

# **Fathers' Experiences of Parenting a Young Adult with Down's Syndrome**

Rebecca Mary Piclet

Submitted in accordance with the requirements for the degree of  
Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

School of Medicine

Division of Psychological and Social Medicine

July 2021

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

The right of Rebecca Mary Piclet to be identified as Author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988.

© 2021 The University of Leeds and Rebecca Mary Piclet

## ACKNOWLEDGMENTS

Firstly, I would like to thank my participants - your time and honesty was greatly appreciated, and it was a real privilege to hear about your experiences. In addition, another big thank you to my two parent consultants for your contributions to shaping up this research.

I would also like to thank my research supervisors, Dr Tracey Smith and Dr Tom Cliffe for all your support, guidance, time, and expertise throughout this process. I feel so lucky to be part of the 'T 'n T' team!

To Lucy Kerrigan (another key member of the 'T 'n T' team!) – I am so grateful we have been able to share so much of this process through choosing similar projects and supervisors – your support, laughter, friendship, and positivity has really kept me going, particularly at those times we have felt this was not achievable!

Thank you to everyone who helped with recruitment – I have not named you for confidentiality reasons, but you know who you are, and your support was invaluable!

Finally, a big thank you to my dad for his support over the past three years in completing this thesis, as well as my friends, both on and off the course – I am not sure I could have done this without all your encouragement, wise words, and much-needed distraction. Thank you!

## ABSTRACT

**Introduction:** Parenting research still focuses predominantly on mothers' experiences. In a systematic review of fathers' perceptions of parenting a child with a developmental disability, Boyd et al. (2019) highlighted that there is still a gap in understanding fathers' experiences of parenting this population and recommended that future researchers use qualitative methodologies to gain a richer understanding of fathers' experiences. Less research appears to have explored the experiences of parents of children with Down's syndrome (DS), and specifically, experiences of parents of older children. This is an identified need, given that the transition to adulthood has been identified to be one of the most difficult times within the life cycle for these parents (Goff et al., 2016). Whilst mothers' experiences of parenting a young adult (YA) with DS have been explored (e.g., Docherty & Reid, 2009), this study aimed to address the gap in exploring fathers' experiences of parenting this population.

**Method:** A qualitative methodology was used to explore fathers' experiences. Participants were nine fathers who were parent to a YA with DS (aged between 18 – 25). Fathers agreed to take part in a semi-structured interview to talk about their experiences. The interview data was subsequently analysed using Interpretative Phenomenological Analysis (Smith et al., 2009). Individual analysis was initially conducted for each participant, before developing a group analysis to capture the shared experiences amongst fathers, as well as their differences.

**Results:** The group analysis resulted in three superordinate themes, and ten associated subordinate themes. The superordinate themes were: *'Internal conflict: negotiating current developmental stage'*, *'Internal conflict: navigating the next steps'* and *'Challenges of the system'*.

**Discussion:** The key findings are discussed in relation to wider relevant literature and psychological theory. A critical evaluation of the study is then presented, before discussing potential clinical implications and suggesting avenues for future research.

## TABLE OF CONTENTS

<b>ACKNOWLEDGMENTS .....</b>	<b>3</b>
<b>ABSTRACT .....</b>	<b>4</b>
<b>LIST OF TABLES .....</b>	<b>8</b>
<b>LIST OF FIGURES .....</b>	<b>9</b>
<b>CHAPTER 1: INTRODUCTION.....</b>	<b>10</b>
Definitions of Key Terms.....	10
Parenting .....	10
Father.....	10
Breadwinner Father .....	10
Father Involvement .....	10
Young Adult (YA) .....	11
Typically Developing (TD).....	11
Disability .....	11
Developmental Disability (DD) .....	11
Down’s syndrome (DS) .....	11
Down’s Syndrome (DS).....	12
Types of DS .....	12
Prenatal and Postnatal Testing .....	12
Associated Comorbidities .....	13
Social, Behavioural and Psychological Functioning.....	13
Looking to The Future .....	15
Review of the Literature.....	16
Parental Roles and Father Involvement .....	16
Parenting a Child that is TD.....	21
Parenting a Child with a Disability .....	24
The Current Study .....	41
Rationale for Study .....	41
Aim .....	42
Research Question.....	42
<b>CHAPTER 2: METHOD.....</b>	<b>43</b>
Methodology .....	43
Ontological and Epistemological Position .....	44
Interpretative Phenomenological Analysis .....	44

Alternative Methodologies Considered .....	45
Semi-structured Interviews .....	46
Method .....	47
Design .....	47
Sampling .....	47
Participants .....	48
Parent Consultants.....	50
Interview Schedule.....	50
Pilot Interviews .....	51
Ethical Issues.....	51
Procedure.....	53
Data Analysis .....	56
Quality Checks .....	59
Reflexivity.....	62
<b>CHAPTER 3: RESULTS.....</b>	<b>64</b>
Overview of Sample.....	64
Pen Portraits .....	67
Participant 1: Jimmy (Son: Richard).....	67
Participant 2: Brook (Daughter: Elizabeth).....	68
Participant 3: Robert (Son: Michael) .....	69
Participant 4: Benny (son: Frankie) .....	70
Participant 5: Harvey (Son: Herbert) .....	71
Participant 6: John (Son: Frank) .....	72
Participant 7: Peter (Daughter: Tamara) .....	73
Participant 8: William (Son: Gabriel) .....	74
Participant 9: Jon (Son: Thomas).....	75
Group Analysis .....	77
Internal conflict: Negotiating Current Developmental Stage.....	83
Internal Conflict: Navigating the Next Steps .....	91
The Experience of Being Caught Between the Areas of Internal Conflict.....	101
Challenges of the System .....	102
<b>CHAPTER 4: DISCUSSION .....</b>	<b>111</b>
Summary of Findings .....	111

Internal Conflict: Negotiating Current Developmental Stage.....	112
Internal Conflict: Navigating the Next Steps .....	112
Challenges of the System .....	114
Findings in Relation to Wider Literature .....	114
Expectations Versus Reality .....	115
Struggles with Acceptance/Denial .....	117
Protector Versus Facilitator.....	118
Responsibility Versus Avoidance .....	120
Guilt .....	122
Hope Versus Uncertainty and Worry .....	126
The System Limiting Future Hopes and Prospects .....	128
Needing to Fight the System to Get Needs Met.....	130
Lack of Trust in the System .....	131
Findings that are Particular to Fathers .....	132
Findings that are Particular to DS .....	133
Strengths and Limitations .....	134
Strengths.....	134
Limitations .....	135
Clinical Implications .....	137
Future Research.....	139
Conclusion .....	141
Final Reflections .....	142
<b>REFERENCES.....</b>	<b>143</b>
<b>APPENDIX .....</b>	<b>166</b>

**LIST OF TABLES**

<b>Table 1: Inclusion and Exclusion criteria .....</b>	<b>48</b>
<b>Table 2: Quality checks implemented to meet the guidelines offered by Yardley (2000) and Elliot, Fischer and Rennie (1999).....</b>	<b>59</b>
<b>Table 3: Demographic information of fathers.....</b>	<b>65</b>
<b>Table 4: Demographic information of young adults.....</b>	<b>66</b>
<b>Table 5: Overview of the superordinate and subordinate themes for each participant .....</b>	<b>81</b>



**LIST OF FIGURES**

<b>Figure 1: Conceptual map of fathers' experiences .....</b>	<b>78</b>
---	-----------

## CHAPTER 1: INTRODUCTION

The current study explores fathers' experiences in parenting a young adult (YA), aged 18 - 25, with Down's syndrome (DS). The chapter will firstly offer definitions of key terms, before setting the context regarding DS. A review of the relevant literature will then be provided, including an overview of the history of parental roles and father involvement, before considering the experiences of parenting a child that is typically developing (TD). This will be followed by experiences of parenting a child with any disability, before narrowing down to consider experiences of parenting a child with a developmental disability (DD), and experiences of parenting a child with DS. Finally, fathers' experiences of parenting a child with DS will be outlined. The rationale for the current study, aim and research question will then be presented.

### Definitions of Key Terms

The following terms have been defined as follows:

#### **Parenting**

The process in which a parent raises their child and supports them to develop and meet numerous physical, emotional, intellectual, and social milestones.

#### **Father**

The male figure within a family who takes on parental responsibility for looking after the child (inclusive of father figures as well as biological fathers).

#### **Breadwinner Father**

A social construct of father identity which portrays a 'good father' as one who earns the income for the family to provide for the families' material needs.

#### **Father Involvement**

Used to describe a wide range of activities that a father may participate in, in relation to their child. This may involve direct one-on-one interaction, such as: play; or supporting in care/education activities. Alternatively, it may relate to indirect involvement, such as: taking on responsibility, attending meetings regarding the family or child's needs.

**Young Adult (YA)**

In relation to the proposed research, this term is used to describe young people aged between 18 and 25. The decision to define young people within this age bracket is based on Arnett's (2000) theory of 'Emerging Adulthood' which is described in more detail later. It is acknowledged that Arnett describes this period as distinct from 'young adulthood'; however, the term 'young adult' seemed most appropriate to describe the young people referred to in this study as this phrase is more commonly used to describe individuals in this developmental stage.

**Typically Developing (TD)**

Whilst all children vary in their speed of development, a child that is 'typically developing' will usually meet certain developmental milestones (such as: crawling and walking) by a certain age (Centers for Disease Control & Prevention; CDC, 2020). In contrast, a child with a disability may not meet some of the milestones, either at the same pace, or sometimes at all.

**Disability**

Any condition that affects an individual's ability to carry out certain tasks or engage with the world around them. Impairments might include: hearing; vision; sensory; cognitive; physical; or a combination of difficulties.

**Developmental Disability (DD)**

The term 'developmental disability' refers to a group of conditions due to an impairment in physical, learning, language, or behaviour areas (CDC, 2020). These conditions begin during the developmental period, often during pregnancy, although some can begin after birth, for example due to injury or infection. Examples of DDs include: Autism Spectrum Disorder (ASD); Cerebral Palsy (CP); Intellectual Disability (ID); and Down's Syndrome (DS).

**Down's syndrome (DS)**

A genetic condition that occurs due to an extra partial or whole copy of chromosome 21 being present in the baby's cells (Down's Syndrome Association; DSA, 2016). On average, one in every 1000 babies in the UK will be born with this condition, and there are around 40, 000 people in the UK who have DS.

## **Down's Syndrome (DS)**

### **Types of DS**

DS was discovered in 1866 by John Langdon Down, an English physician, and is one of the most common genetic causes that impacts foetal development. There are three different types of DS (National Down Syndrome Society; NDSS, n.d.). Trisomy 21 is the most common type, and accounts for about 95% of individuals who have DS. Individuals with Trisomy 21 have three copies of chromosome 21, instead of the usual two copies. Translocation DS is the second most common type, although still only accounts for about 4% of cases. This occurs when an additional partial or full copy of chromosome 21 attaches to a different chromosome, rather than there being an additional chromosome 21 present. Mosaicism is the least common type of DS, only accounting for about 1% of all individuals with DS. 'Mosaic' means 'mixture', and thus, individuals with mosaic DS have some cells with the usual two copies of chromosome 21, but other cells contain three copies of chromosome 21. As a result, individuals with mosaic DS may have fewer features of DS due to some of their cells containing the typical 46 chromosomes.

### **Prenatal and Postnatal Testing**

DS can be diagnosed both prenatally via diagnostic tests (such as an amniocentesis) or postnatally (i.e., after the birth). Whilst diagnostic tests are an accurate way to find out if your baby does have DS, the tests are invasive and therefore carry a risk that the mother will miscarry (DSA, 2020). Pregnant women in England and Wales are also offered prenatal screening and may be offered this in Northern Ireland. Prenatal screening tests do not tell you if your baby has DS but indicates whether your baby has a higher or lower probability of having DS. A non-invasive prenatal blood test (NIPT) is an enhanced screening test that tests for cell-free foetal DNA, specifically chromosome 21 (DSA, 2020). As of June 2021, pregnant women in England who receive a higher chance result of their baby having DS will be offered NIPT (Public Health England, 2021). A postnatal diagnosis at birth requires a blood sample to be taken from the baby to enable a chromosome analysis. It is not possible to make a decision regarding diagnosis until the results of the test are returned (DSA, 2020).

### **Associated Comorbidities**

Individuals with DS will typically have some level of intellectual disability and are likely to develop dementia in later life (Startin et al., 2016; Wiseman et al., 2015). Adults with DS are more likely to develop dementia, partly because DS is associated with premature ageing (Glasson, Dye & Bittles, 2014). Research has suggested that 95.7% of individuals with DS may have dementia by the age of 68 (McCarron, McCallion, Reilly & Mulryan, 2014). There are also several health conditions that are associated with DS. The most common health conditions including congenital heart defects, endocrine disorders, obstructive sleep apnoea, endocrine disorders, epilepsy, vision and hearing issues, dental issues, and a higher risk of infections (Alexander et al., 2016; Hill et al., 2016; Perkins, 2017; Ram & Chinen, 2011; Roizen et al., 2014; Sobey et al., 2015). DS has also been associated with an increased risk of other neurodevelopmental conditions, such as autism and attention deficit hyperactivity disorder (ADHD; Naerland, Bakke, Storvik, Warner & Howlin, 2017). Startin et al. (2020) found that there are differences in prevalence rates of comorbidities between males and females with DS, with a greater prevalence of dementia and autism in females, and psychiatric comorbidities in males. However, it is important to recognise that there is considerable variability in both the degree of intellectual impairment and health comorbidities among individuals with DS (Karmiloff-Smith et al., 2016; Startin et al., 2016). Startin et al. (2020) found that in YAs, socio-economic status (SES), autism, and epilepsy, contributed to some of the variance in cognitive ability.

### **Social, Behavioural and Psychological Functioning**

There is a widely held stereotype that individuals with DS are ‘charming’, ‘sociable’, ‘affectionate’, ‘cheerful’ and generally have good ‘people’ skills (Down, 1866; Dykens, 2007; Fidler, Most & Philofsky, 2008). However, whilst this has led to the assumption that social understanding is comparatively intact in individuals with DS, there is evidence that there are also subtle differences between how a young child with DS might interact and attend to the social world around them in comparison to their TD peers (e.g., Berger & Cunningham, 1981; Carvajal & Iglesias, 2000; Legerstee & Fisher, 2008). Furthermore, that these differences may impact how more complex, socio-cognitive abilities, such as empathy, theory of

mind and emotion recognition may develop later in life. Overall, the research to date suggests that whilst socio-cognitive development in DS appears to develop in a similar manner to that of a child that is TD, there are several qualitative differences in the development of spontaneous gesturing, social referencing, emotional recognition, joint attention, and lower levels of mastery motivation (Cebula et al., 2010; Fidler, 2005; Franco & Wishart, 1995; Glenn, Dayus, Cunningham & Horgan, 2001; Kneips, Walden & Baxter 1994; Legerstee & Weintraub, 1997; Munday, Sigman, Kasari & Yirmiya 1988). When considered together, these differences may contribute in part to difficulties in developing interpersonal relationships and differences in interactions with both peers and adults in educational and social contexts (Cebula, Moore & Wishart, 2009; Wishart, Cebula, Willis & Pitcairn 2007). Whilst there is not a large body of research in this area, available evidence does suggest that by adolescence, many individuals with DS will experience loneliness (e.g., D'Haem, 2008). It is likely that the speech and language difficulties that typically accompany the cognitive impairments seen in an individual with DS may amplify any interpersonal difficulties. Furthermore, they may also impact on mental health and quality of life into adulthood (Cebula, Moore & Wishart, 2009).

