, before increasing again between ages 7 and 11 years old. As interaction terms did not improve the fit of the model, this suggests that there is no difference in trajectory with age between fathers of children with intellectual disabilities and other fathers.

It is unclear why there would be a dip in father-child closeness between the ages of 5 and 7 years of age. As this marks the early years of formal education, fathers may simply have less time to spend with their child when they are at school during the day and so feel less close to them during this transition period. Fathers of a child with intellectual disabilities in the sample were more likely to be unemployed, and therefore more likely to be around their child during the day, when their child was 5 and 7 years old (23.1%, 25.4%) compared to fathers of a child without intellectual disabilities (10.4%, 8.6%). As the decrease in closeness coincides with the child’s first few years of formal education, fathers who are unemployed would not be able to spend as much time with their child as they had prior to the start of school. However, the similar trajectory for fathers of children with and without intellectual disabilities, and the relatively small portion on unemployed fathers in either group, suggests that having less time at home with their child did not significantly impact father-child closeness. Longitudinal data from the Growing up in Scotland Study (Parkes, 2016) also dispute the idea that the reduced amount of time spent with their child is associated with reduced father-child closeness, as father-child relationships did not vary according to whether fathers had shorter working hours. This suggests that it is not the length of time that fathers spend at home that explains the quality of the father-child relationship. Therefore, it seems unlikely that a reduction in the child’s time spent at home with the father during their early school years is responsible for this trajectory.

As a similar pattern exists for both groups of fathers, the fact that many children with intellectual disabilities receive a diagnosis around this age also does not appear a likely explanation for this dip. However, other aspects of transitioning into school may be responsible for this slight change in father-child closeness.

The finding that parents of children with intellectual disabilities are less close to their child than fathers of children without intellectual disabilities is also supported by a study on mothers using an earlier wave of the same data set. Parent-child closeness at age 3 was assessed for main respondents, who were predominantly mothers, and lower closeness scores were reported for parents of a child with intellectual disabilities (Totsika et al, 2014).

8.8.3 Research Question Three: Is father-child closeness of fathers with a child with intellectual disabilities over time associated with child (autism, gender, challenging behaviour) or family (socioeconomic status, marital satisfaction, psychological distress, general health, paternal work-family balance) variables?

While several variables were associated with father-child closeness, these factors may be measuring similar constructs. For example, overall life satisfaction and satisfaction with work/family balance may overlap. Marital satisfaction and psychological distress were the only significant predictor of father-child closeness of fathers whose child had intellectual disabilities in the final model, with higher marital satisfaction and lower psychological distress associated with increased father-child closeness.

The results offer support for family systems theory (Minuchin, 2002), as this theory predicts that parental relationships influence parent-child relationships. This finding is also in keeping with research on father-child relationships within the general population, which recognises that quality of marital relationship is a key factor in father-child relationships (Lamb, 2004). An observational study of father-child interactions with 15 fathers of infants aged an average of 6.3 months old, reported that marital dissatisfaction adversely affected paternal two-way interactions with their child, and thus the security of infant–father attachment (Lundy, 2002). However, this was a small sample and only a very brief video of father-child interactions was used as the basis of interaction and attachment. More robust evidence is provided by analysis of the Growing Up in Scotland Study (Parkes et al., 2017), which comprised a nationally representative data set of children aged 10 years of age investigated factors which influenced father-child relationships. The study reported that fathers who experienced high marital satisfaction were around half as likely to have a poor father-child relationship as those with low marital satisfaction.

Very few studies were identified which investigated the impact of marital satisfaction on father-child closeness in families with a child with intellectual disabilities within the existing literature. However, there is some evidence to suggest that marital satisfaction also significantly impacts father-child closeness in adult children with intellectual disabilities. A study by Essex (2002) was conducted with 96 parent couples aged 55 or above, of an adult child with intellectual disabilities. Fathers with higher marital satisfaction in this study reported feeling closer to their child than those with lower marital satisfaction, and this factor was most strongly related to closeness for fathers of all variables investigated in the study (Essex, 2002).

The associations between marital satisfaction and father-child closeness, and psychological distress and father-child closeness, emphasise the importance of the well-being of members of the family unit, and relationships within the family. Due to this relationship, Essex (2002) suggests that practitioners should consider how parent relationships and parent well-being impacts the family unit, and that when providing support to parents of a child with intellectual disabilities it is important to consider the needs of the whole family. Finding ways to promote the relationship to support the whole family, such as family or couples counselling, may help to maintain these important relationships.

None of the other variables included in this study's analysis were significantly associated with father-child closeness. Where the association between these variables and father-child closeness had been investigated in the literature in various populations, similar results were reported for a number of these variables. An earlier study on data from the Millennium Cohort Study when children with intellectual disabilities were aged 3 years of age also reported that family deprivation was not directly related to parent-closeness of the main respondent (Totsika et al, 2014). Another study examining childhood predictors of fathers' relationships with their adolescent with developmental disabilities, found no association between father-child relationship and socioeconomic status (Mitchell & Hauser-Cram, 2010). However, families in Mitchell and Hauser-Cram's sample were predominantly on a moderate income which may not represent families with a wider range of incomes. The data collection methods in the dataset used in the current study were designed to sample a larger proportion of low-income families. Therefore, a failure to find a significant association between socioeconomic factors and father-child closeness may be due to this limitation of the sample.

Similar to the results in the current study, in the Growing up in Scotland Study, there was no association between fathers in the general population reporting dissatisfaction with their work-life balance when the child was 2 years old and the likelihood of a poor father-child relationship eight years later. However, fathers of male children in this study were statistically more likely to have a poor father-child relationship (Parkes et al., 2017). This is unlike the results of the current study, as fathers were no more likely to experience closeness with a male than with a female child with intellectual disabilities.

There is some evidence in the existing literature to suggest that different factors impact mother-child closeness. A study using earlier waves of the Millennium Cohort Study conducted by Totsika and colleagues (2014) did find a significant relationship between parent psychological distress and mother-child closeness, as well as challenging behaviour and mother-child closeness. There was a significant relationship between mother psychological distress at 9 months and a positive mother-child relationship at 3 to 5 years of age. A positive mother-child relationship also significantly mediated the path to conduct problems and total behaviour problems at 7 years, and the path to conduct problems at 11 years in this study. In Totsika and colleagues' study 47% of mothers were unemployed, compared to 23.1% of fathers in the current study. This difference in time away from the family home between parents in the sample may contribute towards the differing impact of challenging behaviour on parent-child closeness.

8.8.4 Research Question Four: Is father-child closeness associated with the same factors for both fathers of children with and without intellectual disabilities?

The results show that father-child closeness was not affected differently by the factors under investigation.

Strengths and Limitations

As father-child closeness was only reported by fathers in this study, it is possible that this does not reflect the degree of closeness that children feel with their father. The majority of variables investigated for their link to father-child closeness were also self-reported by fathers, which is a limitation of the current study. However, for variables which reflect personal satisfaction with different elements of their lives, such as marital satisfaction, it is difficult to imagine what other more robust measures could have been taken. The general health measure mimics the measure used in the Scotland Census 2011 to assess people's perceptions of their general physical health. During the development of the census, Ipsos MORI Scotland was commissioned to undertake cognitive question testing on a number of included questions. This was done in order to test whether the questions were answered accurately, and to identify any changes needed to improve the clarity of the questions. This approach to critically evaluating and improving survey questionnaires is widely supported (Wills, 2005). The general health question was assessed as requiring no alterations during this process, and so the self-report general health question in the current study is an appropriate measure of father health. Psychological distress was measured using the K6 scale, the validity of which has been supported within the general population, making it an appropriate instrument to measure father psychological distress.

A further strength of this study is the use of data from a nationally representative dataset, which enables researchers to generalise the results from analysis of this data to the general population. The ability to identify individuals with intellectual disabilities within large datasets is often complex or simply impossible. However, the inclusion of sufficient variables to measure cognitive abilities of children in the sample provided an appropriate means of identifying fathers of a child with intellectual disabilities within this dataset. Yet children in this sample received no formal diagnosis of intellectual disabilities and the cognitive measures used to identify this population in the current sample do not take account of adaptive skills. Therefore, the children in this study's sample may have more mild intellectual disabilities than a representative sample of children with intellectual disabilities.

Very few studies have investigated father-child closeness and the factors associated with this relationship, in families of children with intellectual disabilities. The use of growth models to examine this relationship trajectory over time is also novel. Therefore, this study is an important addition to the literature and increases our understanding of the impact of marital satisfaction and father well-being on fathers of a child with intellectual disabilities.

Chapter 9: Final Discussion

9.1 Introduction

This chapter presents a discussion of the findings from the three studies undertaken as part of this PhD project in the context of existing literature, and considers the implications for theory, policy, and practice. The strengths and limitations of the project are then discussed and possible future directions for research presented.

9.2 A reflection on the PhD journey

The focus of the current PhD project evolved over the course of the project. It was influenced by a need to respond to changing circumstances, as well as an increasing understanding of the experiences of fathers of a son/daughter with intellectual disabilities. Prior to beginning my PhD, I was employed as a Research Assistant and conducted a systematic review on patterns of hospital admissions for adults with intellectual disabilities. While reading potentially relevant papers for this review, I discovered a number of studies which collected qualitative data from parents on the experience of their child going into hospital. The majority of interviewed parents spoke of the strain that the experience placed on their own mental health and wellbeing, as they felt compelled to provide round the clock care during the hospital visit to ensure that their son/daughter was well looked after. This was the point at which I first became interested in the experiences of parents of individuals with intellectual disabilities, and how caring affected their mental health in particular.