Research also demonstrates that children with DS show higher rates of externalising behaviours (such as: hyperactivity, impulsivity, agitation, stubbornness) in comparison to children with non-specific ID (Capone, Goyal, Ares & Lannigan 2006; Dykens & Kasari, 1997; Siegel & Smith, 2010). However, these externalising behaviours appear to reduce with age, and instead, internalising difficulties (such as: depression, anxiety, social withdrawal, and secretive behaviour) are more often reported in YAs with DS (Cooper & Collacott, 1994; Dykens, 2007; Evans & Gray, 2000; Foley et al., 2015). Research also suggests that characteristics such as having a high level of social motivation can also decline in older individuals with DS (Fidler, 2005).

Many individuals with DS can live semi-independently with limited support; however, many individuals do remain in the family home (Dyke, Bourke, Llewellyn & Leonard, 2013; Foley et al., 2013). Comparison studies have shown that basic adaptive skills in individuals with DS are reduced when compared with individuals with Prader-Willi, Fragile X, and Williams syndrome (DiNuovo & Buono, 2011).

Lastly, whilst many individuals with DS can function relatively well into adulthood, research has found higher rates of depression for adults with DS in comparison to adults with other ID (Collacott, Cooper & McGrother, 1992; Maatta, Maatta, Taanila, Kaski & Ilvanainen, 2006). In addition, other psychiatric difficulties, such as ADHD, obsessive-compulsive disorder and self-injury behaviours may be more common in individuals with DS (Maatta, Maatta, Taanila, Kaski & Ilvanainen, 2006; Siegel & Smith, 2010). However, discrepant findings have been found in relation to more debilitating mental health difficulties, such as bipolar and psychosis in adults with DS, with some researchers reporting that these conditions are very rare, and others reporting significantly higher rates (Collacott, Cooper & McGrother, 1992; Dykens et al., 2015; Patti & Tsiouris, 2006).

### **Looking to The Future**

Due to medical advances in recent years, the typical life expectancy for a person with DS has now increased, with individuals with DS now living to between 50 and 60 years old, with a small proportion of individuals living into their seventies (DSA, 2016). This has important implications for considering the quality of life for both adults with DS and their parents. A small-scale study in Western Australia (Scott, Foley, Bourke, Leonard & Girdler, 2014) interviewed 12 YAs (aged between 18 – 29) with DS to explore what makes for a ‘good life?’ Participants expressed their desires for autonomous behaviour and ‘*making [their] own decisions*’, independent living, opportunities to work, and being recognised as a YA. Participants also spoke about the importance of having meaningful relationships (including friends, family, and romantic partners), and actively participating in the community. Whilst the findings from this study are not representative of all YAs with DS and may be biased towards YAs who are ‘higher functioning’ due to the inclusion criteria requiring participants to only have mild speaking difficulties, the results highlight what some YAs with DS may find important in their future.

Over recent years, there has been an increase in trying to support individuals with DS with employment opportunities. In 2011, the DSA launched an employment programme called ‘WorkFit’ which aims to train employers about the learning profile of people with DS to enable them to be supported in the workplace. They also provide options to support with internships, work experience and voluntary

work for those where paid work may not be the desired option. Whilst there are no published data available relating to the percentage of people with DS in paid employment, or work experience roles, the latest employment rates for people with disabilities in England (2019/20) suggests that only 5.6% of adults with a learning disability were in paid work (British Association for Supported Employment, 2020). This is in comparison to 74.8% of people aged 16 – 24 years old in the general population (Office for National Statistics; ONS, 2021a).

The next section provides a review of the relevant literature, before outlining the rationale for the current study, aim and research question.

## **Review of the Literature**

### **Parental Roles and Father Involvement**

Historically, around the time of the centralised industrialisation, the father's primary role within the family unit would be that of breadwinner and authority figure, whilst the mother would take on the 'expert' role of caring for their new-born child (Lamb, 2000). However, over recent decades, the role of fathers has changed considerably, with fathers now being expected to have greater involvement in the practical care and upbringing of their child (O'Brien, 2005; Towers, 2007).

There are several factors underlying this shift, including: the changing views of society; emerging literature focusing on father absence and its detrimental effects on the child (Lamb, 2000); and women wishing to be more involved in the paid workforce (Lopez, McWhirter, Rosencrans, Giuliani & McIntyre, 2019).

Despite these changes, there is still a greater focus in the literature on mothers as the primary caregivers, with less research looking at the experiences of fathers (Bourke-Taylor, Howie & Law, 2010; Bromley, Hare, Davidson & Emerson, 2004; Green, 2007).

Before presenting the relevant parenting literature, it is important to recognise that many of the studies included in the following review adopt a 'conventional' view of the family. That is, the idea of the 'nuclear' family structure, in which individuals aspire to marry and have one or more children, all living under the same roof. However, whilst many individuals do still choose to adopt this way of



living, there is much greater diversity in today's culture in terms of the family structures that people choose to live (ONS, 2021b). For example, some individuals choose to live with siblings or friends. Additionally, it is more common today that a couple that once married, and has children, may choose to separate, or legally divorce (ONS, 2020). Furthermore, parenting experiences of same-sex couples also need to be considered. Whilst it has not been possible to consider all these experiences within the remit of this review, it is important to recognise that parenting and raising a child might look very different, dependent on the family arrangements and the structures that people choose to live in. Thus, it needs to be acknowledged that there will be individuals today that have parenting experiences that are quite different from many of the studies included in the review.

### **The importance of father involvement.**

Research that has examined father involvement in families where the child is TD, highlight its importance for both the child's development (Sarkadi, Kristiansson, Oberklaid & Bremberg, 2008) and the general wellbeing of the family (Flouri & Buchanan, 2004). For example, Sarkadi et al. found that father involvement reduced the frequency of psychological difficulties in young women and the frequency of behavioural problems in boys. Additionally, father involvement was found to enhance cognitive development and minimise crime in low SES families. However, it is important to recognise that the evidence for this is correlational, and factors other than father involvement may have contributed to these emotional and behavioural outcomes. Furthermore, research suggests that father involvement may be even more important within a family where a child has a disability due to the additional care and support needs that may be required (Crowe & Florez, 2006).

Whilst research still demonstrates that mothers continue to play a greater role in childcare, both quantitative and qualitative data demonstrate that fathers are more involved in childcare now than in previous decades. Altintas and Sullivan (2017) used Multinational Time Use Study data to look at trends in the time that fathers spend on childcare and housework over a 40-year period, between 1971 and 2010. Fathers from fifteen countries were included and the countries were grouped into four clusters dependent on the type of welfare policy that each country operates. The

sample included men that were aged between 20 and 49, were either married or cohabiting with their partner, and living with at least one child under five years of age. 'Childcare' was classified as anything ranging from physical care activities, through to reading or playing with the child. To be considered 'meaningful', the interaction needed to be the father's primary activity at the time, and it needed to last for at least 15 minutes. The data demonstrated that the Nordic fathers (e.g., Denmark, Norway and Sweden) continue to contribute much more to childcare and family involvement than in the other countries. However, in the Liberal countries (e.g., the United Kingdom, the United States or Canada) – whilst relatively few fathers were involved, those fathers that were involved were spending the greatest amount of time in childcare activities. The authors suggested that possible reasons for fathers' increasing contributions may be down to better education or staying at home/non-employed fathers. Looking at the data, those fathers in the Liberal regime, were less likely to be in employment. This is supported by previous research that found that fathers in the United States who were highly involved in childcare were nearly twice as likely not to be in employment (Pacholok & Gauthier, 2010). These findings suggest that fathers do want to be involved when supported to do so by policy, and that policies need to be focusing on supporting fathers to have family time. In countries such as Sweden where policy does support this, the data demonstrates that by 2014, 25% of all parental leave, was taken by fathers (Swedish Institute, 2016). Whilst this figure does not represent an equal split by mothers and fathers, it does suggest that many fathers are wanting to take a more shared role in childcare when given the opportunity.

Further support for a shift in father involvement in the UK can be seen in qualitative interviews with 100 fathers conducted by Gatrell, Burnett, Cooper and Sparrow (2015). Fathers were invited to participate from two major organisations that allowed for flexible working conditions, supportive of family-friendly working. All fathers were asked about a range of family situations in addition to their work situation, whether they had applied for any flexible working, and their thoughts on future promotions. The authors found a combination of 'breadwinner' fathering styles as well as 'involved fathering' styles. Whilst some of the fathers did express prioritising work and economic provision, others expressed that they would put their childcare over and above paid work and possible promotion. Whilst the authors did

not state what proportion of fathers fell into these two parenting styles, this does provide some support for the notion of a shift in parenting style towards a more 'involved father.'

However, a criticism of this type of research, is that it is likely biased towards those fathers that are wanting to be involved and have their voices heard, and dispute the claims that fathers are unobtainable for research. Furthermore, it is necessary to consider the intersectionality that is also likely to influence involvement across cultures and recognise the diversity of father involvement as opposed to making generalisations. Additionally, the findings from the study by Gatrell, Burnett, Cooper and Sparrow (2015) may not be generalisable as all the fathers in their study were offered flexible working, which is not always available. Miller (2011) states that due to such constraints within the workplace, even though fathers may start off with a paternal desire for involved fatherhood, many employed fathers end up falling back into the gendered pattern of 'breadwinner.'

#### **Reasons why father involvement in parenting might not be as understood.**

According to Dollahite (2004), there are several reasons that father involvement is not well understood. Firstly, the research focus is typically on mothers. Secondly, is that health care professionals used to treat fathers as relatively unimportant in comparison to the mother, who was seen to be more pivotal in the child's development. Thirdly, is the focus on stress and coping, as opposed to the father's creativity and strengths in responding to their child's needs.

The focus on mothers stems from a traditional view of attachment, with fathers being labelled as 'playmate' to their child, and mothers seen as both the primary attachment figure and the source of comfort (Bretherton, 2010). However, in more recent years, researchers have begun to acknowledge that the roles of mothers and fathers may be different, but equally important in parent-child attachment (Bretherton, 2010; Lamb, 2010). Furthermore, that their involvement has differential influences on child behaviours over the course of their child's development. For example, Lamb states that because of typically spending less time with their child and being less familiar with their child's current competencies, fathers are more likely to communicate in ways that challenge their linguistic and pragmatic abilities, thereby teaching their children about the demands of social

exchanges. In addition, Lamb proposes that fathers can also have indirect sources of influence, for example economic support and emotional support to the family. Thus, it is important to explore what factors encourage father's positive involvement with children with additional needs.

### **Factors that may influence father involvement.**

Researchers have highlighted the importance of trying to understand the antecedents that may influence the extent of father involvement (McBride et al., 2005).

*Alliance with a 'parenting role' identity.* According to Identity Theory (Stryker & Burker, 2000), the degree to which a father sees himself in the 'parenting role' will determine father involvement. That is, if the father sees himself in this parenting role, he is more likely to be involved. Furthermore, parental-role identity may be even more important for the father, because in comparison to the maternal figure, their roles tend to be less clearly defined by society and may be seen as discretionary (Parke, 2002; Tamis-LeMonda & Cabera, 1999).

Support for the importance of parental-role identity in father involvement comes from a study by Fox, Nordquist, Billen and Savoca (2015), who looked at the effectiveness of a family-centred service delivery model intended to empower families of children with disabilities. It was found that father identity and father empowerment predicted higher levels of father involvement. The authors concluded that through enhancing father role identity, it may lead to beneficial effects on the lives of children with disabilities. However, a low response rate of 33% from the fathers involved may limit the generalizability of these findings.

It has also been suggested that a father's identity is likely to be influenced by the personality, attitudes, and behaviours of his partner (Rane & McBride, 2000). The idea that father involvement is affected by maternal characteristics has been defined as 'maternal gatekeeping' (Allen & Hawkins, 1999). In a study conducted by McBride et al. (2005), mothers' beliefs about the role of the father were found to moderate the link between fathers' perceptions of their role and the extent of father involvement; however, only when the mother held more positive beliefs about the father role. In contrast, when mother's views were more in line with traditional

beliefs about the father's role, the father's perception of his role as a parent was not significantly related to their level of involvement with their child.

***Views of services.*** Another consideration is the potential impact that the views of services may have on father involvement. Parents of children with disabilities (from birth to 3-years-old) have an important role in early intervention (EI) services to ensure intervention is effective in promoting development (McBride et al., 2017). To examine how EI providers perceive the roles played by fathers, McBride et al. invited EI service providers to participate in an online survey. Results from 511 EI services revealed that service providers were able to see the potential for father involvement to impact on child development, however, they struggled to see fathers as successful targets for EI. Furthermore, service providers did not recognise that their own perceptions may act as a barrier towards father involvement. The authors highlight the need for future research to explore fathers' perspectives of the barriers that limit their involvement in EI services.

## **Parenting a Child that is TD**

### **Experiences of parenting a child that is TD.**

Becoming a parent is likely one of the most challenging responsibilities that is faced within a family (Ladden & Damato, 1992). It requires a shift in existing relationships, the development of new ones, and for parents to take on new roles and responsibilities (Cowan & Cowan, 1995).

#### ***Parenting experiences generally.***

*The transition to parenthood with a new-born.* Research has demonstrated that the transition to parenthood brings both positive and negative experiences (Cowan & Cowan, 1998; Petch & Halford, 2008). Due to the significant changes within the family that occur with the addition of a new-born child, many new parents face a difficult adjustment period as they learn to navigate the differing emotional and economic demands now required (Cowan & Cowan, 1998). However, the birth of a child also brings many positive experiences: joy and happiness for the family; relationship stability; affection; the fulfilment of reproductive needs; and a sense of purpose (Petch & Halford, 2008).

Nystrom and Ohrling (2004) conducted a literature review of studies between 1992 to 2002 that explored both mothers' and fathers' experiences of parenthood during the first year. Thirty-three articles, both quantitative and qualitative were included. The researchers found that there were both similarities and differences in the parenting experience between mothers and fathers. A unifying theme amongst both sets of parents was that the first year was 'overwhelming.' In addition, both mothers and fathers expressed their desire to feel confident in their role as a mother and father. Similarly, both parents spoke about the new demands causing strain; however, gave differing reasons for this. The mothers discussed feelings of powerlessness and inadequacy (Ahlborg & Strandmark, 2001) or feeling bound to the baby (Olsson, Jansson & Norberg, 1998) and restricted in their activities. Whereas the fathers discussed concerns around finding high quality childcare from others and finding time to spend on themselves and with their spouses (Hall, 1992; 1994). Other differences in experience concerned mothers feeling tired and drained (McBride & Shore, 2001; Rogan et al., 1997), whilst some of the fathers discussed feeling hurt by the mother-infant bond and wished they could be closer to the child (Barclay & Lupton, 1999). These differences in experience are supported by previous research that suggests that men and women go through different processes during this transition period (Cowan & Cowan, 1995).