From my initial reading around this topic, the majority of studies concluded that caring negatively impacted parents' mental health, although most research focussed on mothers rather than fathers. While I identified few studies about fathers of a son/daughter with intellectual disabilities from my initial reading, a qualitative study on male and female carers suggested that the experience and impact of caring differed by gender (The Carers Trust, 2014). The mental health of fathers of a son/daughter with intellectual disabilities was therefore initially selected to be the focus of this PhD project. To this end, a systematic review and meta-analysis was conducted to summarise what was currently known about the mental health of fathers of a son/daughter with intellectual disabilities and to identify any gaps in knowledge demonstrated by the findings of the review. The majority of papers identified in the systematic review investigated mental health in fathers who were in their mid-30's to mid-40's, with only one paper including older father carers in the sample (Upadhyaya & Havalappanavar, 2008).

At this stage in the project, the decision was made to focus on older father carers (age 60 or above). While the systematic review revealed that middle aged fathers experienced better mental health than mothers, it was thought that this pattern may differ among older mothers and fathers. It was assumed that as fathers entered retirement they would become more available to assist their partner in caregiving activities, and that this may become necessary if their partner's health deteriorated. At this time of life, the factors which may have accounted for differences between mother and father mental health at an earlier point in their caring journey may not be relevant. For example, where information on number of hours spent caring or working were recorded in the studies included in the systematic review, fathers usually worked full-time while the mother was the main caregiver. As a result, these fathers may not have spent as much time with their child or taken on as much responsibility for day-to-day tasks for their child. It was thought that this may partly explain the difference in mental health outcomes for mothers and fathers in the systematic review and meta-analysis.

Following the decision to focus on the mental health of older fathers, a dataset was identified which would enable an investigation of this topic while providing data on relevant factors such as the number of hours of caring undertaken each week and employment status. As detailed in section 7.1 of this thesis, the original plan to use this dataset at this time was not possible due to long delays in accessing the data from the Scottish Government. Therefore, the decision was made to conduct the qualitative study and to use the results of this study to guide the specific research questions asked in the quantitative project. It was hoped that once the qualitative study had been conducted the desired data set would be available from the Scottish Government.

As the qualitative project focussed on fathers age 60 and over who likely had been fathers of a son/daughter for many years, the interview topic guide was designed to encourage fathers to discuss their experiences from the birth of their child up to the present day. Due to the lack of research on older fathers' experiences, this seemed an appropriate way of learning which experiences had particularly affected fathers and identifying important aspects of their caring journey which could be further explored in the quantitative study.

During the course of these interviews it became apparent that while the mental health of every father was negatively affected in some ways by caring for their son/daughter, they also experienced an array of positive effects. The systematic review in this PhD focussed specifically on mental health and did not include papers which investigated other elements of the caregiving experience, such as personal growth. This was partly because the review chose to focus on quantitative studies to allow for a meta-analysis to be conducted, and partly because I had not anticipated that positive effects of caring would be so central to a fathers' experiences. Further reading about theoretical models of caring in the existing literature revealed that while a number of models allowed for positive perceptions and outcomes (Lazarus & Folkman, 1984; Folkman et al, 1979; McCubbin & Patterson, 1983), one model also described the simultaneous existence of both positive and negative effects of caring (Lawton et al., 1991). Had I been aware that fathers in the qualitative study would describe an experience which involved both positive and negative effects from their caring role, I would have adjusted the systematic review to specifically investigate both negative and positive impacts of caring.

The impact of caring on their mental health was discussed by all fathers, although this was not a stand-alone theme which emerged from the qualitative study. Instead, themes such as the 'battle' for services and the 'importance of family' were much more salient for fathers who participated in the interviews. As so little research has been previously conducted with this age group of fathers of a son/daughter with intellectual disabilities, it felt more appropriate to focus the final study on an area of particular relevance and importance to them. Therefore, the decision was made to move from a focus on only mental health to father experiences more broadly.

Upon completion of the qualitative study the quantitative dataset that I had requested from the Scottish Government was still not available. Therefore, I began searching for a dataset which would allow me to identify fathers of a son/daughter with intellectual disabilities, while investigating a topic which had been of importance to fathers in the qualitative study. One of the themes which fathers spoke about at length and with great passion was the importance of their relationship with their son/daughter with intellectual disabilities, and how this had developed over time. Given recent research which has identified the important role that father-child relationships can have in a child's development (Ferreira et al., 2016; Lamb, 2004, 2010; Meuwissen & Carlson, 2015, 2018), and the lack of research exploring this relationship in the intellectual disabilities' population, this was deemed to be an interesting avenue to explore in the quantitative project. The Millennium Cohort Study was identified as an appropriate dataset which would allow the study of father-child relationships over time.

This study had not been running long enough to contain data on fathers aged 60 and over. However, no other data set could be obtained at this point in the project in time to conduct analysis prior to the end of the PhD funding period. As a result, the quantitative study investigated father-child closeness when fathers were in their late 30's to early 40's. While the experiences of fathers at this stage in their lives were likely different from older fathers included in the qualitative study, this allowed the project to gain insight into the experiences of fathers at different points in their caring journey. Fathers in the quantitative study were also a similar age to the majority of participants in studies included in the systematic review.

9.3 Main findings

As discussed in the introductory chapter of this thesis, very little research has been conducted on the well-being and experience of fathers of a son/daughter with intellectual disabilities. This is despite the fact that evidence suggests that fathers now contribute to household and caregiving tasks more than ever before (Altintas, 2016; Johansson & Andreasson, 2017), and the potential impact of father involvement with their children is recognised within the general population (Parkes et al., 2017; Twamley et al., 2013). There is a dearth of research on the experiences of older fathers, which is of particular significance due to the growing population of fathers who care for their child into old age. To address these gaps in the research, the systematic review and meta-analysis, qualitative study, and quantitative study described above were conducted.

Together, the results of these studies highlight the following:

- Father's experiences of and perspectives on caring evolved throughout their caring journey
- Traditional gender roles appear to continue to operate for fathers.
- Caring for a son/daughter with intellectual disabilities has a significant impact on fathers' well-being, both negatively and positively.
- Marital quality and support significantly impact father well-being and father-child closeness.
- Father-child closeness follows a similar trajectory for fathers with and without a child with intellectual disabilities.

9.3.1 Father's experiences of and perspectives on caring evolved throughout their caring journey

Fathers who participated in the qualitative study were able to reflect back on their experiences over the years, as well as discuss what their future may hold. They spoke about their experiences as a narrative unfolding over time and acknowledged how their life had been altered, both positively and negatively, by becoming a father of a son or daughter with intellectual disabilities. Their experiences can therefore be interpreted through the lens of biographical disruption. Biographical disruption describes illness as an event which disrupts the fabric of an individual's everyday life, and results in a change of their assumptions about their lives, their self-concept, and how they marshal resources to meet the challenges of the disruptive event (Bury, 1982). Parental biographical disruption has previously been described in mothers whose child has intellectual disabilities (Brown, 2016; Todd & Jones, 2005). This perspective also appears to fit with many of the fathers' accounts about the impact that caring had on their lives and sense of identity.

Fathers described the time after diagnosis as a particularly disruptive period of their lives, when they had to adjust their expectations about what achievements and independence might be possible for their child and themselves. Such feelings have also been documented in previous studies, with the time of diagnosis described by many family carers of a child with intellectual disabilities as their most stressful life event (Thomson et al, 2017). While most fathers described a degree of disruption from the point of diagnosis onwards, the majority only directly spoke of a change to their self-concept or identity when their working life was affected. This ties in with the adherence to traditional gender roles previously discussed in this chapter, and the importance that fathers placed on their role as the main breadwinner. Fathers in the qualitative study who gave up their career to become a full-time carer for their son/or daughter struggled with this transition and initially felt that their role in the family, as well as within wider society, became less important following this change. However, a number of these fathers felt that by this stage in their lives they had become experts in the social care system and derived satisfaction from becoming a point of information for other families. They took pride in being sought out by families who were only beginning their caring journey and needed their advice. In this way, while their self-esteem may have been negatively affected by the disruption to their previous identity as main breadwinner, they later developed a new type of identity which bolstered their confidence and self-esteem.

The disruption in the fabric of everyday life that fathers experienced, such as the necessary transition from full-time employment to full-time care, was particularly apparent with relation to normative ideas of the life course in the context of the family. In this context, the life course perspective is a multidisciplinary approach to understanding changes in the lives of families over time. The life course perspective emphasises the importance of considering the past, present and future of families of an individual with intellectual disabilities (Esbensen et al, 2012). It is particularly appropriate to consider this study's findings in the context of the life course perspective as the fathers in the qualitative study were older than the fathers in the quantitative study and reflected back on different periods in their lives, enabling the researchers to explore different points in the caring journey. The findings also revealed that fathers' experiences changed over time, at different stages in their child's lives such as childhood, adolescence, young adulthood, and entering middle age.

According to the life course perspective, family relationships also go through various changes. The quantitative study revealed that this was the case for father-child relationships as fathers described a decrease in closeness with their child with intellectual disabilities between the ages of 5 and 7, followed by an increase between the ages of 7 and 11 years old. As a similar pattern was reported by fathers whose child did not have intellectual disabilities, this suggests that father-child closeness follows a normative pattern during this time period. As higher marital satisfaction was associated with increased father-child closeness, this finding demonstrates the importance of supporting positive family relationships throughout the life course.