*Parents' experiences surrounding the young person's transition during emerging adulthood.* Parenting research has tended to focus on the adaptation process for parents with TD children or explores other areas relevant to specific populations (e.g. where the young person or parent has an illness or disability; cultural differences; gender; employment; sibling relationships). However, research looking at parents' experiences or interactions with their child during early adulthood is relatively limited. According to Arnett's (2000) theory of 'emerging adulthood', the period between the ages of 18 and 25 is distinct from both 'adolescence' or 'young adulthood.' Arnett defines 'adolescence' as the period of 10 to 18 years of age due to several factors that young people in this age bracket typically have in common: living at home with parents; attending secondary school; going through puberty; and experiencing peer culture within school. On the other hand, Arnett proposes that 'young adulthood' applies better to the thirties, where

many people have begun to settle into a more stable period of their life. According to Arnett, most people in their thirties have a steadier career path, many are married, and many also have at least one child. In contrast to these identified periods of ‘adolescence’ and ‘young adulthood’, individuals between the age of 18 and 25 tend to have greater opportunities available to them (e.g., relating to work, relationships) and generally have greater independence, without having the constraints of adult roles and responsibilities that may be more likely to emerge in the late twenties and early thirties. Thus, Arnett suggests that the term ‘emerging adulthood’ captures the more dynamic and fluid characteristics of this age bracket.

One study that has explored parents’ perceptions during the transitions surrounding emerging adulthood and their relationships with the young person, is that of Kloep and Hendry (2010). Kloep and Hendry conducted semi-structured interviews with 59 parents whose children were between the ages of 18 and 25. The authors identified four ‘clusters’ that represented different parental strategies during this period: 1) Letting go (n=14); 2) Reluctant acceptance (n=19); 3) Holding on to (n=23); and 4) Power fights (n=6). Out of the 59 parents, only 14 suggested that they were pleased that the young person was becoming independent. In contrast, many parents described difficulties relating to the YA’s autonomy. Some parents reported feeling that they had less power to influence the young person’s choices, others talked about a loss of role, or missing their child. Lastly, a few parents reported difficulties due to not approving the life-style choices of the young person. A criticism of this study is that fathers were largely underrepresented in the sample. Therefore, the findings are more representative of mothers’ perceptions, rather than parenting perceptions more broadly.

***Fathers’ experiences only.*** As with parenting research more generally, there is a paucity of research that aims to explore fathers’ experiences of parenting TD children at older ages. To date, the literature has focused mainly on earlier experiences of parenthood, such as: men’s experiences of pregnancy (Condon 2006; Finnbogadottir, Svalenius, & Persson, 2003), experiences during the early postnatal period (de Montigny & Lacharite, 2004; St John, Cameron & McVeigh, 2005), and men’s experiences during the transition to fatherhood (Chin, Hall & Daiches, 2011; Kowlessar, 2012).

*The transition to fatherhood from pregnancy to experiences with a new-born.*

Chin et al. (2011) conducted a metasynthesis of qualitative studies published between 2002 and 2008 that explored fathers' experiences in their transition to fatherhood, from pregnancy to 14 months following the birth of their child. Eight studies were included: three conducted in the UK; two in Sweden; and one in Australia. Three main themes were identified: 'emotional reaction to phases of transition'; 'identifying their role as father'; and 'redefining self and relationship with partner'. Fathers spoke about experiencing an array of emotions following the birth: amazement; love; responsibility; confusion (Deave & Johnson, 2008). Some fathers spoke about consciously thinking about how they were brought up, and how they would want to be like their own father, or vice versa (Deave & Johnson, 2008; Fagerskiold, 2008; St John et al., 2005). Fathers also spoke about needing to provide financially for their family and considering both immediate and future needs (Premberg, Hellstrom & Berg, 2008; St John et al., 2005). Lastly, fathers described noticing changes in their personality, as well as noticing how becoming a father had changed their relationship with their partner (Bradley, McKenzie & Boath, 2004; Deave & Johnson, 2008; Fagerskiold, 2008; Premberg et al., 2008; St John et al., 2005).

Further research is needed to explore fathers' experiences of parenting a child that is TD at other developmental stages.

## **Parenting a Child with a Disability**

### **Experiences of parenting a child with any disability.**

Research demonstrates that parents of children with disabilities or complex needs will face an additional set of challenges to parents of TD children. Whilst the added responsibilities and roles will be dependent on the nature of the child's disability, one experience that is frequently reported in the literature is that of taking on numerous different roles to ensure that their child's needs are being met (Coad et al, 2015; Kirk, Glendinning & Callery, 2005; Tong, Lowe, Sainsbury & Craig, 2008; Tyerman, Eccles & Gray, 2017). As a result, it is not surprising that this added responsibility can feel overwhelming for many parents (Hatzmann, Maurice-Stam, Heymans & Grootenhuis, 2009; Tong et al., 2008; Tyerman et al., 2017). Some of the other experiences that are reported include: fatigue; loss of personal leisure time;



and marital conflicts (McAndrew, 1976). Researchers have also found that parents of children with disabilities often feel disconnected from others or feel that others are not able to understand what they are going through (Tong et al., 2008; Tyerman et al., 2017). Furthermore, that these parents have greater worries about their child's future and concerns about their child being accepted by society (Tyerman et al., 2017). Lastly, parents frequently report receiving insufficient information relating to their child's condition and seeking greater levels of support and understanding (Kepreotes, Keatinge & Stone, 2010; Tong et al., 2008; Tyerman et al., 2017). Whilst some of these experiences are also evident within families of TD children, these appear to be amplified where the child has a disability, due to increased caregiving responsibilities.

Whilst both positive and negative experiences have been acknowledged and reported in the literature concerning parenting a child that is TD, there has been a greater tendency to focus on the negative experiences that accompany parenting a child with a disability (Boerner, Schulz & Horowitz, 2004; Heiman, 2002; Landsman, 2003). This focus has been largely due to the societal discourse that diminishes the value of adults with disabilities (Barnes, 1997; Linton, 1998; McKeever & Miller, 2004) and therefore expects parents to be negatively impacted by the 'burden' of raising a child with a disability (McKeever & Miller; Priestley, 2003; Read, 2000). Green (2007) aimed to examine the nature of the social experience of mothering a child with a disability utilising a mixed methods approach. Disabilities included in the study were: CP; DS; head trauma; Spina Bifida; and other diagnostic categories not specified. In addition to some of the difficulties experienced, the mothers identified a range of positive experiences, including: greater courage and strength to face any situation; personal growth; a strengthening of existing relationships; increased competence; and greater appreciation for what is most important. Furthermore, many of these mothers perceived that their 'burden of care' is a result of societal constraints, as opposed to emotional distress.

Bronfenbrenner's Ecological Systems Theory (1977) is important in considering the influence of societal constraints on parents' beliefs and expectations relating to parenting a child with a disability. Ecological Systems Theory offers a

framework for understanding the relationships between an individual, an individual's family, and wider society. The theory describes how many layers situate around the individual, each level having the ability to influence one another. According to this theory, the attitudes, ideologies and cultural values that are present within the society that the individual inhabits, will impact on, not only the individual, but those in the individual's 'microsystem', such as family and friends. Thus, the experiences of these individuals are often limited by the expectations of society and people around them.

### **Experiences of parenting a child with a DD.**

*Parenting experiences generally.* As documented within the literature on parenting a child with any disability, parents of children with a DD are often faced with additional challenges than those with a child that is TD. For example: dealing with difficulties in the educational system; being met with social stigmas within society; and managing finances to meet the additional needs of the child (Glidden, Billings & Jobe, 2006; Murphy, Christian, Caplin & Young, 2007).

Bourke-Taylor, Howie and Law (2010) interviewed four mothers with children between the ages of 8 and 15, who had been diagnosed with a DD (CP; ASD; and ID) to investigate their experiences. The two overarching themes identified were: the impact on the mental health of mothers; and issues that mothers found challenging. Mothers acknowledged the impact of numerous daily stressors on their mental wellbeing, with many mothers describing the child's birth or diagnosis to be one of the most difficult times. The issues that mothers found challenging were categorised into different levels. Issues relating to the child; the mother; the family; the service; and the environment and community. For example, difficult experiences relating to 'the child' were often relating to meeting the child's needs or learning to cope with certain behaviours. In relation to 'the mother', mothers described feeling that they were missing out on having time for themselves and socialising with friends. 'The Family' was used to describe difficulties with their partner, either if the partner was unhelpful, or in the sense that their marriage was no longer the priority. Mothers also spoke about fears or guilt for siblings, and most mothers reported a loss of support from extended family. Regarding 'the service', mothers described finding services difficult to access and the difficulty in

being faced with waiting lists. Lastly, ‘the environment and community’ challenges related to the stigma that some mothers faced. Furthermore, some described finding difficulties with the physical accessibility of certain places within their community. However, whilst these findings are helpful in providing some insight into the experiences of parenting a child with a DD, only mothers were interviewed in this study. This is problematic as one cannot assume that these experiences are the same for fathers.

Additionally, as is the case for families that have a child with any disability, some of the challenges that exist for families with different DDs will be unique. For example, some of the challenges when parenting a child with ASD may include: supporting social and communication development (Ludlow, Skelly, & Rohleder, 2012); managing repetitive behaviours and restrictive interests (Bearss, Johnson, Handen, Smith & Scahill, 2013; Ludlow et al., 2012; Myers, Mackintosh & Goin-Kochel, 2009); and an intolerance of uncertainty (Hodgson, Freeston, Honey & Rodgers, 2017; Rosen & Knauper, 2009).

As found within the broader disability literature, there are fewer studies that have focused on the positive aspects of parenting a child with a DD. However, the literature demonstrates that many parents can identify positive aspects of parenting their child as well as the challenges. Beighton and Wills (2019) carried out a systematic review of primary research to identify what parents of children with IDs describe as the positive aspects of parenting. The following themes were classified: personal development; personal strength; a new perspective on life; the child as a source of happiness and fulfilment; improved or expanded relationships; the positive effect that the child has on others; increased spirituality or religiosity; and a caring role. Furthermore, Taunt and Hastings (2002) asked four fathers and ten mothers of children with a DD about the positive impact of their children on their families. Positive experiences included: contact with others; opportunities to help other families with a disability; siblings demonstrating increased sensitivity, greater maturity and responsibility; and increased support and closeness to others within the family.

*The transition to adulthood for young people with a DD.* In addition to the adjustment and diagnosis stage, research suggests that the transition to adulthood for

young people with a DD is particularly challenging for families (Cheak-Zamora, Teti & First, 2015; Stewart et al., 2014). Parents are required to play an active role in the organisation of: post-secondary education; employment; social participation; and residential living (Chambers, Hughes & Carter, 2004; Stewart et al., 2010, 2014). In their mixed-methods study, Leonard et al. (2016) explored parental worries and concerns regarding the transition of their child to adulthood. Participants were either parent to a young person with DS or a young person with any ID, aged between 17 and 24. Some of the main findings from parents included: the impact of the transition on family life; stress on the family and concerns about finances; worries about their child's capacity to cope without the structure and support of school; mixed emotions towards navigating available services; a desire to continue to support their child towards independence and social connections in the future; and uncertainty about the future and worries about what will happen when they are no longer around to provide support.

Similar findings have been found in more recent research conducted by Codd and Hewitt (2020) and Wong, Ruble and Brown (2020). Codd and Hewitt utilised IPA to explore ten parents' views regarding the transition to adulthood for their son or daughter (aged 18 – 25) with an ID. Whereas Wong et al., explored this transition process in 13 parents of adolescents and YAs (aged 15 – 27) with ASD. In both studies, parents spoke about this period of transition being overwhelming, and a sudden change that brings about uncertainty and worry. In Wong et al.'s study, this was accompanied with thoughts regarding their own health and mortality. For the parents in Codd and Hewitt's study, this anxiety seemed to conflict with their desire to support the YA's independence, but recognising the YA's vulnerability. Parents in both studies also spoke about experiencing a lack of support from services, or insufficient support and resources, which appeared to leave some parents feeling isolated.

However, research has also found that parents are differentially affected during the transition period by the young person's diagnosis. Blacher, Kraemer and Howell (2010) conducted a study to explore parents' expectations relating to the young person's transition to greater independence post-school. Parents were recruited if they had a YA with: autism (n=30); DS (n=68); CP (n=95); or an

undifferentiated learning disability (n=53). The authors found that diagnosis influenced parental expectations of their child's living outcomes. For example, for parents of YAs with DS, the majority expected their child would remain in the family home in the future; however, this was not expected by parents of YAs with autism. Differences were also found regarding parents' views relating to vocation or employment outcomes. For example, parents of YAs with CP did not appear to be confident about their child entering the workplace; however, parents of YAs with DS and YAs with autism seemed to be more optimistic about their son or daughter's prospects of working in the future.

However, as discussed previously, the tendency for parenting research to focus on mothers' experiences is still a significant issue as differences in the experiences of mothers and fathers have been consistently reported (Kayfitz, Gragg & Orr, 2010; Pelchat, Lefebvre & Perreault, 2003). For example, Kayfitz et al., reported that mothers tend to describe more positive experiences with their child with autism than do fathers. This appears to support other findings which suggests that fathers of children with autism may experience greater levels of stress than mothers (Potter, 2017; Rivard, Terroux, Parent-Boursier & Mercier, 2014).

*Fathers' experiences only.* Boyd, Iacono and McDonald. (2019) conducted a systematic search of research published from 2000 to 2017 that explored the experiences of fathers of children with a DD, beyond a deficit-based approach. Any studies that also collected data from the mothers was required to present the data separately for fathers. Twenty-one studies met the inclusion criteria (12 quantitative, 9 qualitative).

Within all 12 quantitative studies, both mothers and fathers were included as participants. Two key findings emerged within the quantitative literature. First, are the differences in experiences found between mothers and fathers. For example, the stress of fathers has been suggested to be mediated by participation in activities relating to their child (Azar & Badr, 2010; Dyer McBride, Santos & Jeans, 2009) whereas mothers' reported wellbeing appears to be positively correlated with the fathers' ability to participate in activities with their child (Glidden, Billings & Jobe, 2006). Second, are the differences in how mothers and fathers cope with challenging experiences. For example, research has shown that fathers may use more cognitive

coping approaches, and mothers rely more on social supports (Barak-Levy & Atzaba-Poria, 2013). However, the findings related to coping approaches for fathers are less consistent than for mothers (Boyd et al. 2019).