Fathers in the qualitative study spoke of the adaptations that the entire family unit had made to accommodate the changing circumstances of having a child with intellectual disabilities. Those with other children acknowledged that having a sibling with an intellectual disability had altered the amount of time that they could spend with their other children, as well as the financial resources that were available for them. However, there were also stories of positive disruption. One father mentioned that his other two daughters had received grants to study at university due to the family's reduced income. He spoke of this as a positive disruption, as his daughters would otherwise have accumulated some debt, had the family circumstances not changed to make them eligible. A number of fathers also mentioned that another child within the family had chosen to become a psychologist or special education teacher in order to support other individuals with intellectual disabilities. These fathers attributed their child's career choice entirely to having a sibling with intellectual disabilities, and so the life course trajectories of other members of the family were also affected.

As fathers reached or approached their retirement, the distance between what they had originally assumed their retired life would look like and what was now possible was also a source of worry or disappointment for many. Most fathers felt that what a typical man could expect from his retirement would not be possible for them. This was particularly the case if their son/daughter continued to need physical care and assistance with personal care tasks. At this point in their lives, fathers were having to reduce the amount of physically challenging tasks that they performed, such as lifting their child in and out of bed, as they began to experience physical limitations themselves. Some fathers also received more help from services than they had in earlier stages of their caring journey and so were able to have more time to pursue their own interests. This led some to reassess what they wanted from their retirement and to make plans for how this could be achieved.

While all fathers described some degree of disruption to their lives, expectations for the future, and self-concept, many also emphasised that they were and had always been a father first. The importance of this identity to fathers had not changed by having a child with intellectual disabilities. As has previously been discussed, fathers in the qualitative study described their caring and advocating activities as a natural part of being a father. In this way, they continued to hold the self-concept of being a father, although the everyday tasks involved in this role may have changed after learning that their child had intellectual disabilities.

Whether fathers viewed having a child with intellectual disabilities as a disruption to their life story, or not, the data from the qualitative study clearly demonstrate the importance of investigating fathers' experiences and the impact of caring across the entire life course. More research is required to better understand the impact of having a son or daughter with intellectual disabilities on fathers at different stages of their lives. Such research could enable services to better meet the needs of fathers across life events.

9.3.2 Traditional gender roles continue to operate

While there was mixed support for the association between fathers' well-being and financial resources, the majority of studies included in the systematic review did support existing research which has linked poor socioeconomic circumstances to poor adult health and well-being in the general population (Prag et al., 2016; Wilkinson & Pickett, 2009). Financial resources and the worry over being able to provide for their family was also clearly a source of concern for fathers who participated in the qualitative study. The desire to serve as a competent breadwinner, expressed by fathers in the study, ties in with the traditional gender roles that the majority of men in this study appeared to subscribe to. As discussed in the introductory chapter, various studies have reported an increase in father participation in caregiving and household tasks over time (Altintas, 2016; Johansson & Andreasson, 2017). Yet older fathers who participated in the current study did not appear to have made many strides towards challenging traditional gender roles by sharing caregiving tasks more equally with their wives.

Studies in the systematic review which reported employment status or number of hours of caring also demonstrated the continuation of traditional gender roles for fathers of a son/daughter with intellectual disabilities. For example, Rowbotham and colleagues (2011) investigated the roles in caring for an adult child with intellectual disabilities for 12 mother-father couples, and found that mothers spent significantly more hours each day completing caregiving tasks. This is not surprising as the majority of fathers in the sample worked full-time while the majority of mothers were unemployed, giving them more time to engage in such tasks. However, while mothers spent more time on caregiving tasks, there was no difference between genders in the number of areas that parents assisted their child, the level of caregiving difficulty reported, or the perceived helpfulness of their partner with regards to their involvement in family responsibilities. This suggests that when fathers are working full time, employment is viewed as part of their family responsibilities. These findings certainly support the results of the current qualitative study, as fathers spoke of the importance of their role as a provider, and that due to their time at work they were not as available to assist their wife with caring activities.

In Rowbotham's (2011) study, fathers were aged 55-65 years old and the majority were working full-time, while in the current qualitative study the sample was made up of older fathers aged 60-68 years old. The unequal distribution of caring tasks reported by fathers in both samples remained evident even in fathers who had retired and were no longer out of the house at work each day. In the current qualitative study, fathers who had retired continued to use language such as 'filling in' to describe their contribution to caregiving. This suggests that even when they were more available to split the caring load equally, mothers continued to do the bulk of the work. A similar division of labour has been reported by studies of elderly parents caring for older adults with intellectual disabilities (Essex, 2002; Essex & Hong, 2005). As these studies have focussed on middle aged and older parents it is unclear if the division of caregiving tasks would be more equal in households with younger parents. It is important to investigate this in order to inform future service provision and explore the usefulness of existing employment legislation for younger fathers who need or wish to take time off work to care for their child.

The accounts of fathers in the qualitative study also revealed a gender difference in how a normative family lifecycle was disrupted or changed by having a child with intellectual disabilities. In families where fathers remained the main caregiver, they described their wives giving up work to care full-time as an inevitable and expected change. Children were directly referred to as their wife's domain by multiple men, and full-time child care a natural occupation for women. Whereas, when fathers felt that they too had to leave their employment to become carers, they described this as a huge loss to their sense of identity and purpose in life. As mothers were not interviewed in the qualitative study, it is possible that they also felt this sense of loss but that their husbands were unaware of this due to traditional societal expectations for women. For most fathers, the need to begin full-time caring occurred when their child reached the teenage years and their wife was no longer able to cope by herself. Previous research has identified the teenage years as a time of significant disruption for mothers of a son/daughter with intellectual disabilities (Todd & Jones, 2005). Mothers in this study identified changes in opportunities for socialising, the departure of other children from the family home, and physical changes associated with mid-life as among the events which particularly impacted upon the family unit. Fathers in the current study also spoke of these changes as highlighting the differences between themselves and their peers who did not have a child with intellectual disabilities. In this respect, the lifecycle disruption during middle age appears to be similar for both mothers and fathers. Further research which would be beneficial to gain further understanding of how the normative lifecycle may be impacted differently for mothers and fathers.

Expectations of being a father are shaped by the particular family unit as well as wider societal forces. For many, legislation has significantly influenced the degree of involvement in caregiving and household tasks. The fathers in the qualitative study became parents to a child with intellectual disabilities when there were limited options for taking additional time off work to care for their child. This finding is supported by research into the restrictions that policies put on fathers' ability to take time off work to participate in caring for their child (Olchawski, 2016). The stress that fathers experienced immediately after their child's birth, or after receiving a diagnosis was exacerbated by the fact that they were unable to take much time to spend at home with their family. More recently, Shared Parental Leave 2014 has provided the opportunity for fathers to share up to 50 weeks of leave with their partner. While a number of issues remain with this legislation, from the accounts of fathers in this study, this appears to be an important step forward for fathers who wish to be more involved in caring for their child. However, a more flexible parental leave policy is required in order to meet the needs of fathers who may have to use the leave with less warning than current legislation allows. Fathers who are not anticipating their child to be born with disabilities may not have expected the need to use their leave so soon after the birth of their child, and preventing fathers from taking this time more flexibly may put additional strain on mothers who are left to care for a child with additional support needs while their partner is at work.

A gender difference was also evident in terms of what fathers in the qualitative study felt had been gained by the lifecycle disruption of having a child with intellectual disabilities. Fathers spoke at length about how important it was to become an expert advocate for their son or daughter. As previously discussed, fathers appeared to become empowered and gained a new purpose from adopting this role. A number of fathers who participated in the current project felt that service providers often did not acknowledge their role in their son/daughter's life, and would automatically direct all correspondence to their wife. In this way, the battle for services appeared to be gendered, with fathers feeling largely ignored by professionals. One father described a time when he brought his daughter to an appointment, only for the receptionist to look past him as if to say "where's their mother?" Fathers felt that while both parents were involved in the battle for service, their wives were the main point of contact for service providers and were seen to hold a more important role in their child's life. Fathers often adopted a role where they would coach their wife on who to call and what to say in order to obtain necessary services. In this way, they remained behind the scenes but felt that it was their knowledge and advice that allowed the family to receive the support that was needed. Various metaphors used by the fathers, such as the military metaphor of being an 'aide de camp' for their child, convey this idea that they played an essential role in the background. From these accounts, it appears that services continue to reinforce traditional gender roles, which can leave fathers feeling disengaged and excluded. Campaigns encouraging fathers to take ownership of caring responsibilities and informing service providers of their importance may increase the number of fathers who share caring with their partner, thereby challenging gender stereotypes and reducing the burden on mothers.

A gender difference was also reported in the systematic review, with mothers experiencing poorer mental health than fathers. Many of the fathers in the qualitative study also felt that having a child with intellectual disabilities had been harder for their wife than themselves, as they were not around as often and experienced a break from caring by being at work during the day. As discussed in Chapter Four, the results of the systematic review also suggested that employment can serve as a buffer to the impact of caring on parents of a son/daughter with intellectual disabilities (Olsson & Hwang, 2006). If the apparent higher impact of caring on mothers is due to the increased number of hours that they spend caring for their son/daughter with intellectual disabilities, then this gender difference may not occur in studies of couples who divide employment and caring roles more equally. While fathers were found to have better mental health than mothers, the results of the systematic review demonstrated that they do experience poorer health than fathers in the general population. Therefore, service provision must be made for supporting father carers as well as mothers. More work needs to be done to determine what type of support would be most helpful to fathers.