In the qualitative studies, six of the nine studies included focused solely on fathers. A variety of approaches were utilised (five studies using a phenomenological approach, three using grounded theory, and one not identified). Overall, the key themes found in the qualitative literature were: the journey of adapting to the diagnosis; the importance of thinking and planning for the future; challenges/involvement with health services; and how participation within the family is shaped by the father's experiences and perceptions.

The findings illustrate that fathers often face these challenging times with little support. This may explain why most of the studies included in the review still addressed methods of coping responses, despite an attempt by the authors to move beyond this focus. Boyd et al. (2019) offer recommendations for future research to address a current gap in understanding the experiences of fathers in parenting a child with a disability and how they perceive their role. The authors propose that future research should focus on qualitative methodologies that look in more detail at fathers' experiences. It is suggested that this approach may also help to determine factors that might influence fathers' participation within their families. Furthermore, such research may help to support professionals working in the field to develop more effective interventions to better engage fathers and their families.

More recent research has utilised qualitative methods to explore the experience of fathers in more detail. Davys, Mitchell and Martin (2017) utilised IPA to explore the roles, needs and concerns of seven fathers who had an adult (over the age of 20) with a learning disability. The mean age of adults with a learning disability was 32. The main themes revealed fathers' shock at diagnosis and the impact of learning disability on their lives. In addition, that fathers' perceptions towards their adult child and their own roles were varied. Fathers appeared to value support from family and peers; however, fathers made greater negative comments, rather than positive comments in relation to support received from services. Fathers expressed concerns towards the future, particularly in relation to the uncertainty and practicalities of future planning. Lastly, some fathers described difficulties being

emotionally open with other males, referring to male stereotypes in society, such as needing to be a “*rock*”, “*breadwinner*” and “*macho*”.

In another study, Thackeray and Eatough (2018) utilised IPA to explore five fathers’ experiences of parenting a YA with a DD. However, a limitation with this study is that the diagnosis of the YAs varied (three YAs with autism; one with DS; and one identified to have severe learning difficulties with autistic features). This could have influenced the fathers’ experiences and therefore the extent to which the researcher can make links between the fathers’ accounts.

Within the existing literature, research has often grouped DDs together or it has focused on certain DDs over others. Looking at the breakdown of studies included in the Boyd et al. (2019) review illustrates this: three studies investigated ID, five grouped DDs together, two looked at developmental delay, six focused on ASD, three CP, and the remaining two considered other variables relating to gender. A significant limitation of grouping DDs together is that this creates less homogeneity and risks losing the specific experiences that relate to specific DDs (Bostrom & Broberg, 2014; Meadan, Stoner & Angell, 2015). Therefore, research should consider focusing on one type of disability to gain a more accurate understanding of fathers’ experiences within that population. At present, fewer researchers have appeared to explore the experiences of parenting a child with DS.

### **Experiences of parenting a child with DS.**

This section will first provide an overview of parenting experiences generally, before outlining those studies that explore fathers’ experiences, highlighting the gap that the researcher intends to address.

***Parenting experiences generally.*** One of the biggest differences and important implications on gathering more research on parenting a child with DS, is due to the often-pessimistic view that individuals within society hold regarding having a child with DS (Cuskelly, Hauser-Cram & Van Riper, 2008). This is supported by the fact that parents are offered the opportunity to terminate their child if they discover via non-invasive screening (NIPT) that their child has the chromosome abnormality. However, in contrast to this negatively held belief of what a life with a child with DS may be like, some researchers have reported a ‘DS

advantage.’ This refers to parents of children with DS reporting to experience lower levels of stress, increased positivity and greater support strategies than parents of children with another DD, such as ASD and Fragile X Syndrome (Hartley, Seitzer, Head & Abbeduto, 2012; Ricci & Hodapp, 2003; Smith, Ronski, Sevcik, Adamson, & Barker, 2014). However, some researchers have challenged this claim, stating that this ‘advantage’ is a result of other variables, such as household income, parental age and the child’s adaptive behaviours (Corrice & Glidden, 2009; Stoneman, 2007). Additionally, those parents that might be struggling more with their child may not wish to participate in research (Cuskelly et al., 2008). Therefore, these findings appear to be up for debate.

*Generating a balanced view.* Regardless of these contradictory views, it is important for research to capture a more balanced view of what parenting a child with DS might be like (Cuskelly et al., 2008). A study by Farkas et al. (2018) in the United States aimed to do just that, by asking 435 parents of children with DS via an online survey to describe both their positive and negative experiences with their child. Grounded theory and thematic coding were used to analyse the parent responses. Two of the dominant themes were salient in data relating to both positive and negative experiences: ‘impact on the parents and other people’ and ‘social acceptance/connection (and lack of).’ Parents described the joy that their child brings to their family and others, such as: bringing their family closer, and making their family more compassionate. Parents also spoke about how their child was ‘accepted’ within schools and included in mainstream education classes. However, conversely, parents also reported that the impact on them had been negative because the future for their child is unknown, and they had to adjust to the diagnosis and let go of previous expectations and dreams. In addition, parents spoke about society’s lack of understanding for DS and the assumptions and stereotypes that others have for their child. Furthermore, the discrimination that they have faced within schools, including some teachers not allowing their child to participate fully in classes, was challenging for participants.

*Differences in mothers’ and fathers’ experiences.* However, as is demonstrated in other parenting research, differences in the experiences of parenting a child with DS have been found between mothers and fathers (Pelchat, Lefebvre



Perreault, 2003). Pelchat et al. conducted focus groups with nine parents (four couples and one mother) who had a child born with DS (aged between two and five years old). The authors noted that fathers spoke more of extended family issues: feeling disheartened by others' lack of ease with their child; and wishing for greater support from their extended family. Whereas mothers were more focused on marital issues or their ability to be a good mother and appeared to feel comfortable around extended family. Another difference related to how parents wanted others to see their child. Whilst mothers described wanting others to recognise their child's uniqueness, fathers spoke about hoping that others would see their child as 'normal.' Despite the study only including a small number of participants, the finding that differences exist in the experiences of mothers and fathers is corroborated by other disability research (e.g. Kayfitz, Gragg & Orr, 2010; Potter, 2017; Rivard, Terroux, Parent-Boursier & Mercier, 2014), highlighting the need to understand parents' experiences separately when considering how best to offer support.

*The impact of different stages of the life cycle.* It has also been suggested that there may be different challenges at different stages of the life cycle. Family System's Theory (Turnbull, Turnbull, Erwin, Soodak & Shogren, 2011) can provide a helpful framework for understanding the family more closely. Specifically, the theory addresses the following: family characteristics; interactions; functions; and life cycle. The family life cycle forms an integral part of the family system and highlights the different transition stages that a family typically experiences throughout the years. There are many different stages throughout the lifecycle; however, some of the key stages include: birth and early childhood, childhood, adolescence, and adulthood. These stages tend to be characterised by key events or 'age-appropriate' milestones that signify each developmental stage. Over the years, families experience two types of transitions – those expected or unexpected. For families where there is a child with a disability, these transitions are often unexpected (i.e., typically not planned), may not look the same, and often do not happen at the same times as for children that are TD.

Research has found that the demands of parenting a child with DS may increase with age (Cuskelly et al., 2008). Goff et al. (2016) looked to explore the experiences of families of children with DS among four different age groups, based

on 'stages' of family development (Rodgers & White, 1993). The different age groups were: under 5 (early childhood); 5 -11 (middle childhood); 12 – 18 (adolescence); and over the age of 18 (chronological adults). They found that parents experienced the early stage and later stages as most difficult and reported the lowest levels of coping during these stages. The researchers suggested that during early childhood, parents are having to adjust to the idea that their child has a disability as well as their child's level of development and society's views of their child. However, whilst parents of children over the age of 18 may share some of the same challenges, these parents were also able to discuss their child's accomplishments and often spoke about how comparable their child was to other YAs who are TD. However, this group spoke about a fear for the future, including a worry about what will happen to their child if they are not alive to support them, and how they will cope financially. Other stressors that were reported included: less day-to-day support being available now that their child is out of the school system and concerns about their child's living arrangements and long-term care. Thus, the lower coping strategies reported in this group may be due to these additional stressors that exist that are less likely to be experienced by parents of children who are TD.

Despite the recognition that varying challenges may exist at different stages of the life cycle, researchers have tended to group the ages of the child together when looking to explore parent perceptions of having a child with DS (e.g. Durmaz et al., 2011; Marshak, Lasinsky & Williams, 2018; Takataya, Yamazaki & Mizuno, 2016). The age ranges for the children with DS in these studies were between 1 – 18, 3 – 30, and 3 - 20 respectively. Durmaz et al. interviewed 100 parents living in Turkey about the impact of a having a child with DS and compared these answers with those of 100 parents with TD children. Parents of children with DS were found to be as happy within their marriages as parents with TD children; however, despite this, parents of children with DS were more likely to predict the possibility of divorcing their partner. In addition, a major problem with having a child with DS was financial difficulties. It was found that in families where there was a child with DS, it was 1.2 times more likely that both the mother and father were working in comparison to the control group. Furthermore, more mothers appeared to take responsibility for their child with DS, whilst the rate of the employed fathers was significantly greater than the mothers. The authors suggest that these findings may

be due to the added financial pressures in conjunction with society's expectation that the mother looks after the family whilst the father attempts to meet the family's financial needs.

*Experiences of parenting a YA with DS.* Although numerous studies have investigated the experiences of adulthood and the transition from adolescence into adulthood for families of children with ID or DD more broadly (Cheak-Zamora, Teti & First, 2015; Leonard et al., 2016; Stewart et al., 2014; Young et al., 2017), little research has looked to explore these experiences solely for parents of YAs with DS.

Dyke, Bourke, Llewellyn, and Leonard (2013) conducted semi-structured interviews with 18 mothers who either had a YA with DS (aged between 18-30) or a YA with Rett Syndrome (aged between 18-33) to examine their perspectives of this period. The authors found that mothers of YAs with DS described more difficult pathways to achieve the desired outcomes for their son or daughter than mothers of a YA with Rett Syndrome. Whereas, for the mothers of YAs with Rett Syndrome, a significant concern was the loss of therapy services for the YA. These findings further highlight that whilst some similarities in experience may be shared amongst parents of YAs with a DD, that experience also seems to vary depending on the YA's diagnosis.

One possible reason that there has been less research looking at YA experiences for this population, is that individuals with DS are expected to have a shorter life expectancy. However, individuals with DS are now living longer (DSA, 2016). Therefore, research needs to address this gap and consider the experiences of parents of young people with DS as the young person leaves school and enters early adulthood. Furthermore, as previous research has demonstrated that parents entering this period of transition with their child with DS may be experiencing additional levels of stress (Goff et al., 2016), it is important to gather further research to help professionals consider whether these parents need any additional support and what can be done to better support these families during this period of transition.

One study that has addressed this gap, is Docherty and Reid (2009). The researchers utilised IPA to explore the attitudes, values, goals and expectations underpinning the experiences of eight mothers of YAs with DS (aged between 19 – 29 years). Four superordinate themes were identified. Firstly, 'identifying stages of

development.’ This referred to the need to anticipate the next steps and trying to remain ahead to be organised. Parents also spoke about having to challenge their natural intuitions to protect the YA and keep them at home, whilst also being mindful of the YA’s capabilities. Secondly, ‘defining and shaping adulthood.’ Mothers spoke about gradually introducing the YA to adult values and responsibilities. They also described wanting the young person to realise that they could achieve their goals, and not feel limited by having DS. Thirdly, the role of ‘gate-keeping and facilitating.’ Mothers found themselves organising the YA’s activities and needing to remain aware of their rights to access facilities. Lastly, the value and goal of ‘self-reliance and independence.’ Mothers felt it was necessary that the young person became independent. They worried about ageing and how their offspring would cope. Mothers looked forward to a reduction in parental responsibilities as the YA becomes independent and having a more relaxed relationship with them.

These findings both support and contradict previous research. Parental concerns regarding their future and ability to continue to support their offspring into older age has also been documented by Leonard et al. (2016) regarding the transition of a YA with DS or ID. In addition, these parents also expressed a desire to support their child to become independent. In contrast, previous research that has explored the views of parents with a YA with an ID has found that parents are more inclined to maintain a ‘parent-child’ relationship, rather than promote and support the young person’s independence (Baron, Ridell & Wilson, 1999). This is the opposite of that described by the mothers interviewed by Docherty and Reid (2009). One possible explanation for this discrepancy is due to the wider legislative changes relating to inclusion and equal access to resources for people with disabilities that have been introduced since Baron et al.’s study; however, this is not certain. Future research would therefore be needed to investigate these beliefs in the present-day context. Furthermore, the findings of Docherty and Reid only provide insight into the experiences of mothers with a YA with DS.

Another study that has explored the experiences of parents of YAs with DS is Hudnall (2014). Thirty-eight parents of YAs (aged 18 -29) were invited to complete either a written or online survey, in which they were asked to select and

rank their goals for the future of the YA. Parents were also asked how close their children were to achieving these goals and what resources or supports have helped or hindered this process. Thirteen parents also opted to complete an additional follow-up telephone interview to elaborate on their answers provided in the survey. Many of the goals described by parents map onto those vocalised by the YAs with DS interviewed in Scott et al.'s (2014) study discussed earlier. Specifically, parents spoke about safety, friendships, independent living, paid employment, and access to healthcare. However, unfortunately, parents reported that there were often barriers in place, meaning that these goals were not frequently achieved. Barriers to achieving these goals included: lack of transportation options, housing and opportunities for social interaction and paid employment.

According to the Social Model of Disability (Oliver, 1983), individuals are disabled, not due to any difference or impairment, but by these barriers put in place by society. The social model challenges the traditional medical model of disability, which sees the problem as the person with the disability. Rather than making adaptations within society to meet the individual's needs, the individual is made to feel they are unable to participate due to their difference or impairment. For example, an individual may not be able to go to a certain place because they cannot walk, and the building does not have a lift or ramp. The social model would advocate that this is not the fault of the individual, and that society should be made more accessible to accommodate for this difference.

However, again, a significant limitation of Hudnall et al.'s (2014) research is that only one father was recruited to this study out of the 38 parents in total. Therefore, it cannot be said that the findings in the present study are inclusive of paternal goals and perspectives of their YA children with DS. Given that the research has consistently shown that mothers and fathers experience the roles of parenting differently, this highlights a need to separately explore the experiences of fathers in this area.

*Fathers' experiences only.* The following section will outline papers that explore fathers' experiences of parenting a child with DS, before presenting the rationale for the current study. The researcher has chosen to group these studies according to their foci.

*Receiving a diagnosis and adaptation.* In addition to researchers grouping different ages of child together, there has also been a tendency to focus on parents' experiences following receipt of a diagnosis and the adaptation and adjustment period. Three studies have been identified which explore fathers' experiences at this time. Both Fleming, Fickenscher, Guditis, Bell and Hultquist (2013), and Lowitt and Averill (2014) interviewed fathers about their experiences following their child's diagnosis of DS. Fleming et al. were concerned with how fathers experienced the delivery of the diagnosis, whereas the focus for Lowitt and Averill's study related to how fathers found the immediate postnatal support in hospitals. Findings illustrated that fathers tended to experience the postnatal diagnosis as insensitive and pessimistic. Furthermore, that healthcare professionals should receive improved training to deliver this type of news (Lowitt & Averill, 2014).

Ridding and Williams (2019) conducted a grounded theory study in the UK, to explore how fathers adjust to parenting a child with DS. Fifteen fathers who had a child with DS under the age of ten were included in the study. All fathers interviewed described having made a positive adjustment, despite acknowledging challenges along the way. Some of the challenges described were: experiencing an emotional rollercoaster; the presence of comorbidities; comparing their child to others; difficulties accessing support; challenges to relationships; renegotiating the spousal relationship; and challenges to the gender role. Fathers said that they deliberately employed strategies to help achieve positive adjustment, for example: recognising the positives; and changing jobs if their employer was not supportive or flexible.

*Personal impacts, perceptions and feelings.* Four studies appear to focus on views and feelings more generally. In their study in the United States, Marshak et al. (2018) looked at the impact of having a child with DS on fathers. Thematic analysis was used to analyse the responses from 311 biological fathers via an open-ended survey. Four major themes emerged: personal growth; joy and gratitude; stress and anxiety; and sadness, loss and depression. Thus, whilst most fathers expressed positive experiences with their child, these tended to coexist with similar negative experiences, reflecting a mixture of emotions seen in previous literature. However, one criticism of this research is that the age of the child or young person with DS

ranged broadly from 3 – 30 years of age. Thus, the experiences of fathers included in the study will likely be affected by factors, such as the amount of time that has passed since diagnosis, as well as differing challenges that occur throughout the life span. Another limitation is that the authors utilised thematic analysis for qualitative survey data, rather than interviews. Therefore, the data may not be as detailed, or capture fathers' experiences as fully.

In another study conducted in Japan, Takataya et al. (2016) used focus groups to generate discussion with the fathers about their feelings towards having a child with DS. They also found that the fathers spoke of both positive experiences (such as: personal growth and 'feeling like a father') in addition to difficult experiences (such as: emotional turmoil and attitudes towards disability). However, similarly to Marshak et al. (2018), the findings are difficult to interpret due to the wide age ranges of the child (3-20 years of age). Furthermore, the cultural and societal differences that exist in Japan might be partially accountable for some of these findings.

How, Barton, Smidt, Valentin and Wilson (2018) conducted semi-structured interviews in Australia, with five fathers of children with DS aged between 13 months and 7 years to examine their views on the availability of NIPT. The fathers had mixed views towards NIPT, recognising that some of the benefits included having more time to prepare, research and adjust to the reality of having a child with DS. However, the fathers feared that NIPT may be used as a measure to eliminate DS as an 'undesirable disability', rather than as a tool to help prospective parents make informed choices. The fathers described their overall experiences as parents as a positive and rewarding one, despite recognising and reporting some of the challenges that accompany having a child with DS, such as developmental differences and increased medical problems. Whilst the fathers in this study may not be representative of all parents as the majority were recruited from an online forum that advocates for disability rights, the findings do support other researchers that have called for a more balanced view for prospective parents.

Sheldon, Oliver and Yashar (2020) conducted a study in the United States and recruited 175 fathers, utilising an online survey to ask open-ended questions about the rewards and challenges of parenting a child with DS. Key themes for

rewards that emerged from the data included: positive attributes and behaviours of the child, feeling positively changed by their child, having a rewarding parent-child relationship, experiencing positive relationships with others (e.g., partner, family), and 'other' responses (e.g., 'never a dull moment'). Key themes for challenges included: challenging behaviour and development, fathers' thoughts, behaviours, and emotions (e.g., inadequate social life, sadness, concerns about the future), negative attitudes and behaviours of others, problems with the system and institutions, and 'other' responses (e.g., 'there are no challenges', or challenges being no different with a child without DS). However, as discussed in relation to other studies, the authors have not attempted to specify an age range for the child with DS, and therefore the age of the child ranged from new-born to 36 years. Furthermore, the fathers' ages ranged from 29 to 82 years. Thus, the various developmental stages and accompanying challenges that can occur for both the child and the father during these age ranges, make it difficult to interpret these findings.

*Hope and coping behaviours.* Two studies explore the roles of hope and coping behaviours in fathers of this population. Firstly, Armijos-Yambay and Sierra (2019) aimed to investigate the experience of 'pedagogical hope.' Pedagogical hope is described as the experience of children's possibilities. Thus, those fathers that are 'pedagogically hopeful' encourage the best from their children. Ten fathers who were considered 'pedagogically hopeful' after an initial screening, were selected for interview. The child or young person with DS ranged from 5 to 30 years of age. Four themes were composed: First, a pedagogically hopeful father is both realistic and optimistic. Second, they believe in their child's strengths. Thirdly, the father trusts in their ability to positively influence the life of their child. Fourth, they are open to surprises and are not limited by past experiences. It is suggested that having pedagogical hope may help to push past pre-conceived barriers that often limit the self-realisation of children and young people with DS.

Secondly, Bentley (2015) used a mixed-methods approach to explore the attitudes and coping behaviours of fathers. Fathers' responses were separated into three different clusters: mastering; connecting; and thriving. 'Mastering fathers' were identified as using action-oriented strategies, such as pushing their child to achieve and to try harder. 'Connecting fathers' seemed to have a sense of



satisfaction and participated more in the DS community, increasing social support networks. Lastly, ‘thriving fathers’ appeared to positively reframe their experiences and spoke about having a greater sense of meaning and purpose to life.

*Importance of the relationship between health professionals.* Lastly, Docherty and Dimmond (2018) utilised IPA to explore how these fathers perceived their experience with health professionals. Seven fathers living in the UK who had a child with DS between the ages of two and seven were included in the study. The findings reflected both positive and negative experiences in their interactions with health professionals. Positive experiences described related to receiving clear communication with direct statements. In addition, fathers particularly valued it when health professionals provided them with a balanced view of parenting a child with DS. Negative experiences involved: feeling excluded (this was reported by all seven fathers); not being listened to; feelings of inequality in comparison to their partner; and lack of on-going support as new parents.

## **The Current Study**

### **Rationale for Study**

Despite research highlighting the importance of father involvement for a child’s development (Sarkadi et al., 2008), and a shift in the historical view that it is the mother’s responsibility to care for the child, there is still a greater focus on mothers within the parenting literature (Bourke-Taylor et al., 2010; Bromley et al., 2004; Green, 2007). This is an issue, not only because fathers’ voices are not always heard, but because differences in the experiences of mothers and fathers are consistently reported across different parenting populations (Kayfitz et al., 2010; Pelchat et al., 2003; Potter, 2017; Rivard et al., 2014). In their review of fathers’ perceptions towards parenting a child with a DD, Boyd et al. (2019) conclude that there is still a gap in our understanding of fathers’ experiences of parenting a child with a DD. They propose that future research utilising qualitative methodologies is needed and that this will help to support professionals develop more effective interventions to support fathers and increase engagement within these families. A significant limitation within the existing literature, is that researchers have often

grouped different DDs together. However, in doing this, one risks losing the specific experiences that relate to specific DDs. In looking at the current literature, there appears to be less research that has explored the experiences of parents of children with DS. Furthermore, of the literature that has explored experiences within this population, there has been a tendency to place greater focus on negative experiences, colluding with the often-pessimistic view of what it must be like to parent a child with DS (Cuskelly et al., 2008). In addition, despite research indicating that the transition to adulthood may be one of the most difficult times within the life cycle for those parenting a child with a DD (Cheak-Zamora et al., 2015; Stewart et al., 2014), little research has looked at the experiences of parenting a YA with DS. Although Docherty and Reid (2009) have looked at mothers' experiences of parenting within this population, it cannot be assumed that fathers' experiences will be the same. Furthermore, despite Hudnall (2014) conducting a study within this population, the aims were specifically focused around finding out what goals the parents had for the YA with DS and what helpful or unhelpful resources assisted in achieving these goals. In addition, all but one of the 38 parents recruited to the study were mothers. This highlights the need to still explore fathers' experiences of parenting a YA with DS. Conducting this piece of research will meet the gap in the literature and help us to understand how fathers perceive this developmental stage and illustrate if there are any implications for relevant services.

### **Aim**

To explore the experiences of fathers of YAs aged 18 – 25 with Down's syndrome.

### **Research Question**

The following research question is proposed: What are fathers' experiences of parenting a YA aged 18 – 25 with DS?

## CHAPTER 2: METHOD

This chapter will firstly describe and justify the chosen methodological approach of Interpretative Phenomenological Analysis (IPA). The method will then be outlined, including the study design, sampling, ethical considerations, and procedures, along with justifications for decisions made. Finally, the data analysis process and quality checks utilised are presented, before concluding the chapter with a reflexive statement.

### Methodology

Qualitative research methods seek to understand how people experience specific situations or conditions, and how they make sense of their world (Willig, 2013). Furthermore, they allow us to collect rich, complex, and multi-dimensional experiences, which is crucial when trying to step into the shoes of participants (Mason, 2002).

Given that the aim of the current piece of research was to broaden our understanding of the experiences of fathers in parenting a YA with DS, a qualitative research methodology was deemed most appropriate. Using quantitative methodology was also discounted as a recent systematic review of fathers' perceptions of parenting a child with a DD (Boyd et al., 2019) highlighted that there have been fewer qualitative studies that have focused solely on fathers. Out of the 21 studies that met the inclusion criteria for the review, only six studies were qualitative and included fathers only. This is a limitation of the current literature as fathers' voices are often minimised within the parenting research due to the sample often having a greater proportion of mothers (Davis et al., 2010; Gray, 2003).

Another limitation of the existing qualitative literature is that researchers often group together DDs, rather than exploring experiences relating to a specific DD (Bostrom & Broberg, 2014; Huang, Tsai & Kellett, 2012; Thackeray & Eatough, 2018). In grouping DDs together, less homogeneity is created and the researcher risks losing the specific experiences that relate to different DDs. Thus, in addition to a need for richer and more detailed information to be gathered from

fathers, it is suggested that research should focus on one type of disability. This will enable a more accurate understanding of fathers' experiences within that population.

### **Ontological and Epistemological Position**

Qualitative researchers can hold a variety of epistemological and ontological positions. Whilst ontology asks about nature of reality (i.e., what is there to know?), epistemology is concerned with how this can be measured (Willig, 2013). My own position is that of a relativist ontology, which assumes that there is no single truth or reality. This emphasises the role of interpretation in constructing reality and proposes that the researcher is central to the research process and that an individual's reality is dependent on the subjective interpretations of the researcher (Willig, 2013). Furthermore, my epistemological perspective is that of a phenomenological orientation. In taking a phenomenological position, the researcher's focus is on trying to understand the quality of an individual's experience, and how they make sense of this, rather than whether it is 'really' going on (Smith et al., 2009; Willig, 2013).

### **Interpretative Phenomenological Analysis**

IPA is a qualitative approach that seeks to understand how an individual makes sense of their experiences (Smith et al., 2009), whilst also paying attention to the wider social and cultural context (Willig, 2013). There are three key areas that underpin IPA methodology. These are as follows: phenomenology, hermeneutics, and ideography (Smith et al., 2009).

Firstly, phenomenology relates to the philosophical approach to understanding the lived experience of an individual (Smith et al., 2009). Edmund Husserl, the founder of phenomenology, asserted that phenomenological enquiry is focused on that which comes into consciousness for the individual. Husserl stated that consciousness is intentional, and that consciousness is always focused on something, whether that is a memory of an event, or a tangible object (Smith et al., 2009). Phenomenological research aims to capture the phenomenon as it is experienced, on its own terms, as opposed to using predefined categories (Smith et al., 2009).

The second major influence on IPA is hermeneutics, which is the ‘theory of interpretation’ (Smith et al., 2009). The process of IPA is often described as a ‘double hermeneutic process’, meaning that it involves: firstly, the participants trying to make sense of their world; and secondly, the researcher then trying to make sense of the participants’ meaning making. (Smith et al., 2009). As a result of this dual process, it is important for researchers to acknowledge their influence in the analytic process and on the data. Researchers are strongly encouraged to engage in a process called ‘reflexivity’, which involves documenting one’s personal position, as well as thoughts and reflections throughout the process to enable any influence on the analysis to be transparent.

The third major influence on IPA is idiography. Idiography refers to a commitment to examining the ‘particular’ individual experience (Smith et al., 2009). This focus on detail and understanding of an individual perspective within a particular context explains why IPA studies typically use smaller sample sizes, as it enables the researcher to not lose the detail of the individual experience, whilst also conducting analysis at the group level.

Given that IPA is concerned with understanding individual’s experiences as well as the meaning that is attributed to these experiences (Smith et al., 2009), it was felt that IPA would be the best fit with the aims of the current piece of research.

### **Alternative Methodologies Considered**

Thematic Analysis (TA; Braun & Clarke, 2006) is a common qualitative research method used, and was considered for this research. TA enables the researcher to identify, analyse and report themes within the data. It also allows the researcher to condense a relatively large data set into smaller organised categories or themes (Braun & Clarke, 2006). However, whereas IPA aims to understand both the unique individual experience as well as consideration of any shared experiences or meaning made across participants (Smith et al., 2009), TA focuses only identifying common themes across the dataset (Braun & Clarke, 2006). Thus, TA may result in any nuances within the individual experience being lost. For this reason, TA was disregarded.

Grounded Theory (GT; Glaser & Strauss, 1967) was another method considered. GT aims to discover emerging patterns within the data and use this to

generate new theories. However, given that this research seeks to learn more about individual experiences, rather than linking the commonalities between participants to develop theory, GT was also discounted.

Finally, Discourse Analysis (DA; Potter & Wetherell, 1987) was also considered as a potential methodology. DA focuses on the ways that the participants use language to describe their experiences, as opposed to providing a way of understanding the meaning that individuals make from these experiences. Given that the present study is fundamentally concerned with the lived experience of participants, rather than how language is used, and how experience has been influenced by discourse, IPA seemed better placed to answer the research question of this study.

### **Semi-structured Interviews**

One-to-one interviews were deemed the most suitable method to collect data for this study. Smith et al. (2009) advise that one-to-one interviews can offer the best means to accessing rich, detailed, first-person accounts of an individual's experience.

Smith et al. (2009) do state that other data collection methods can elicit this type of information in the right circumstances, and the use of questionnaires and focus groups were considered for this study; however, were decided against for the following reasons. Firstly, it was felt that a questionnaire would not capture the level of detail that is required for an IPA study. Furthermore, participants may refine and limit their responses in a way that is less likely in a conversational-type interview that is freer flowing and enables the researcher to gather a richer and closer account of the experience. Secondly, it was hoped that fathers may be more willing and comfortable to share their experiences on a one-to-one basis, as opposed to a group situation with people they had not met. In addition, there is a risk that in focus groups, some participants' voices may not be heard, and it can be difficult to capture the individual experience due to the group dynamics influencing the content of what is discussed.