While it may come as no surprise that older fathers continue to operate within traditional gender role norms, it remains noteworthy the fathers in this study were only aged 60-68 and so they and their wives likely have many years of caring ahead of them. If the majority of the burden continues to fall on mothers, even after fathers have retired, this suggests that mothers will require extra help as they age.

Some fathers in the qualitative study also spoke of or alluded to the effect of their child’s gender on their relationship. While all fathers emphasised their affection for their son/daughter with intellectual disabilities, the nature of the relationship differed by gender. Fathers who had a daughter spoke more about the importance of providing her with help and support, and admitted that they were very protective of her. While, those with a son did not use this language. Instead, these fathers tended to describe engaging in rough and tumble play or physical competitions as their method of bonding with their son. Humour was often identified as an important aspect of their relationship with their child, regardless of their child's gender. However, physical humour such as attempting to trip one another up was only discussed by fathers who had a son. This pattern has also been identified in the general population, with physical play more common among fathers and sons than fathers and daughters (Parkes et al, 2017). This study also reported that sons are more likely to have a poor father-child relationship than daughters (Parkes et al, 2017). However, this was not evident from the accounts of fathers in the qualitative study, or the results of the quantitative study. When the association between father-child closeness and child gender was tested in the quantitative study, no significant association was detected between these variables. This was true for both fathers with and without a child with intellectual disabilities. The difference in these results may be attributable to the fact that father-child relationship quality in the Parkes (2017) study were reported by children, rather than fathers, and was measured from the child's response to nine statements about their relationship with their father. Further exploration of relationship quality, using a more sophisticated tool, between fathers and their son/daughter with intellectual disabilities may reveal a similar gender difference. Such research could help us to better understand father-child relationship quality, and how different bonding activities may affect these relationships. This in turn could inform future support provided to fathers of a child with intellectual disabilities.

9.3.3 Caring impacts fathers' well-being, both negatively and positively

The results of the systematic review and qualitative study demonstrate that caring for a son/daughter with intellectual disabilities can negatively affect the mental health and well-being of fathers. Similar results have been reported by various studies in the current literature, which compare mothers of a son/daughter with intellectual disabilities to mothers in the general population (Cairns et al., 2014; Thomson et al., 2017b). These findings also challenge the idea that since fathers generally operate as the secondary carer in families where the child has a disability (Essex & Hong, 2005), they are unaffected by having a son/daughter with intellectual disabilities.

Father carers who participated in the qualitative study also reported a negative impact of caring on their well-being. One father summarised the way that caring had affected himself and his wife: '*It's affected, well it's affected us financially, it's affected us mentally, it's affected us socially*." However, these fathers emphasised that fighting for services had the biggest effect on their well-being. As one father stated: "*It's been a battle all the way. And that's probably had more of an effect on my mental health than actually having to deal with a son with learning disabilities, if I'm honest about it*." This finding suggests that having a child with intellectual disabilities does not automatically lead to poorer health outcomes for fathers, and that the stress which fathers experienced in their caring role was largely attributed to the lack of support which fathers experienced when interacting with services.

From the qualitative study, the statutory support available to families with a son or daughter with intellectual disabilities appears to be inadequate. As discussed in Chapter One, only a minority of working carers report that they receive adequate services to support them in their role (Brimblecombe, Pickard, King, & Knapp, 2016; Milne, Brigden, Palmer, & Konta, 2013). All fathers in the current study experienced problems obtaining appropriate resources or services for their child, and the stress that they experienced fighting for services took a significant toll on their well-being. This indicates that a lack of service provision and barriers to receiving services and supports negatively affects fathers, and this in turn is likely to negatively affect the child that they are caring for.

Due to the reduction in available supports, as well as a series of negative experiences with individual staff working within the social and care services, fathers in this study were more likely to turn to informal sources of support such as family, friends, and other parent carers. While fathers often received much needed support from these sources, as they approached old age it became particularly important that they receive support from formal channels. Receiving help and guidance from the social and care services is vital for parents who are trying to set up a secure plan for their child's future, as many felt it was not possible or inappropriate to rely on family to care for their child after they end their caregiving role.

The majority of fathers in the qualitative study did not feel that they were given adequate guidance or information about supports and services that they were entitled to, particularly at the beginning of their journey, during transition between schools, and transition from child to adult services. This is especially concerning as the Community Care and Health (Scotland) Act stated that it was the duty of the local authority to inform carers of their rights and inform them about available services (Community Care and Health (Scotland) Act, 2002). This act also legislated for 'partnership working' between carers and services. At the time that this act was passed, fathers in the qualitative study had a child with intellectual disabilities with a mean age of 15 years. Yet these fathers still experienced significant difficulties obtaining relevant information about transition, available services in their area, or their rights as carers during their child's teens and early twenties. Even now, sixteen years after the act was passed, when working towards setting up their son/daughters future living arrangements fathers felt that there is a lack of information and transparency. From the accounts of the older fathers in this study the Community Care and Health (Scotland) Act does not appear to have translated into actual partnership working or information sharing. This is particularly unfortunate as a number of fathers in the current study felt that they had managed to become an expert in the social care system, and that gaining such expertise had a positive effect on their well-being. Therefore, fathers could benefit from receiving more information from services at the beginning of their caring journey, and being respected as expert care partners.

More recently, the Carers (Scotland) Act 2016, stated that carers must be provided with an Adult Carer Support Plan and local authorities must provide support to carers based on their individual needs identified in this plan. Information and advice services must also be provided for carers within the local authority (Scottish Executive, 2016). This act has only recently been passed and so fathers have likely not yet experienced the potential benefits of this legislation. Further work should be done with fathers in the years following this legislation to determine if the lives of fathers and their son/daughter with intellectual disabilities are positively impacted by this new act.

While no single theoretical model accurately represented the experiences of caring that fathers described in this study, similarities did exist between these models and the findings in the qualitative study. The theoretical models of stress and coping described in Chapter Two all support the idea that having a son/daughter with intellectual disabilities does not necessarily lead to stress, and that how fathers appraise the situation plays an important part in whether fathers perceive an event as stressful (Lawton et al., 1991; Lazarus & Folkman, 1984; Folkman et al, 1979; McCubbin & Patterson, 1983). Findings in the systematic review and qualitative study support the importance of such an appraisal system, as fathers described the importance of various coping methods which they employed to alleviated stress. Further work should be conducted to investigate which coping strategies are most successful for mitigating stress among fathers, as this could guide the approach taken by practitioners who support such individuals.

The existence of both positive and negative effects of having a child with intellectual disabilities, which was acknowledged by the Two Factor Model of Psychological Well-being (Lawton et al., 1991), was also supported by this study’s findings. The negative impact of caring was acknowledged by all fathers, and yet the majority also emphasised the many positive effects that caring had on themselves and their family. One father summarised these feelings by saying: ‘*Mark is Mark, and Mark has enriched our family in a way that would never have happened had he not been Mark’*. These perceived benefits included personal growth and awareness of the difficulties faced by people with disabilities, increased maturity and resilience of their children, and forming a close bond with their son/daughter with intellectual disabilities. Existing literature on parents’ experiences of raising a son/daughter with intellectual disabilities also acknowledges the many ways that caring can positively impact parents (Griffith & Hastings, 2014; Hastings & Taunt, 2002). It is important for practitioners to be aware that having a child with intellectual disabilities can result in both positive and negative outcomes. By also discussing positive aspects of caring, practitioners can reduce the focus on problems experienced by parents, which may be beneficial for father mental health.

The findings from the systematic review and qualitative study also provided some support for the application of the Double ABCX model (McCubbin & Patterson, 1983). Significant associations between father mental health and financial resources, marital relationship quality, and perceptions of their child were reported. The impact of pile-up stressors described in the Double ABCX Model is the only model of stress and coping which takes account of the long-term nature of caring described by fathers in the qualitative study, and how individual stressors build up with time. The long-term nature of caregiving is also addressed by the caregiving models discussed in Chapter Two. While these models were formulated from research on carers for people with dementia, some models include elements which were important to fathers in the qualitative study. In addition to acknowledging the long term nature of the caring role, these models also made reference to other important elements of caring which were discussed by fathers in the current study, such as the positive aspects of caring, the desire to increase the cared-for person’s independence, and anticipating the need to put future care plans in place for after they are no longer able to continue caring. Contrary to a number of the caregiving models reviewed in Chapter Two, fathers in the qualitative study did not identify reciprocal caring as an aspect of their current relationship with their son/daughter, although this may have been due to their relatively good health and adequate support systems. As the oldest father was 68 years old, it is possible that a sample of older fathers would have reported more mutual support between them and their offspring.

Despite the overlap between certain aspects of these caring models and the experiences recounted by fathers in the qualitative study, no one model fully captured the caring journey of fathers of a son/daughter with intellectual disabilities. A model of caring for fathers in this population would also need to take account of the fact that caring for their child begins at birth, and that while this is an expected aspect of parenting, the caring role continues into their child's adulthood. Fathers in the qualitative study all described the gradual realisation of the implications of having a child with intellectual disabilities, and what this would mean for them in the future. This was a difficult transition for fathers and one which is not captured in existing caring models critiqued in Chapter Two. Further qualitative work with fathers of a son/daughter with intellectual disabilities at different ages would be required to create a caring model which could adequately outline the caring journey for these types of fathers. Such a model could be helpful for policy makers and practitioners by providing an outline of the various stages of caregiving that these fathers pass through, and enabling them to target appropriate supports and services at different points in the caring journey.