Semi-structured interviews were chosen over structured or unstructured interviews due to wanting to achieve a balance between having a loose structure and focus point, whilst also wanting to be guided by the participants' experience. A

semi-structured interview seeks to combine certain features of a formal interview with those from an informal conversation (Willig, 2013). Thus, there are clear roles of ‘interviewer’ and ‘interviewee’, and the interviewer will have an interview agenda (e.g., an interview schedule or topic guide) to try and ensure that the interview stays relevant to the research question. However, this is intended to be used flexibly, and therefore allows for a more conversational approach, as well as being able to tailor the questions asked to the specific participants’ experience and the language used (Willig, 2013).

## **Method**

### **Design**

A qualitative design was chosen using semi-structured interviews to explore fathers’ experiences of parenting a YA with DS. Interviews were then analysed using IPA, initially at the individual level, before undertaking analysis at the group level to illustrate the similarities and differences amongst fathers’ experiences.

### **Sampling**

Purposeful sampling was used to recruit participants. This is consistent with the aims of IPA, and the hope that this research can offer insight into a particular experience and perspective (Smith et al., 2009). I also carefully considered the homogeneity of the sample and sought to try and ensure the sample was as homogenous as possible. This is important to enable the researcher to explore convergence and divergence within the sample in detail (Smith et al., 2009). In recruiting fathers who have a YA between the ages of 18 and 25 years old, this did invite some heterogeneity into the sample; however, as previously discussed, this age bracket was chosen due to Arnett’s (2000) theory of ‘Emerging Adulthood’, and therefore an expectation that this period will also bring many similarities in terms of experiences during this time. Analysing all participant interviews individually in detail, before moving on to the group analysis allowed for exploration of each individual’s experience, and therefore captured some of the nuances that may have occurred due to any heterogeneity within the sample.

Smith et al. (2009) state that there is no right answer when it comes to sample size for an IPA study. However, it is expected that sample sizes will be smaller, due to the focus on the individual experience. Smith et al. advise that between four and ten interviews would be sufficient for those conducting research as part of a professional doctorate, and thus this was my aim for the current study. I chose to stop recruitment after recruiting nine participants to the study to ensure that I would be able to give enough time and attention in the analysis and write up to each individual experience.

### **Participants**

Nine fathers, aged between 52 and 68 years old, who were parents of a YA with DS were recruited to this study. All fathers described themselves and the young person as: ‘white’, ‘white/British’ or ‘White/Caucasian.’ Seven of the YAs were male and two of the YAs, female. According to their fathers, both female YAs had ‘autistic tendencies’, but did not have a diagnosis of autism.

### **Inclusion and exclusion criteria.**

Table 1 presents the inclusion and exclusion criteria, alongside the rationale for each criterion.

**Table 1: Inclusion and Exclusion criteria**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>	<b>Rationale</b>
Fathers of any age who are a parent to a YA with DS. Fathers may be biological fathers to the young person, or any male who assumes a paternal parenting role to a YA with DS.	If the YA does not have a diagnosis of DS.	This was the primary focus of the study and therefore an essential criterion.



Fathers must have contact with the young person.	If the father does not have contact with the young person.	This is because the research is looking to explore fathers' experiences of 'parenting' this population of YAs, in which 'parenting' requires some contact and involvement with the YA.
The YA must be between the ages of 18 – 25 (plan A; plan B -18 - 35).	If the YA is not aged between 18 and 25 (or 18 – 35 for plan B).	Arnett (2000) identifies the period of 18 - 25 years as being distinct from both 'adolescence' (defined as the period between 10 to 18 years of age), and 'young adulthood' (individuals in their thirties) due to the types of opportunities and life events that typically occur during this time period. Therefore, this age bracket was used to try and retain as much homogeneity as possible. If this was not possible, it was decided to extend this to allow for YAs up to the age of 35.
Understand and speak English as a first or second language.	If the father would require an interpreter to take part in the interviews.	This is because understanding and speaking English is necessary to ensure rich data collection, which is essential for IPA analysis.

Have access to a telephone or videoconferencing to enable interviews to take place remotely if necessary.	Would be unable to take part in interviews over telephone or videoconferencing if the location is too far.	The researcher would not be able to travel to locations too far afield due to limitations of the research budget.
---	--	---

---

### **Parent Consultants**

To ensure that the research is meaningful to fathers of YAs with DS and to those with a DD more broadly, I sought to recruit some parent consultants within this population to help design and shape the research throughout. I recruited two parent consultants (both fathers who have a child with autism) through contacting an assistant psychologist who ran a monthly ‘Dad’s group’ in Wales. The group exists to provide peer support for fathers who have a child with a disability. The two fathers were consulted in the early stages of the project, including support with shaping the research question, the development of the topic guide, reviewing documents and piloting the topic guide. One of their recommendations was that I try to get a sense of how the YA contributes to the family and what they bring that is unique. I had not thought of this before; however, I decided to add this into the topic guide as a prompt question as it felt like a nice way to gather some wider contextual information about the YA and the family dynamics. Their input was extremely valuable in shaping and conducting this research. As a thank you, a donation was made to their chosen charities (Sparkle Foundation in Wales), totalling £75.

### **Interview Schedule**

To facilitate a semi-structured interview, a topic guide was developed that consisted of open-ended questions and prompts to try and generate a rich description of each fathers’ experience. The interview topic guide (see Appendix A) included a few ‘warm-up’ questions to allow participants to ease into the interview, and get used to the style of questions, hopefully enabling participants to feel more comfortable talking freely about their experiences. Five ‘topic areas’ were then included, before suggestions of a couple of closing interview questions.

The topic areas were developed by holding in mind the research question, considering previous literature relating to the current project, recommendations offered by Smith et al. (2009), and conversations with both parent consultants and thesis supervisors to develop and refine ideas. It was decided that the topic areas would invite participants to share their experiences moving through time from birth through to young adulthood, with the hope that this would capture important contextual information that may relate to the fathers' experience of parenting their son or daughter since they have been 18. Finally, I carried out two pilot interviews, one with one of the parent consultants, and another with another Psychologist in Clinical Training (PICT). This was to see how the topic guide was received and whether it facilitated conversation around potentially important areas without being too restrictive.

### **Pilot Interviews**

Due to the parent consultant being a parent to an adolescent son with autism, I slightly tailored my questions to go with his experience. However, this pilot interview was helpful in providing me with confidence that it was okay to ask prompts around more sensitive areas if they were to arise. Furthermore, to consider how to ask questions around disability at the beginning of the interview.

The rationale for piloting the topic guide with a PICT was so that they could role play a father to a YA with DS, and therefore I could use the topic guide as it was. Both interviews acted as a reminder to hold the topic guide loosely and to adapt and come back to certain topics if the participant brings something else to the interview.

### **Ethical Issues**

Ethical approval was sought from The University of Leeds School of Medicine (SoMREC) to ensure that full consideration had been given to the rights of potential participants and to minimise the possibility of harm. This was granted on the 13<sup>th</sup> of July 2020 (see Appendix B for confirmation email). The ethical issues considered for this study are outlined below.

**Informed consent.**

All participants that met the inclusion criteria for this study received information detailing the purpose and nature of the study to enable them to give fully informed consent. They were told what to expect of the interview and given the opportunity to ask any questions before deciding whether to take part. Participants were also told the type of topics that would be covered prior to the interview taking place and were made aware that the write up of the study will include verbatim extracts from participants and that these may also be present in the report if published. Lastly, participants were informed that they did not have to take part in this research.

**Anonymity and confidentiality.**

Participants were informed that interview data would only be only seen by myself and the transcriber. Furthermore, that any identifiable information would be removed, and pseudonyms given, ensuring that the data is anonymised. At the end of each interview, I asked participants if they would like to choose their own pseudonym for themselves and the YA. Only one participant asked that I choose this myself.

**Right to withdraw from the research.**

Participants were able to withdraw their contribution to the study up to one week after the interview date and were reminded that they would not have to give a reason for this. None of the participants interviewed requested to withdraw their data.

**Participant distress.**

In planning this research, it was considered that discussing topics relating to potentially difficult experiences might cause a participant to become upset during an interview. Participants were advised of this possibility in the participant information sheet (PIS; see Appendix C) that they were given prior to consenting to taking part in the research, and they were made aware that they did not need to answer any questions that they did not want and could have a break or terminate the interview at any point.

During the interviews themselves, a couple of participants did become a little tearful when recounting the initial stages of finding out about diagnosis; however, both fathers told me that they had expected this, and did not take me up on the offer of a break and wanted to continue with the interview. At the end of the interview, several of the fathers said that the process had felt very helpful, as they do not usually get the opportunity to talk about their experiences in this way.

### **Data protection.**

Participants were informed in the PIS that all interviews would be recorded on a recording device, and that the interview would be transferred from the recording device as soon as possible following the interview to a secure computer and then deleted from the recording device. As stated in the PIS, all identifiable information was anonymised when transcribed, and transcribers were asked to sign the University of Leeds transcriber confidentiality form prior to having access to participant interviews. Participants were also informed that all other electronic information (such as demographic information) would also be stored in a secure space, and that any information containing personal information relating to the project would be deleted after three years from the completion of the project.

### **Procedure**

#### **Recruitment.**

Recruitment for the study began at the end of July 2020 and ran through to the end of October 2020. Participants were recruited through two avenues: 1) Identified charities and groups for parents and families who have children with DS; 2) Identified charities that support the involvement and work of YAs with DS. Specific names of charities and groups will not be given for confidentiality reasons.

See Appendix D for recruitment documents distributed. The information stipulated the inclusion criteria for the study and asked that potential participants contact me via email if they were interested.

There were three phases to the recruitment process to manage the numbers of fathers coming forward to participate. Each phase consisted of two or three identified charities or support groups. At each phase, the recruitment became more widespread. Therefore, phase one consisted of local recruitment avenues, whereas

phase three involved promoting the research via the national Down's Syndrome Association (DSA).

It was decided that if more than ten individuals did come forward, I would explain that I was recruiting on a first come, first served basis, and therefore only the first ten individuals who expressed their interest would be able to participate in the study.

Two prompt emails were sent at each recruitment phase to ask if the charity or group would be happy to re-share the research information. Four participants were successfully recruited within the first week of commencing phase one of the recruitment process; however, no participants were recruited during phase two. As a result, I decided to move to phase three at the beginning of September. To promote this project through the DSA, I completed a brief research proposal form and explained how I thought the study may benefit people who have DS and their families. The DSA promoted the research twice on their website and on their Facebook page. The remaining five participants were recruited by the end of October 2020.

Any fathers who expressed their interest were asked if they had contact with the young person. All fathers that got in touch met this criterion and were given the PIS detailing the aims and purpose of the study and what was involved, enabling them to make informed consent. Following this, fathers had one week to decide if they would like to take part. If I had not heard anything back following one week of giving out the PIS, I sent a follow-up email to see if they were still interested in taking part. All fathers that expressed interest stated that they would like to take part after reading the PIS, and therefore I proceeded to arrange a suitable date to take consent and carry out the interview.

### **Interviews.**

Due to Government and University guidelines as a result of COVID-19, all interviews took place remotely and participants were asked if they would prefer to have the interview over phone or via video conferencing (e.g., skype, or zoom, or any other application that was permitted under the UoL data protection guidelines). Interviews lasted between one hour and 16 minutes and one hour 57 minutes. All interviews were audio recorded, including verbal consent to take part in the study

which was captured at the start of the interview by asking a series of questions pertaining to the research and reading a pre-agreed script (see Appendix A).

At the start of each interview, participants were reminded that:

- They could take a break or terminate the interview at any point.
- If for any reason they wished for the interview to be terminated, but wanted to continue at another time, this could be arranged.
- They did not need to answer any questions they felt uncomfortable with.
- Any identifiable information would be removed from the transcripts.
- They could withdraw their interview data up to one week after the interview had been conducted.
- Whilst most of the interview would be focusing on experiences since their son or daughter has been 18, that I would first ask some questions about experiences leading up to this age for context. This information had also been explained to participants over email when agreeing on a date and time for interview.

Participants were also given the opportunity to ask any questions prior to the interview starting.

During the interviews, the topic guide was used flexibly dependent on fathers' responses to the questions asked. I used prompts where necessary to support fathers to elaborate on their responses or to gather more specific information relating to what had been shared. If a participant started talking about experiences of young adulthood straight away, I tried to follow this where possible; however, was mindful to come back to ask questions later to gather enough contextual information to help make sense of their experiences. At the end of the interview, participants were asked about any demographic information that had not already come up in the interview. They were also asked if they would like to receive a summary of the research findings upon completion. All fathers said that they would.

### **Transcription.**

All interviews were audio-recorded and transcribed, including the non-semantic content (e.g., pauses, laughter, signs, umms, repetitions). I transcribed the first interview myself and the remaining eight interviews were transcribed by a

university approved professional transcriber. Upon receiving each transcript, I re-listened to the interview and checked to ensure the accuracy of the transcription. Any amendments were then made if necessary. I also ensured any identifiable information was removed, and that pseudonyms were used consistently throughout the transcription.

### **Data Analysis**

The interviews were analysed using the six stages recommended by Smith et al. (2009). Smith et al. describe the process taken in IPA as both iterative and inductive, meaning that the researcher will explore the transcriptions in detail, re-reading the data many times, and in doing so, aim to ensure that any interpretations have been driven from the data. I attended In-House IPA training through the University of Leeds, which consisted of two planning meetings and two analysis meetings (around 16 hours in total) and provided additional support and guidance for using the IPA methodology. During this process, I added any reflections in my reflexive diary (see 'Reflexivity' section below) and used thesis supervision as well as support from peers also using IPA to discuss progress at each stage. Each interview was analysed individually before moving on to the next participant. Group analysis only took place after completing all individual analyses.

#### **Step 1: Reading and re-reading.**

The first stage of analysis involves building familiarity with the data. I created a table with three columns, and pasted the transcript in the middle, allowing for exploratory comments and reflections to be made on the right, and comments relating to emergent themes to be made on the left. After listening to the audio-recording to check the transcript for accuracy, I then re-listened to the recording and read and re-read the transcript and made notes of any reflections or recollections from the interview. I then organised the interview data according to three categories by highlighting the transcript as follows: grey (off-topic, but possibly useful context), blue (on-topic, experiences since the young person has been 18+), and yellow (key quote/feels important). I also started to create a pen portrait to provide context to situate the findings, and to capture some of the participant's unique experience.



**Step 2: Initial noting.**

I then began conducting a line-by-line analysis of the transcript, making notes with three separate foci: 1) Descriptive comments (i.e., general comments, key phrases said); 2) Linguistic comments (i.e., use of metaphor, repetition, laughter, intonation); and 3) Conceptual comments (i.e., thoughts on the possible meaning behind what has been said by drawing on psychological knowledge as well as own life experience). See Appendix E. for an example from one of the transcripts. I re-listened to the audio recording during this stage to ensure that the comments seemed to fit with what had been said, and *how* the participant had said it. I then shared these initial ideas during thesis supervision to see if my supervisors thought they made sense and matched their interpretation from the data.