9.3.4 Marital quality and support significantly impact father well-being and father-child closeness

The systematic review indicated that the amount of marital support or quality of the marital relationship was positively associated with father well-being. This finding is in keeping with research on factors associated with positive mental health in mothers of children with intellectual disabilities (Kersh et al, 2006). Findings from the quantitative study also highlighted the importance of marital support. Marital satisfaction was identified as one of the only significant factors in the final model of father-child closeness, with higher levels of marital satisfaction associated with greater father-child closeness. Given the importance that fathers in the qualitative study placed on having adequate support to assist them during their caring journey, it is perhaps unsurprising that marital satisfaction was an important aspect of building positive relationships with their child.

However, other findings from the qualitative study are contradictory. For example, only one father named his wife as an important source of support when asked about people or organisations that helped him in his caring role. Fathers in these interviews talked about their role being to support their wife, and not the other way around. This is interesting as, from their own descriptions, most of their wives completed the majority of caregiving tasks for their son/daughter. In this way wives were supporting their husbands' careers by providing day-to-day care for their child, and so allowing fathers to continue working outside the house. Yet fathers did not appear to associate these actions with providing support for them. This may be another example of traditional gender roles in action, with caregiving activities assumed to be the natural domain of the mother and therefore not considered to be providing extra support.

Alternatively, this may be because fathers appeared to view themselves and their wives as one unit in their efforts to care for their child. The language that fathers used during the interviews support this, as they very rarely used the pronoun 'I', but instead usually referred to 'us' or 'we'. Fathers talked about being part of a team with their wife and so may have answered the question on sources of support from the point of view of who/what supported them as a couple, rather than him personally.

The positive associations between marital quality, father mental health and father-child closeness supports Family Systems Theory (Minuchin, 2002). Previous research on the impact of family members on one another has also offered support for this theory. A recent review of the literature concluded it is not only children with intellectual disabilities who impact other family members, but that all members of the family unit impact one another (Hastings, 2016). This theory is supported by the results of the quantitative study as no difference was identified in the impact of marital satisfaction on father-child closeness between fathers with and without a child with intellectual disabilities. Therefore, high marital satisfaction appears to be an important aspect of forming positive father-child relationships, regardless of whether the child has intellectual disabilities or not. Fathers in the qualitative study also reported that having a child with intellectual disabilities impacted other members of the family unity. This provides further evidence of the importance of recognising the impact of each family member on one another, and policy makers should consider this when designing family services. Services must work with the whole family and focus on meeting their wider needs, rather than solely focussing on the difficulties of the individual with intellectual disabilities

The review by Hastings (2016) also called for further longitudinal work on the influences of members of the family unit upon one another, and of the positive impact of having a child with intellectual disabilities in the family. The current project has taken steps to address this by conducting longitudinal analysis on father-child closeness within families containing a child with intellectual disabilities, although more work is needed to gain a fuller understanding of this relationship over the whole caring journey.

9.3.5 Father-child closeness

Father-child closeness did not remain stable over time in the quantitative study, with a similar pattern expressed for both fathers of a child with and without intellectual disabilities. The decrease in closeness between the ages of 5 and 7 and increase in closeness between the ages of 7 and 11 years old was unexpected. Since this pattern was similar for both groups, it suggests that the decrease between the first two waves of data was not due to factors associated with intellectual disabilities. This may instead be related to the transition into formal schooling around this age. While it is important to note that this decrease in closeness was very slight, it may be beneficial for additional services to be provided for families around the time that their child is transitioning into formal schooling.

The quantitative analysis did reveal that fathers of a child with intellectual disabilities reported feeling less close to their child at all three time points. While no comparable studies were identified in the literature, it has been reported that mothers of children with intellectual disabilities view their relationship more negatively than mothers of children without intellectual disabilities (Totsika et al., 2014). This finding is concerning as father-child closeness has been associated with a number of positive outcomes for both father and child within the literature, as discussed in Chapter One and Chapter Eight. It is important to determine which factors are associated with closeness for this population in order to better support relationships within the family unit, particularly as fathers age.

A link between relationship quality and coping style has been identified in a longitudinal qualitative study conducted with Swedish parents of a child with intellectual disabilities between the diagnosis of their child's disability and a follow-up five years later (Bostrom & Broberg, 2014). Fathers initially adopted avoidant coping styles in response to their child's diagnosis but experienced a change in their perception of fatherhood and of their relationship with their child over time. Those who were able to make this transition reported an improvement in their mental health and their relationship with their child. A number of fathers in the qualitative study also made reference to avoidant coping techniques during the early years after their child's diagnosis. The findings from Bostrom and Broberg's (2014) study suggest that promoting non-avoidant coping styles may aid the development of stronger father-child relationships. Further research is required to determine if these results extend beyond the five-year follow-up point in their study. However, if avoidant coping strategies are also associated with poorer father-child relationships later in the caring journey, it may useful for practitioners to offer support which assists fathers to develop healthy coping styles which are associated with positive father-child relationships.

Father-child closeness has implications for later in life as such feelings are an important factor motivating adult children to provide care and support to their aging parents (Whitbeck et al, 1994). This is particularly important for fathers of a son/daughter with intellectual disabilities, as older fathers often report receiving some degree of support or care from their adult child in later life. While fathers in the current study did not describe receiving such support from their child with intellectual disabilities at this point in their lives, it is likely that they will receive some assistance from their child as they grow older and more dependent. Due to the current strain on the social care system, resulting from the UK government's current austerity policies (Krugman, 2013; Reed & Lawson, 2011), the reliance on family members to care for one another is essential. Therefore, supporting family members to do so will reduce their need for expensive crisis services.

9.4 Challenges, strengths, and limitations of the project

This PhD project presented a number of challenges for the researcher. Recruiting fathers for the qualitative study proved especially challenging. As discussed in Chapter Five, identifying fathers who were eligible to take part in the study was extremely difficult and so the final sample was made up of only seven fathers. This was a barrier to achieving the thematic saturation of categories advocated by Constructivist Thematic Analysis. However, given the time restraints associated with a PhD project, as well as the heterogeneity of the recruited fathers, it is unlikely that such thematic saturation could have been achieved with additional participants. While thematic saturation was not achieved, rich detailed accounts of fathers' experiences were obtained from the qualitative study which have added to the knowledge base on life for fathers with a son/daughter with intellectual disabilities.

Another difficulty with this study was the fact that individuals with intellectual disabilities form a fairly heterogeneous group, and so fathers' experiences of parenting such individuals vary widely. While all fathers had a son/daughter with cognitive deficits and limited adaptive capacity, the degree of intellectual disabilities varied from mild to profound. When fathers described their son/daughter with intellectual disabilities it was also apparent that they all had a range of different types of intellectual disabilities, as well as different additional physical and mental health conditions. Additionally, fathers who participated in the study also lived across a range of councils in Scotland and so had varying number and quality of support services available to them. As a result, fathers' experiences of their caring journey were all unique.

As was explained in Chapter Seven, due to issues obtaining access to the secondary data set originally intended for this project, an alternative data set was used. The Millennium Cohort Study contained data on fathers who were significantly younger than those in the qualitative sample. Fathers in the first few waves of the Millennium Cohort Study were just beginning their caring journey, when their child was aged 5 and 7 years old. At this age a diagnosis may only recently have been made. In contrast, the fathers in the qualitative study had a son/daughter with intellectual disabilities aged 28 to 37 years old and had been caring for a number of decades. Their experiences and perspective on caring were therefore likely to be very different. However, in keeping with the exploratory sequential design of the project, the focus selected for analysis of the Millennium Cohort Study was informed by analysis of the qualitative study. The age of fathers in the quantitative sample was also similar to those in studies included in the systematic review and meta-analysis, allowing the results of this first study to partially guide which factors were included in the growth model analysis in the final study. Given the changing gender norms documented in the literature, it was useful to examine the father-child relationship in this younger generation of fathers whose attitude to caring is likely very different to the older fathers included in the qualitative study.

Despite the age difference between participants in the qualitative and quantitative studies, one of the study's biggest strengths was the use of a longitudinal data set to examine father-child closeness over time. This nationally representative cohort provided the researcher with a large sample size of fathers of a son/daughter with intellectual disabilities, and numerous measures which were relevant to the area of study. A further strength of the study was the novelty of the topic under investigation. As previously discussed throughout this thesis, very little work has been done to examine the well-being and experiences of fathers of a son/daughter with intellectual disabilities. Including an in-depth qualitative study with older father carers, who are a growing cohort within the UK, provided new insights into their experiences and offers valuable information about the experiences of this population to policy makers and practitioners.

A number of limitations with the project require the findings to be interpreted with caution.

As the systematic review and meta-analysis focussed on the mental health and well-being of father carers, the search strategy did not result in the inclusion of papers which examined the potential benefits of their caring role. This is an important aspect of a father's experiences, as illustrated by the results of the qualitative study, and so the failure to include these studies does not give an accurate picture of the caring journey. However, as the positive impact of caring was discussed by all fathers in the qualitative study, this aspect of fathers' experiences was still represented in the current project. The rich volume of data collected through the qualitative approach also enabled a fuller examination of this aspect of fathers' lives than would have been possible through a systematic review of existing papers.

9.5 Further research

Prior to conducting the current study, no existing studies were identified within the literature which explored father carer well-being and experiences in such detail, particularly older fathers. This highlights the need for further longitudinal research to examine fathers' experiences into older age. The systematic review found support for the association between low socioeconomic status, low marital satisfaction, and challenging behaviour with poor father well-being. These factors and others should be investigated through a longitudinal study to explore which factors are important in supporting father mental health over time. This would be possible through the Millennium Cohort Study dataset and would provide useful information for service planners and policy makers.

Additional research could also conduct mediation analysis to examine the factors which mediate the relationship between father-child closeness and marital satisfaction. Given the positive outcomes associated with father-child closeness, and the importance of marital satisfaction identified in the current project, an understanding of the factors which mediate this relationship could inform how service provision could support relationships within the family unit. It would also be interesting to repeat the study with mothers of children with intellectual disabilities to determine if marital satisfaction is also the most important factor for their relationship.

The dearth of information made available to fathers on their child's condition or how to navigate the social care system suggests that more must be done in this area to support fathers. It would be helpful for future researchers to work with fathers in order to create a guide which could help new fathers to navigate with the system, and share their experiences. Such a project could also be empowering for the fathers involved in the creation of a guide. One of the fathers in the current study stated that he was glad that he had taken part in the interviews as it was a vehicle for him to share his knowledge with fathers who were 'coming up', and that it was gratifying to be able to pass on what he had learned over the years.

9.6 Concluding remarks

This PhD project aimed to increase understanding of the well-being and experiences of fathers of a son/daughter with intellectual disabilities. Including a qualitative component in this project ensured that fathers were given a voice to describe their caregiving journey and its impact on their well-being. This project has demonstrated that fathers experience both positive and negative effects of having a child with intellectual disabilities in the family unit. A review of the research identified mixed evidence for various factors associated with better father well-being and caring experiences. However, the importance of marital quality on father well-being and father-child closeness in families with a child with intellectual disabilities was corroborated by both the systematic review and the quantitative study.

The apparent continuation of traditional gender roles for older fathers of a son/daughter with intellectual disabilities emphasises the need to provide further support to older mothers, and not to assume that caregiving is being equally distributed between two people in these households. It is also vital that social workers and other practitioners recognise that a lack of information and support has a detrimental effect on the mental health and well-being of fathers. By providing fathers with accurate and up-to-date information about available services, fathers can make better decisions about their child’s current and future care. Such transparency will also protect against poor mental health outcomes for both fathers and their son/daughter with intellectual disabilities.

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Appendices

Appendix A: Carer Policy Documents

Recent UK legislation relevant to carers and fathers are listed below:

- The Carers (Recognition and Services) Act 1995
- The Employment Rights Act 1996
- The Employment Relations Act 1999
- The Carers and Disabled Children Act 2000
- The Community Care and Health (Scotland) Act 2002
- The Carers (Equal Opportunities) Act 2004
- The Work and Families Act 2006
- The Equality Act (2010)
- The Care Act 2014
- Shared Parental Leave 2014
- The Social Services and Well-being (Wales) Act 2014
- The Regulation and Inspection of Social Care (Wales) Act 2016
- The Carers (Scotland) Act 2016

Appendix B: Systematic review search strategy

The following Ovid MEDLINE search strategy was used and was adapted as appropriate for other databases:

1 (mental or learning) adj3 (handicap* or disability* or difficult* or impair* or deficien* or incapacit* or delay* or problem* or sub-average) .tw.

2 (disorder or condition or disabilit*) adj3 (intellectual or learning or development* or neuro-development*).tw.

3 "down syndrome".tw.
4 Learning Disorders/
5 or/1-4

6 depression.tw
7 mental disorders/ or anxiety disorders/ or “bipolar and related disorders”/ or behaviour disorder/ or delirium/ or dissociative disorder/ or emotional disorder/ or mental instability/ or mood disorder/ or neurosis/ or personality disorder/ or psychosis/ or psychosomatic disorder/

8 "mental health".tw.
9 (mental adj2 (disorder* or problem* or condition*)).tw.

10 (well-being or wellbeing).tw.
11 or/6-10
12 fathers/ or single parent/ or single-parent family/
13 father*.tw.
14 paternal.tw.
15 single parent.tw.
16 Caregivers/
17 carer*.tw.
18 dad*.tw.
19 parent*.tw.
20 or/12-19

21 5 and 11 and 20

22 limit 21 to (English language and humans)

23 limit 22 to yr= 2000-current

Appendix C: CASP scores for each paper included in the systematic review

Study	**CASP Item**	**Level of Risk**	**Details**
Azar (2010) **Score= B3**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from special education centres for children with ID.
	Was the exposure accurately measured to minimise bias?	Unclear	Means of measuring ID was not reported.
	Was the outcome accurately measured to minimise bias?	Low	The Parenting Stress Index was used, which is a commonly used measure.
	Have the authors identified all important confounding factors?	Low	Confounding factors are discussed.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A

	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Unclear	Results are unexpected as stress levels were similar, yet mothers take on most caregiving tasks in Lebanese society.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Foster et al (2010) **Score= C1, 2**	Was the cohort recruited in an acceptable way?	Low	Recruited through parent and researcher Smith-Magenis syndrome list serve.
	Was the exposure accurately measured to minimise bias?	Unclear	ID measure was not reported.

	Was the outcome accurately measured to minimise bias?	Low	The center for epidemiologic studies depression scale, Becks Anxiety Inventory and Caregiver well-being scale were used, which are commonly used self-report measures.
	Have the authors identified all important confounding factors?	High	Level of child's ID was not reported, which could be a confounding factor. The sample size of fathers was also very small.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.

	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Gerstein (2009) **Score= B2**	Was the cohort recruited in an acceptable way?	Low	The families were from a longitudinal study. The sample was recruited from community agencies serving families with children with ID, so it may not represent families not accessing these services but the risk is small.
	Was the exposure accurately measured to minimise bias?	Low	Children in the study were assessed for ID through their Mental Development Index score and BSID-II measure. Both are commonly used to measure mental development in children. These were administered at home.
	Was the outcome accurately measured to minimise bias?	Low	Daily Parenting Hassle measure was used to measure stress, which is commonly used self-report measure.
	Have the authors identified all important	Unclear	Parental age and level of child's ID were not reported, which could be confounding factors.

	confounding factors?		
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.

Giallo (2015) **Score= B3**	Was the cohort recruited in an acceptable way?	Unclear	The sample was recruited from families involved in a previous study of children in a challenging behaviour programme. These families were identified through schools and advertisement in newsletters of organisations specializing in support for families with children with ID. Sample contained some children who had both ID and ASD.
	Was the exposure accurately measured to minimise bias?	Low	The measure of ID was not reported in this study although all children had been assessed as having ID.
	Was the outcome accurately measured to minimise bias?	Low	The Depression Anxiety and Stress Scale was used, which is a well-known measure. Based on mental health in the past week.
	Have the authors identified all important confounding factors?	Unclear	Children all had challenging behaviour, so results may be different for children without challenging behaviour. Also demonstrates that families have sought help. These were identified by the authors.
	Have the authors taken account of the confounding factors in the design?	Unclear	Acknowledged but design not altered to account for this.
	Was the follow up of subjects complete enough?	Low	N/A

	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Low	Confidence intervals are not wide.
	Do you believe the results?	Low	Results are supported by previous studies.
	Can the results be applied to the local population?	Low	The results can be applied to other families whose child has ID and challenging behaviour.
	Do the results of this study fit with other available evidence?	Low	Results are supported by previous studies.
	What are the implications of this study for practice?	Low	Implications for practice and future research are considered.
Griffith (2011) **Score= B3**	Was the cohort recruited in an acceptable way?	Low	The families were recruited from a pre-existing database held by the research team and through national parent syndrome support groups.
	Was the exposure accurately measured to minimise bias?	Low	Parents reported that their child had been diagnosed with ID.

	Was the outcome accurately measured to minimise bias?	Low	Questionnaire on Resources and Stress short form, Hospital Anxiety and Depression Scales, and Genetic Syndrome Stressors Scale, which are commonly used self-report measures.
	Have the authors identified all important confounding factors?	Unclear	Level of child's ID were not reported, which could be a confounding factor.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified. Small sample sizes for each of the syndromes, although this is partly because the syndromes are rare and so difficult to recruit these parents.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.

	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Unclear	Due to the small number in the sample it is difficult to say if the sample is sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Gupta (2010) **Score= B3**	Was the cohort recruited in an acceptable way?	Low	Recruited from schools for children with ID.
	Was the exposure accurately measured to minimise bias?	Low	ID measure not reported.
	Was the outcome accurately measured to minimise bias?	Low	Quick Stress Assessment Test was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Unclear	Level of child's ID & number of children with ID in sample were not reported, which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Low	Confounding factors not discussed.

	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Unclear	Due to the small number in the sample it is difficult to say if the sample is sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Hedov (2000) **Score= B1**	Was the cohort recruited in an acceptable way?	Low	Randomly recruited through child's paediatrician.

	Was the exposure accurately measured to minimise bias?	Low	Parents reported that their child had been diagnosed with Down Syndrome.
	Was the outcome accurately measured to minimise bias?	Low	Swedish version of the SF36, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID were not reported, which could be a confounding factor.
	Have the authors taken account of the confounding factors in the design?	Low	No.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.