**Step 3: Developing emergent themes.**

After completing step 2, I re-read all exploratory comments and began to develop emergent themes by incorporating the comments together in a way that tried to capture the experience for the individual. After completing individual analysis for the first couple of participants, I decided to put these emergent themes into an excel spreadsheet and simultaneously copy over the corresponding quote. This enabled me to print these out together which helped in making sure that my ideas were grounded in the data.

**Step 4: Searching for connections across emergent themes.**

At this point, I cut out all emergent themes and corresponding quotes and began mapping these out into superordinate and subordinate themes on a table. I took photos and shared these ideas with my thesis supervisors at various points during this process, refining my ideas until I felt that I had found the ‘best fit’ for what I felt that participant was experiencing. An example of this can be seen in Appendix F.

**Step 5: Moving to the next case.**

I then repeated steps 1 to 4 with each participant, before beginning the group analysis. Whilst it is not possible to completely shut off any thoughts or ideas that have already arisen during the analysis process with previous participants, as encouraged by Smith et al. (2009), I tried to bracket off any pre-conceived ideas, to

ensure that every participant was respected for their individuality. Using my reflective journal was helpful in being aware of my thoughts and how they may be impacting on the way that I was analysing the data.

### **Step 6: Looking for patterns across cases.**

After completing all nine individual analyses, I read through each participant's themes several times and looked to find any similarities between participants, and whether any themes might fit together under a new superordinate theme, or if any subordinate themes might be re-clustered to capture a shared experience amongst the group. I then mapped these ideas onto a table, first adding my ideas of the group superordinate themes, and then adding on the subordinate themes from individual analyses until all experiences were captured on the table. See Appendix G for an illustration of this process. I then made a tally of how many participants had experienced each subordinate theme. I decided to leave out any experiences that only came up for maximum of three participants, due to wanting to ensure that the group analysis captured the majority of fathers' experiences. However, any experiences that only applied to three participants or fewer were included in the pen portraits, alongside any individual experiences that diverged from the group analysis.

Again, I took photos of my ideas and shared these with my supervisors, collapsing and renaming subordinate and superordinate themes several times until I felt that the group analysis provided a clear representation of how I had made sense of the fathers' experiences. To support in my own sense-making, I created a conceptual map of how I perceived these experiences. This was also updated and refined throughout this process and is presented in the results section.

### **Individual and group analysis.**

Only the group analysis will be presented in the results due to analysis revealing that many of the experiences were shared amongst the fathers interviewed, despite there also being differences in the quality of these experiences. The group analysis hopes to illustrate both the shared experience as well as recognising the differences amongst the group. Individual experiences that feel unique to participants will be discussed separately in the pen portrait section of the results.

## Quality Checks

Quality checks are an essential consideration for maintaining good quality IPA research. Therefore, to ensure that the current piece of research is reliable and valid, I referred to the guidelines proposed by Yardley (2000) and Elliot, Fischer and Rennie (1999). Elliot et al. outline the following seven criteria for qualitative studies: ‘owning one’s perspective’, ‘situating the sample’, ‘grounding in examples’, ‘providing credibility checks’, ‘coherence’, ‘accomplishing general vs. specific research tasks’, and ‘resonating with readers.’ In addition, Yardley proposes four principles for IPA researchers to use flexibly as a guide: ‘sensitivity to context’, ‘commitment and rigour’, ‘transparency’. and ‘impact and importance.’ Table 2. illustrates the quality checks implemented in the present study.

**Table 2: Quality checks implemented to meet the guidelines offered by Yardley (2000) and Elliot, Fischer and Rennie (1999)**

<b>Guideline</b>	<b>Steps taken by researcher</b>
Owning one's perspective <i>(Elliott et al., 1999)</i>	I have tried to be transparent about my own perspectives, thoughts, and feelings towards this research and in response to the interviews. I have included a reflexivity statement which acknowledged my own experiences of having a father, as well as prior experience supporting a YA with DS. Keeping a reflective diary throughout this process was extremely helpful in capturing personal reflections prior to and following each interview, and during data analysis, so that I could be aware of these when analysing and writing up the results. I also used this to note any conversations and reflections around decisions that arose out of supervision. I have recorded some of these reflections in the write up of the results.
Situating the sample <i>(Elliott et al., 1999)</i>	A detailed pen portrait about each participant has been included to provide contextual information for the findings. In addition, I have

provided an overview of the sample and key demographic information that helps the reader to situate the sample.

- Grounding in examples  
(*Elliott et al., 1999*)
- Quotes have been provided in both the pen portraits, and group analysis to provide evidence for each theme. I have also included a table that illustrates whether themes were present or absent for individual participants to enable the reader to make sense of how these experiences were shared amongst the group.
- Providing credibility checks  
(*Elliott et al., 1999*)
- I utilised supervision at regular intervals during which I shared full transcripts and sections of data at different stages of analysis. This enabled me to gather my supervisors' perspectives on how the data may be interpreted, as well as their thoughts on my exploratory comments and discussion of individual and group themes. Examples of different stages of the analysis process are presented in the appendices.
- Transparency and coherence  
(*Elliott et al., 1999, and Yardley, 2000*)
- I have sought to achieve transparency by providing detailed accounts of each stage of the research, including the design, recruitment procedures, interviews, and data analysis. I have also incorporated into the results chapter a conceptual map to illustrate how I have made sense of the findings. I have used verbatim quotes to hopefully show readers how these interpretations and themes have arisen from the data.
- Accomplishing general vs specific research tasks  
(*Elliott et al., 1999*).
- The results suggest that there are some similarities in fathers' experiences of parenting a YA with DS; however, it is important to recognise that only nine fathers were interviewed, and the intention of IPA research is not to generalise the findings. Therefore, I have tried to highlight individual experiences throughout the write up of the research, so that readers can recognise that any conclusions can only be applied to the population included.

Resonance with readers, impact and importance <i>(Elliott et al., 1999 and Yardley, 2000)</i>	<p>I designed the study alongside two parent consultants. This included developing the final research question, topic guide and piloting the interview. This involvement was key in trying to ensure that the research is important and meaningful to its readers.</p> <p>Furthermore, to the best of my knowledge, this is the only study that has explored fathers' experiences of parenting a YA with DS.</p> <p>During the interviews, when asked what attracted them to the research, many fathers expressed that they had never been invited to do anything similar, or that the focus on parenting has generally been on mothers. This was one of the main reasons for conducting this piece of research and therefore highlights its importance and hopefully benefit to potential readers. In addition, through immersing myself in the analysis process, I have tried to capture as close as possible, the entirety of fathers' experiences, including those which may be difficult to express.</p>
Sensitivity to context <i>(Yardley, 2000)</i>	<p>In analysing the data and writing up the results and discussion, I have carefully considered the fathers' contexts and maintained an awareness of how these may influence the experiences vocalised.</p> <p>To support the reader, I have tried to weave in demographic information and specific details within the write up of the group analysis where it feels important in understanding their individual experience.</p>
Commitment and rigour <i>(Yardley, 2000)</i>	<p>This has been evidenced through my commitment to the research process, including the planning of this study, and dedication to following the step-by-step analysis process suggested by Smith et al. (2009). I also attended additional in-house training to ensure that I was able to collect the right type of data and analyse the interviews beyond providing a superficial understanding of the data.</p>

---

## **Reflexivity**

As previously discussed, it is necessary when conducting IPA research to acknowledge how the researchers' own beliefs and pre-conceptions can influence the analysis process due to the double hermeneutic (Smith et al., 2009). As a result, I have included a reflexive statement below stating my own pre-conceptions of fatherhood and of YAs with disabilities to enable the reader to recognise my position to support in the transparency of the findings. I have also incorporated some reflections throughout the results chapter which I noted in my reflective diary during the interview and analysis process and discussed during supervision.

### **Reflexive statement.**

I am approaching this piece of research from the position of a 29-year-old female with my own experiences of having a father. Having lost my mum to cancer when I was 15, my father has been my only parental role model for some time. In addition, at the time I was conceived, my mother had been given only two years to live following surgery from a brain tumour. Therefore, at the time, my father had made the joint decision that he would like them to go through with the pregnancy and planned to raise me on his own. I am aware that this experience will have likely shaped my own beliefs about fatherhood, perhaps towards an assumption that fathers do wish to be more involved in raising their child. I recognise that some fathers may or may not have planned to have a child and may or may not have considered their views surrounding having a child with a disability. This is something I tried to hold in mind when conducting the interviews.

In addition, both prior to starting on the Clinical Psychology Doctorate and whilst on the course, I have worked with both families and young people with disabilities. My first support worker role involved being assigned the key worker to a YA with DS in a supported living service. I remember the mother to this individual telling me that she hoped her daughter would settle into independent living as she feared that she was getting older and worried about what her daughter would do when she was no longer around. I am aware that this role may have influenced my thoughts on the focus of parenting during this developmental period, and perhaps left me with an assumption that this might be a view of most parents of YAs with DS. I tried to be mindful of these prior experiences and interactions when designing

the topic guide and ensuring that I remained asking open-ended questions during the interview so that fathers could discuss their own experiences and thoughts relating to young adulthood, rather than being drawn in to asking leading questions, based on my own pre-conceptions.

## CHAPTER 3: RESULTS

This chapter presents the findings from the research. Firstly, an overview of participants interviewed will be presented, along with a ‘pen portrait’ for each individual, and general reflections on the interviews as a whole. The pen portrait provides contextual information for understanding the group analysis. The group analysis will then be presented, offering a detailed description of each superordinate and subordinate theme, and is supported by verbatim extracts from participants. ‘Reflexivity boxes’ have been included to incorporate some of my own reflections during this process.

### Overview of Sample

Nine fathers aged between 52 and 68 years old who were parents to a YA (aged 18-25 years old) with DS were interviewed for this study. Demographic information that helps place fathers’ experiences in context is provided in Table 3 and Table 4. This includes age, marital status, living arrangements and occupation for the father, and age, sibling order, occupation, marital status and living arrangements for the YA.

All fathers described themselves and the young person as: ‘white’, ‘white/British’ or ‘White/Caucasian.’ All fathers had at least one other child (number of children in each family ranged between 2 and 4) and were all married to the mother of the YA discussed in the interview. None of the siblings had any developmental difference.

Seven of the YAs were male and two of the YAs, female. According to their fathers, both female YAs had ‘autistic tendencies’, but did not have a diagnosis of autism. None of the YAs had any children of their own.



**Table 3: Demographic information of fathers**

<b>Participant pseudonym</b>	<b>Age</b>	<b>Marital Status</b>	<b>Living Arrangements</b>	<b>Occupation</b>
Jimmy	68	Married	With wife and Richard	Employed
Brook	59	Married	With wife and Elizabeth	Employed
Robert	57	Married	With wife and Michael	'Full-time Dad'
Benny	58	Married	With wife and Frankie	Employed
Harvey	52	Married	With wife and Herbert	Employed
John	58	Married	With wife and Frank	Employed
Peter	58	Married	With wife and Tamara	Employed
William	60	Married	With wife and Gabriel	Employed
Jon	52	Married	With wife only	Employed

**Table 4: Demographic information of young adults**

<b>Young Adult pseudonym</b>	<b>Age</b>	<b>Sibling Order</b>	<b>Occupation (pre-lockdown)</b>	<b>Marital Status</b>	<b>Living Arrangements</b>
Richard	19	Youngest sibling	Unemployed	Single	At home
Elizabeth	19	Youngest sibling	Unemployed	Single	At home
Michael	18	Eldest sibling	Unemployed	Single	At home
Frankie	21	Youngest sibling	Part-time Barista	Relationship	At home
Herbert	19	Eldest sibling	Part-time in restaurant	Single	At home
Frank	22	Eldest sibling	Unemployed	Single	At home
Tamara	24	Youngest sibling	Kitchen Technician	Relationship	At home
Gabriel	18	Youngest sibling	Unemployed	Single	At home
Thomas	24	Eldest sibling	Unemployed	Single	Supported accommodation

## Pen Portraits

This section provides an overview of each of the nine fathers interviewed for this study and aims to provide contextual information helpful for making sense of the results. I will present the fathers' reasoning for taking part, a brief snapshot of their experience of finding out about diagnosis, and a summary of any experiences that felt important pre- and post-18 years of age. An attempt has also been made to capture any key experiences that diverged from the group analysis. Quotes used from interviews with participants will be presented in *italics* and with quotation marks.

### Participant 1: Jimmy (Son: Richard)

Jimmy's interest in taking part was that he had "*never been invited to anything similar*" (line 100) or had the opportunity to do so. He also shared that he had a "*sympathy for [my] need as well*" (line 111) due to conducting his own research previously.

Jimmy explained that he and his wife had not had any pre-natal tests and that it was "*a real shock*" (line 375) when they found out that Richard had Down's syndrome. Jimmy described an initial thought that "*a monster's been born*" (line 384), before realising that "*no, I've got a beautiful little Down's baby*" (line 389).

Jimmy described difficulties in finding the right schools for Richard and having to adjust their expectations of initially wanting Richard to go to a mainstream school. Jimmy said that Richard ended up going to a special school, and "*that was one of the best thing's that has happened to him*" (line 736). He felt this was "*good for his quality of life, the quality of his education, and also, you know, good for making friends*" (line 760).

Jimmy described there not being much change since Richard turned 18; however, they have started to think "*what is the next step?*" (line 1231). He said that part of this transition has been helped by one of Richard's best friends having "*already gone to this, this college*" (line 1271) that Richard will be going to. Jimmy shared that he does not feel that Richard has "*any concept of, of the future*" (line 994), and that "*he's just...happy as he is*" (line 995).

Jimmy described his current father roles as: “*food provider*” (line 1825), “*setting a good example*” (line 1886) and “*partly, being a friend*” (line 1893) to Richard. He shared that they “*still spend a lot of time throwing stones into water*” (line 1506).

When thinking about the possibility of semi-independent living, Jimmy stated that “*it would be a massive, a massive change*” (line 2376) and said: “*I’d worry...I worry...that he wouldn’t miss me.*” (line 2268).

Throughout the interview, Jimmy referred to stories he had been told by others, and the importance of certain people and professionals in Jimmy’s life “*who’ve had a significant a significant input*” (line 2398), and “*probably, well definitely, lifting our expectations, rather than lowering them*” (line 2412).

### **Participant 2: Brook (Daughter: Elizabeth)**

Brook was attracted to the research because he likes to be “*forward thinking*” (line 108) and likes to “*see people interested in this sort of thing because there’s very little out there*” (line 109).