	Can the results be applied to the local population?	Low	There is no reason to believe the sample is sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Islam (2013) **Score= B5**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from ID schools and organisations.
	Was the exposure accurately measured to minimise bias?	Unclear	ID measure not reported.
	Was the outcome accurately measured to minimise bias?	Low	The Quick Stress Assessment Test was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Unclear	Level of child's ID, age of fathers and children was not reported which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Unclear	Confounding factors not discussed.
	Was the follow up of subjects complete enough?	Low	N/A

	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Unclear	Implications for practice are not considered by the authors.
MacDonald (2010) **Score= B1**	Was the cohort recruited in an acceptable way?	Low	Randomly recruited through ID services.
	Was the exposure accurately measured to minimise bias?	Low	Receipt of service provision from recruitment organisations was conditional on having an ID.

	Was the outcome accurately measured to minimise bias?	Low	Questionnaire on resources and stress, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID and parent age were not reported, which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Low	No
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	There is no reason to believe the sample is sufficiently different from the population to cause concern.

	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Marchal et al (2017) **Score= C2,2**	Was the cohort recruited in an acceptable way?	Low	Recruited from participation in a medication trial for people with DS.
	Was the exposure accurately measured to minimise bias?	Unclear	ID measure was not reported.
	Was the outcome accurately measured to minimise bias?	Low	The Distress Thermometer for Parents was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	High	Level of child's ID was not reported and only parents of ‘healthy’ children were included, which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Low	No
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A

	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	High	Parents of children with an Apgar score below normal were excluded and so this is a 'healthy' subgroup of parents of children with DS.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
McCarthy (2010) **Score= B2**	Was the cohort recruited in an acceptable way?	Low	Randomly recruited through Fragile X society.
	Was the exposure accurately measured to minimise bias?	Unclear	Fragile X was reported by parents.
	Was the outcome accurately measured to minimise bias?	Low	The Brief Symptom Inventory was used, which is a commonly used self-report measure.
	Have the authors identified all important	Low	Level of child's ID was not reported and parents were asked to report on their child with the

	confounding factors?		highest support needs, which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Low	Confounding factors are considered.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	There is no reason to believe the sample is sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.

Norlin (2013) **Scrore= B2**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited by staff at service centres for children with disabilities, so it may not represent families not accessing these services but the risk is small.
	Was the exposure accurately measured to minimise bias?	Unclear	Did not report how ID was measured.
	Was the outcome accurately measured to minimise bias?	Low	BDI-2r (a modified version of Beck's Depression Inventory) and Family Impact Questionnaire were used to measure mental health, which are commonly used self-report measures.
	Have the authors identified all important confounding factors?	Low	Yes.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.

	What are the results of the study?	Low	Results are adequately reported
	How precise are the results?	Unclear	Confidence intervals not given
	Do you believe the results?	Low	Results are supported by prior studies
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors
Olsson (2002) **Score= B2**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from community based programmes providing services to families of disabled children.
	Was the exposure accurately measured to minimise bias?	Unclear	Children in the study were assessed for ID through parent reports.
	Was the outcome accurately measured to minimise bias?	Low	Beck's Depression Inventory was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID was not reported, which could be a confounding factor. Takes other factors into account.

	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.

Olsson (2006) **Score= B2**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from community-based programmes providing services to families of disabled children.
	Was the exposure accurately measured to minimise bias?	Unclear	Children in the study were assessed for ID through parent reports.
	Was the outcome accurately measured to minimise bias?	Low	Beck's depression inventory was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID was not reported, which could be a confounding factor. Takes other factors into account.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.

	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Olsson (2008) **Score= B1**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from community based programmes providing services to families of disabled children.
	Was the exposure accurately measured to minimise bias?	Low	Parents reported that their child had been diagnosed with intellectual disabilities.
	Was the outcome accurately measured to minimise bias?	Low	Version of the Beck's Depression Inventory (BDI-2r) used to measure mental health, which is commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID were not reported, which could be a confounding factor.
	Have the authors taken account of the	Low	Recruitment method may have resulted in only families who seek help being identified.

	confounding factors in the design?		
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	There is no evidence that the sample is sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Rowbotham (2011) **Score= C1,3**	Was the cohort recruited in an acceptable way?	Low	The sample was recruited from public and private-sector groups providing services to carers of adults with ID.
	Was the exposure accurately measured to minimise bias?	Unclear	Children in the study were assessed for ID through the

			Adaptive Behavioural Scale which was carried out by parents.
	Was the outcome accurately measured to minimise bias?	Low	The General Health Questionnaire-28, which is commonly used self-report measure.
	Have the authors identified all important confounding factors?	High	Very small sample size.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.
	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.

	Can the results be applied to the local population?	Unclear	No evidence to suggest that the participants were sufficiently different from the population to cause concern, but the sample size was very small.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.
Stoneman (2007) **Score= B3**	Was the cohort recruited in an acceptable way?	Unclear	The sample was recruited from early intervention programmes, pre-schools, parent groups and referrals from community members. Comparison group contains some children with autism- number not known.
	Was the exposure accurately measured to minimise bias?	Unclear	Did not report how ID was measured.
	Was the outcome accurately measured to minimise bias?	Low	Centre for epidemiologic studies depression scale & Questionnaire on resources and stress were used, which are commonly used self-report measure.
	Have the authors identified all important confounding factors?	Low	Level of child's ID was not reported, which could be a confounding factor.

	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported
	How precise are the results?	Unclear	Confidence intervals not given
	Do you believe the results?	Low	Results are supported by prior studies
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern
	Can the results be applied to the local population?	Low	The results are supported by prior studies
	Do the results of this study fit with other available evidence?	Low	Implications for practice are considered by the authors
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors

Upadhyaya (2008) **Score= B2**	What are the implications of this study for practice?	Low	Recruited from those who attended the Karnataka Institute of Mental Health, Dharwad.
	Was the exposure accurately measured to minimise bias?	Low	ID measured using the Binet-Kamath test of intelligence.
	Was the outcome accurately measured to minimise bias?	Low	Centre for epidemiologic studies depression scale was used, which is a commonly used self-report measure.
	Have the authors identified all important confounding factors?	Unclear	Level of child's ID and parental age were not reported, which could be confounding factors.
	Have the authors taken account of the confounding factors in the design?	Low	Recruitment method may have resulted in only families who seek help being identified.
	Was the follow up of subjects complete enough?	Low	N/A
	Was the follow up of subjects long enough?	Low	N/A
	Did the study address a clearly focused issue?	Low	The study question was focussed. It was clear which population was studied and which outcome measures were selected.
	What are the results of the study?	Low	Results are adequately reported.

	How precise are the results?	Unclear	Confidence intervals not given.
	Do you believe the results?	Low	Results are supported by prior studies.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Can the results be applied to the local population?	Low	No evidence to suggest that the participants were sufficiently different from the population to cause concern.
	Do the results of this study fit with other available evidence?	Low	The results are supported by prior studies.
	What are the implications of this study for practice?	Low	Implications for practice are considered by the authors.

Appendix D: Participant information sheet for qualitative study

University of Glasgow | College of Medical, Veterinary & Life Sciences

PARTICIPANT INFORMATION SHEET

The experience of caring for a son/daughter with intellectual disabilities: older father carers' perspectives.

We would like to invite you to take part in a research study. Before you decide if you would like to take part, it is important that you understand the nature of the study and what taking part would involve for you. Please read the following information carefully and discuss with others if you wish. Feel free to contact us if there is anything that you would like to ask after you have read this information sheet.

Who is conducting the research?

The research is being carried out by Kirsty Dunn who is completing a Doctorate in Psychological Medicine at the University of Glasgow. The research is being supervised by Dr. Deborah Kinnear, Professor Andrew Jahoda, and Dr. Alex McConnachie from the University of Glasgow.

What is the purpose of the study?

We want to better understand the experiences of fathers who care for their son/daughter with learning disabilities over time. The study will involve talking to older fathers who care for their son/daughter with learning disabilities, like yourself, to find out more about experiences at different times throughout your time as a caregiver. You will be asked about your experience of caring during your child's early years, as they grew up, and more recently. You will be asked about how your relationship with your child and your caregiving role has changed over time. You will also be asked about if/how caring has affected your well-being. It is hoped that the interviews will provide us with a better understanding of fathers' experiences of caring for their son/daughter with learning disabilities and how we can provide better supports and services for them in the future.

Why have I been invited?

We are inviting fathers who are involved in the care of their son/daughter with learning disabilities, and who are aged 60 years of age or older to take part in the study. We believe that you may be eligible to take part.

What does participation involve?

If you decide to take part in the study, participation will be as follows:

1. You should sign and return the consent form in the included stamped envelope.
2. Kirsty will contact you by phone and answer any questions you may have. Kirsty will arrange an appointment at a time and place that suits you, if you would like to take part. (She will be happy to visit you at your home). Interviews will be carried out in private, with only the interviewee and Kirsty present.
3. Before you begin the interview, you will have the opportunity to ask any further questions that you may have.
4. Kirsty will ask you some questions about your experiences as a father.

How long will the interview last?

The interview should take no longer than one hour to complete and will be recorded with your permission in order for me to listen to it and take notes.

Do I have to take part?

No. Participation is entirely up to you. If you agree to take part, you should sign and return the consent form. We will then contact you to arrange an interview. You may decide to withdraw from the study at any time.

Is the information confidential?

Yes. All of your information will be treated as strictly confidential and stored anonymously. Your name or any other names given in the interview will be changed so that the details from the interview cannot be traced back to you. Only members of the research team will be able to access this information. Individuals will not be identified by any of the findings and your details will not be given to any other organisations or businesses.

Who has reviewed the study?

The study has been reviewed and approved by the University of Glasgow's College of Medical, Veterinary and Life Sciences Ethics Committee.

What if you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance or any of the contact persons indicated below. If would like to speak to someone who is not closely involved in the study, then you can contact Dr Deborah Kinnear. She may be contacted at either Deborah.kinnear@gla.ac.uk or by telephone: 0141 211 0688.

If you have any further questions?

We will give you a copy of your signed Informed Consent Form to keep. If you would like more information, the researcher contact details are below:

Researcher(s) Contact Details:

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Appendix E: Consent form for qualitative study

University of Glasgow | College of Medical, Veterinary & Life Sciences

Centre Number:
Project Number:
Subject Identification Number:

CONSENT FORM

Title of Project: The experience of caring for a son/daughter with intellectual disabilities: older father carers perspectives.

Name of Researcher(s):

Mrs Kirsty Dunn, Dr. Deborah Kinnear, Prof. Andrew Jahoda, Dr. Alex McConnachie

Please initial each box

I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I understand that my data will be stored for up to 10 years. ☐

I am aware and agree for the interview to be recorded with a digital voice recorder. ☐

I agree to take part in the above study. ☐

Name of subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Appendix F: Qualitative interview schedule

Preamble: Thank you for agreeing to participate in this study. Remember that how much you say is entirely up to you. Please feel free to stop me at any time if you're feeling uncomfortable about anything. Are you happy to continue?

1. Tell me about caring for your son/daughter.
2. What does caring for your son/daughter mean to you?
3. What were the early years like caring for your son/daughter?
   (Prompts: What was it like before school, starting school?)
4. What was it like after they left school?
5. What is it like caring for your son/daughter now?
6. Has your relationship with your son/daughter changed over time? Can you tell me more about that?
7. Does your caregiving role affect your life now differently than it did in the past?
   Can you tell me more about that?
8. How has being a carer affected you/your well-being?
   (Prompts: Is it easier/more difficult now?)
9. What things have helped you in your caring role?
   (Prompts: Are there any people/services who have helped?)
10. What things have made being a carer more difficult?
    (Prompts: What things have been difficult about caring?
    Any people/services/situations?)
11. Is there something else you'd like to talk about that we haven't discussed so far?

Thank you for your participation.

Appendix G: Profiles of interviewed fathers

Seven fathers participated in the qualitative study. Below are brief profiles of these fathers, using pseudonyms to protect their identity:

Interview 1- Mr Walker

Mr Walker is aged 64 and has been retired for a few years. He lives with his wife and daughter who is 28 years old and has intellectual disabilities. Mr Walker previously worked full-time while his wife stayed home to care for their daughter. Now that he's retired he's more available, although he still describes his wife as the main caregiver for his daughter.

Mr Walker has a particularly close bond with his daughter and frequently attends concerts, football matches, and pub nights with her. He remarks on how similar they are in temperament and how he can see himself in her, from her sense of humour to her desire to be in the spotlight and in the centre of things. This father received support mostly from friends and family over the years. His daughter has also been involved in a local training organisation which has been a great source of support and enjoyment, both for herself and for the whole family. He is now heavily involved with this organisation and sits on the board. Mr Walker is starting to make plans for his daughter's future by putting different things in place but accepts that you can only do your best and focus on taking things one step at a time.

Interview 2- Mr McKay

Mr McKay is 68 years old and is retired. He lives with his wife and 37-year-old daughter with intellectual disabilities, and also has another daughter who is his eldest. He was told early on that his daughter would be disabled but didn't know in what way or to what extent. Doctors originally predicted that his daughter was unlikely to live past 20 years of age, so he and his wife were determined to give her the best possible life while she was with them. His wife has been his daughter's main caregiver as he worked full-time. This arrangement has not much altered since his retirement. The family experienced difficulties finding a school that would cater for the fact that their daughter had physical and learning disabilities. Once they were able to get their daughter into a suitable school, the school was very helpful. The family have spent the last few years looking for a house for their daughter that she could share with a few other people with similar support needs. This has been going on for nearly 12 years and has hit a number of road blocks. He wants to make sure that something is put in place and that his eldest doesn't feel that it is her responsibility to care for her sister.

Interview 3- Mr Thomson

This father is 64 years old and lives with his 28-year-old daughter and his wife. He also has an elder daughter and a younger son. His daughter with intellectual disabilities was originally labelled with 'slow progress' and didn't get an official diagnosis until she was two years old. The family were given worst case scenarios following the diagnosis and their daughter wasn't expected to live past her teens. However, she doesn't have many of the physical conditions often associated with her particular type of intellectual disabilities. Mr Thomson has a good relationship with his daughter and admits that he still treats her as his 'wee girl', which he doesn't do with his other grown children. He speaks of his daughter with great affection and describes her as a very sociable and caring person. He talked about the impact that caring has had on his other children and feels that they might have been missing out on some things when the family was younger. However, he feels that they have greatly benefited from having their sister in the family. As he works long hours his wife is the main carer for their daughter, and Mr Thomson feels that his wife has been the one most affected by stress. When speaking about the future, he talked about the importance of giving his daughter the opportunity to increase her independence and to get a place set up for her to live away from home.

Interview 4- Mr Hughes

Mr Hughes is 64 years old and lives with his wife. His 29-year-old son with severe intellectual disabilities and autism lives in a specialist facility in England, and he also has two older daughters who live away from home. He had to give up his work to care for his son full-time alongside his wife, but he describes it as being less of a choice and more of a necessity. Mr Hughes feels that caring has restricted their social circle as without appropriate respite they can't go out to socialise. The father has received support over the years from a number of charities and from their consultant psychiatrist. They have had limited assistance from family and have relied on more formal supports and services. His son has displayed challenging behaviour since he was around four years old and managing this has become more challenging as his son has become bigger and stronger. Due to issues finding an appropriate placement in Scotland, their son has been relocated to England. The family were initially resistant to having him moved out of the country but feel much happier about the hospital where he is now. The father is starting to think about the future for his son and wishes him to be closer to home.

Interview 5- Mr Murphy

Mr Murphy is 60 years of age and continues to work full-time while his wife cares for his son. He lives with his wife and his 34-year-old son with Down Syndrome who is profoundly deaf in one ear. He also has two younger daughters who do not live at home. There are times where Mr Murphy feels disappointment and wishes things would be different but at the same time feels that his son has enriched the family's lives. The father is very proud of his son and talked about his achievements throughout his life, such as the medals he won in the special Olympics. The family haven't relied on charities or organisations for support as they are regular church goers and have received their support from this community. Mr Murphy's son has an excellent relationship with his sisters and goes running with them. The father is very proud of how his daughters have always made space for their brother in their lives and included him. The father talked about the desire to give his son more independence but has concern over the quality of care he would receive in supported accommodation. As he's about to retire Mr Murphy is becoming more aware of how his retirement will be different from others, in that they won't have the same freedoms to do things by themselves.

Interview 6- Mr Kendall

Mr Kendall is aged 61 years old and lives with his wife and 28-year-old son with cerebral palsy and intellectual disabilities. He also has two older daughters who do not live at home.

Mr Kendall talked about how he knew that something was wrong relatively early on but didn’t get a diagnosis until his son was 9 months old. Due to his wife’s health, Mr Kendall performs all the physical caregiving tasks for his son while she focusses more on his mental health. His son was later also diagnosed with mental health problems and learning disabilities, and his parents are currently pushing for a formal diagnosis of autism. Mr Kendall’s son is a very social individual and needs to have a full and busy life to keep him happy and content. This father previously had a high-ranking position but gave up his work to care for his son full-time when his son required more support than his wife could give on her own. He describes this decision as less of a choice and more of a foregone conclusion. He sometimes feels guilty that he can’t provide the same lifestyle for his family as he used to, and that he is living off his son’s benefits. Mr Kendall also worries that his daughters missed out on things growing up. He is starting to notice the impact of his own ageing on his ability to care. However, he doesn’t trust that social work will be able to care for his son as well as he and his wife do, so he is reluctant to give them more control.

Interview 7- Mr Lampton

Mr Lampton is aged 67. He is retired and lives with his wife and his 33-year-old daughter with intellectual disabilities. He also has two older daughters who do not live at home. Mr Lampton’s daughter doesn’t communicate verbally and has some restrictions in her mobility. However, he was initially told that she would be unable to even sit up, so she has exceeded the expectations of medical professionals in a number of ways. The father also describes her as having a happy and easy-going nature. As his wife is a nurse she is able to spot symptoms early on and often cares for his daughter when she is in hospital. She performs most of the care and all of the personal care for his daughter. The family received a great deal of help from family and friends, particularly his wife’s family. Mr Lampton worries that his other daughters missed out on certain aspects of family life. One daughter was particularly affected and struggled with an eating disorder during her teens, which the father partly attributes to the impact of their home life. He noted certain ways that caring for his daughter has affected him over the years, particularly the amount of planning which goes into doing things for his daughter and how that has changed him. The relationship that the father has with his daughter was described as strong and protective. Both parents feel a need to get their daughter settled in her own accommodation while they are still able to organise this. The father feels that now is the right time for his daughter to move to this facility, but this has taken some time to come to terms with.