Brook shared that he had “*always wanted to be a fa-a daddy*” (line 236). He and his wife were made aware that Elizabeth had several health complications and had greater chances of having Down’s syndrome at the first pregnancy scan; however, believe that: “*Life is life, whatever it is. Life is life*” (line 452). Brook described what sounded like a very difficult and traumatic start to Elizabeth’s life – having to have heart surgery, amongst other things, and being in and out of hospital.

Brook expressed difficulties doing the right thing by Elizabeth and shared: “*we’ve not done the right thing for her at all in, in, in the umm, in the schooling side*” (line 563). He and his wife wished that Elizabeth had gone to a special school from the start as “*she’d have got more input into er, what she needed*” (line 734).

Brook described his wife as the “*main carer*” (line 1677) and explained that he had taken a “*24-hour job particularly so I could support her in all this*” (line 1699). He described having a good relationship with Elizabeth, and that they “*play swords and we play ball quite a bit outside, and she always calls me if there’s a technical problem*” (line 1372).

Brook explained that *“it’s a stressful time at the moment”* (line 1185) when discussing what decisions need to be made regarding college and thinking about the possibility of supported accommodation. However, that, Elizabeth *“doesn’t want to grow up”* (line 1579) and was *“not wanting to move out or do anything of that nature”* (line 2180).

Brook explained that Elizabeth is *“quite vulnerable”* (line 904) and gets *“all the colds going”* (line 900). It was clear how much COVID-19 had impacted on the family in terms of thinking about Elizabeth’s future: *“we’ve got to just keep on going, basically through this damn pandemic and umm, keep her safe”* (line 1828).

### **Participant 3: Robert (Son: Michael)**

Robert’s reasons for wanting to take part were firstly, wanting Michael to be *“accepted into society”* (line 102). Secondly, to *“help other families through our experience”* (line 135), and thirdly, *“hopefully widening experience among professionals”* (line 140).

Robert described the birth as a *“very upsetting and tough time”* (line 354), and it was not till a couple of days later that the hospital told them they had *“serious concerns”* (line 347) and that Michael had Down’s syndrome. Robert shared that Michael was *“a fantastic little baby and we had a very good time with him”* (line 386); however, he also described wondering what this meant for their future.

Robert explained that when Michael was one, he stopped working to become Michael’s *“main carer”* (line 2803) and supporting Michael *“became a huge focus on our life”* (line 799). Robert felt that in contrast to their original beliefs, Michael has been able to achieve most things they would have hoped for by this age. Robert shared that *“turning 18 . . . does bring. . . an element of newness in that he’s well aware that being 18 is a milestone and that when you’re 18 you have [chuckles] more of a say in things”* (line 1384). Robert shared that one of his difficulties is *“seeing Michael as not being 18, and not being as independent as he thinks he is and he wants to be, and I want him to be”* (line 1745).

Robert said that independent living is *“something that, that is what he. . . he wants to be, and he gets a lot of pri-pride out of”* (line 675) and that it will also be good for him and his wife *“as we start thinking about retirement and doing things*

*that we want to do” (line 664). However, there was a concern that COVID-19 will have impacted on their progress: “it does feel like he’s missed a big chunk of stuff. . . and has probably forgotten a lot of the things that were...starting to come along.” (line 992). “Hopefully umm, he hasn’t completely umm, lost the confidence about going into shops and buying things” (line 998).*

#### **Participant 4: Benny (son: Frankie)**

Benny told me that *“of all the opportunities I’ve ever had to-to to, to partake, I never have. And I just thought maybe it’s time to, to do something as a dad because, you know I’m sure it’s fair to say dads are, traditionally with Down’s Syndrome, been a little bit, I don’t know; their views and feelings have been a little bit overlooked” (line 94).*

Despite having no prenatal tests, Benny said that he had been thinking *“quite a lot” (line 335)* about Down’s syndrome before Frankie was born. Benny said that *“it didn’t worry me” (line 361)*, but that finding out was still a traumatic time, and he *“didn’t bond with Frankie initially” (line 776).*

He told me how he has received counselling, (not related to Frankie); however, felt that this *“has given me better insight into those emotions” (line 1584)* and *“the fact that I’ve been quite open with you is probably a little bit to do with the fact that I’ve already expressed a lot of this stuff” (line 1587).* Benny told me early on how he may get emotional during the interview, but states *“it’s actually because. . . I wished I’d have known then what I know now” (line 502).*

Benny described that it has been *“one achievement after the other in terms of things we’d never thought he’d do” (line 852)*, and that this has continued into adulthood. Benny shared that, since 18, from a practical point of view, things are *“still challenging and, and tough sometimes but things are. . . generally er, a lot easier” (line 1667).* Benny shared that *“a turning point was [Frankie] legally being able to have a drink. Then we started going for a pint together, and then we can go to a gig and have a drink together” (line 2188)*, and through *“shared interests” (line 2205)*, they’ve become *“closer and closer umm, as a father and son” (line 1684).*

Benny said that they do *“talk to Frankie about” (line 1986)* the future and envisage that *“he’ll have a job” (line 1988)*, and *“he will live in, in some sort of*

*supported accommodation*” (line 1989). However, Benny, shares that he does worry, *“not just how I’d cope; how would he cope”* (line 2022).

### **Participant 5: Harvey (Son: Herbert)**

Harvey’s reason for wanting to take part in this research was very practical: *“I just saw it and, you know I’m a father of a young person with Down Syndrome. So, I thought, ‘W-why not?’”* (line 94).

Harvey said that having children *“was just a natural progression”* (line 165) after getting married. They found out that Herbert had Down’s syndrome *“postnatally”* (line 218), and Harvey vocalised feeling *“angry with everybody who said ‘sorry,’”* (line 419). He identified that *“I think that was just easier to be angry with them um, you know it was quite a good outlet”* (line 414).

Harvey described that *“there have been so many milestones”* (line 602), *“and it never occurred to us that he shouldn’t do these things, so, he’s just done them”* (line 607). He also described Herbert as being, a *“constant for all of us”* (line 713) and added that he *“probably brings out the best in all of us too”* (line 714).

Harvey said that *“there hasn’t been sort of a huge pivot post-18”* (line 1451) but thinks that *“when he finishes at college”* (line 1459) will be a *“bigger jump”* (line 1468). He said that *“the bureaucracy changes”* (line 1314) and the *“money side of it”* (line 1302) changes, but they have not had any issues yet. A big fear seemed to be *“losing as much influence”* (line 2189) on Herbert, and gave the example that *“medically now, we’re not the final say, are we?”* (line 1310).

Harvey spoke about recognising that Herbert *“has limitations”* (line 1632), but that *“if he’s shown how to do the things properly and slowly, in his own time, then he will pick them up”* (line 1629). He expressed concerns around supported living and said he *“would be a bit more selective”* (line 2295). However, that they *“know other people who are in that process, and-and the young adults love it so, er, I think we would have to let go a bit”* (line 2296).

Harvey shared that he has not taken much advice as a father, but that *“one thing I will take advice on”* (line 2505) will be *“finding the right words which [Herbert] will understand”* (line 2509) *“if he chose to be sexually active”* (line 2415).

### **Participant 6: John (Son: Frank)**

John expressed wanting to take part because: *“I don’t often get the chance to do this” (line 154)* and *“talk about my views of this kind of thing! (line 155)*. Additionally, he described seeing it as *“an opportunity to, to hopefully, I don’t know, maybe help other people” (line 162)*.

John explained that they did not find out that Frank had Down’s syndrome for three weeks after the birth because his blond hair *“created quite a stir in hospital” (line 203)* due to both mum and dad being dark-haired. John described how this gave them *“a different start on life” (line 220)* as *“we had Frank who then, we discovered had Downs.” (line 215)*. John said that *“we’ve just tried to keep it as normal as possible really! He, he’s attended mainstream school most of his life. He’s at an agricultural college now” (line 356)*.

John described how *“the Mums network more and so they find out about ... things like the benefits and what you can do and what you should say to medical professionals and all of this kind of thing” (line 395)*, whereas *“I don’t think Dads share that kind of stuff and I think that’s one of the things that I, I wish I’d done more of” (line 399)*.

He shared that Frank is: *“hilarious! He cracks us up! You know his humour is just ... bone dry and just fantastic.” (line 1204)*. He explained how Frank is into puppeteering and *“we have a lot of fun with that kind of stuff” (line 1264)*. John mentioned that generally, they *“try to see the positive in stuff rather than the, the negative stuff” (line 1372)*, *“and the negatives are usually around ... em ... next stage of the future and the bureaucracy as I say that surrounds him” (line 1377)*. He explained they are *“trying to think of, of, of where we can go and what we can do to ... em help Frank have em a fuller, meaningful life” (line 851)*.

John described how he and his wife *“haven’t got anyone that we can rely on” (line 543)* for support, and therefore they *“have to do things separately sometimes” (line 585)*. He articulated worrying about *“what happens over the next 10 years?” (line 615)* and not wanting to put the *“burden” (line 844)* of responsibility onto his younger son.



### **Participant 7: Peter (Daughter: Tamara)**

Peter replied: *“I assumed that I was helping you”* (line 97) when asked what attracted him to the research project.

They found out that Tamara had Down’s syndrome *“on the day she was born”* (line 178), although had some indications from previous scans, *“so it wasn’t a complete surprise”* (line 181). Peter said that he did not really have any specific memories from this time, as that there’s *“not much difference in babies at that stage”* (line 189).

Peter described several achievements of Tamara’s, including: *“the Duke of Edinburgh”* (line 269), the *“special Olympics”* (line 278) and *“loads of charity stuff”* (line 509). He mentioned that, whilst not diagnosed, Tamara is *“on the [autistic] spectrum. She likes to line things up and... she doesn’t like anything new”* (line 408). Peter shared that this is *“very mild”* (line 439) and joked that *“she might have inherited that from me”* (line 431) or his wife.

Peter shared that he works a lot, and his wife *“more of less sort of looks after Tamara full time”* (line 516). He explained that his *“wife has built all sort of things to allow her to go along”* (line 527) and accommodate *“Tamara in society”* (line 518). Peter described how they try to eat together, but that his role is *“mainly driving [Tamara] places”* (line 966) when his wife has put this in his diary.

He described how they tried to *“organise it so [Tamara] could go and share in a shared house”* (line 566) with her friends, but this fell through. Peter hoped that this *“would have been a very good solution”* (line 593) to the issues they found in residential living. Whilst Peter stated that *“it’s not really a problem”* (line 574) that Tamara still lives at home, he expressed that: *“I think respite care is something that people ought to have in this situation, because you forget what life was like before”* (line 610).

Peter described parenting Tamara since she’s been 18 as *“just like the same as all the others”* (line 692). *“She’s the one that’s going to be around when I’m gone, so er. Yeah, better make life as good as we can for her, so if I’m gone tomorrow she’s well set up and all the rest of it”* (line 716).

### **Participant 8: William (Son: Gabriel)**

William described wanting to take part because of some of the challenges they have experienced in *“bringing up, um, a child with a disability”* (line 103). He added: *“You get people without the direct experience of bringing up a child with special needs, giving you advice, that's always quite difficult because they aren't walking in your shoes.”* (line 112).

William shared that he always saw himself *“having a family”* (line 282), and that they didn't have any pre-natal tests with Gabriel because his wife's values were *“I'm going to have this child whatever”* (line 306). Therefore, finding out that Gabriel had Down's syndrome *“was a shock”* (line 312). He described how *“you're sold the dream that your child will be the centre and the reality is somewhat, somewhat different from that”* (line 126).

William described that in terms of Gabriel being an adult, *“there's been no change”* (line 231). However, that it *“drew into focus”* (line 235) certain things *“because his legal status changed”* (line 235). William also shared that *“one of the challenges is trying to teach him those social boundaries. And trying to teach him in a way that doesn't, um, hurt his feelings”* (line 193). He expressed difficulties having *“a child whose emotional development is not where it needs to be for that sort of transition”* (line 1269).

Whilst open to exploring *“limited residential stuff to give him some preparation for adulthood”* (line 419), William shared that *“I'd rather I'd rather have him at home and we bring the care to him, rather than place him out in society because the risk is too great”* (line 445). William described how he and his wife have had *“conversations about Gabriel and his future”* (line 796) over dinner; however, have not been sure if Gabriel has understood as, whilst his expressive language is not great, his receptive language is better.

William expressed that: *“the most important thing is, giving him some sort of purpose, and some sort of self-worth”* (line 975), and that there are *“things on the bucket list”* (line 1185) that he is looking forward to doing with Gabriel when COVID-19 is no longer restricting, such as: *“take him to the pub and buy him a pint”* (line 1172), *“go to a football match”* (line 1180), and do *“a parachute jump”* (line 1183).

### **Participant 9: Jon (Son: Thomas)**

Jon was attracted to take part in the research because, you don't get asked *"Dads' views on having children with Down, Down syndrome. A lot of things that are focused on, on the Mum which is understandable I suppose"* (line 104).

Jon told me that it was *"quite traumatic"* (line 145) finding out that Thomas had Down's syndrome, and *"not what we were expecting"* (line 146). He described that you almost think it is one of the *"worst things that can happen"* (line 158), but then *"when you sort of live it, you realise it's not! It's probably one of the best things!"* (line 159).

He shared that *"it hasn't been easy"* (line 428) going through education and learning to *"understand his feelings"* (line 430), but that *"he's come a long way"* (line 433) and has achieved a lot. Jon mentioned that parenting has *"been a lot easier"* (line 715) since Thomas has been 18 because he has *"calmed down"* (line 716), which he feels *"was just maturity"* (line 717) but enables them to *"do more things together as a family"* (line 925). He told me that going to residential college at 19, *"was really good for [Thomas]"* (line 733) as he gained *"a bit more confidence"* (line 742).

Thomas now lives in supported living (coming up to 2 years). Jon described how they *"used to do everything together"* (line 468) before Thomas moved out. However, feels that *"he's doing the right thing! He's going to, you know, pick up all these new skills and it was the best place that he could go"* (line 493).

Jon described that as a result, his role has shifted and is now *"less as a carer"* (line 1151); however, *"we spend more time I think organising. . . to make sure that things are set up that he can go and do them!"* (line 1153). Jon commented that his relationship with Thomas is *"still really good"* (line 515) and they *"try to do things together as much as [they] can"* (line 516). He expressed that it *"is a bit of a shame"* (line 1595) that things are so complicated to *"to get [Thomas] into places or the support that he needs"* (line 1546); however, he is *"used to it"* (line 1577) now.

**Reflexive Box 1.** Reflections on the interviews.

One of the things that I really appreciated in interviewing these fathers, was that I genuinely felt that they all tried to be as honest with me as they could. This included some of the fathers sharing with me thoughts and feelings that they had not shared with their wives. Understandably, talking about thoughts and feelings comes easier to some people than others, and I did notice that some fathers found it quite hard to stay talking about thoughts and feelings around more difficult topic areas.

I also noticed a tendency for fathers at times to offer their wives' thoughts and feelings towards a situation rather than their own, and therefore, at points, I needed to try and encourage them to share how *they* felt, if they were able. I wondered whether this was related to something that a couple of fathers had shared during their interviews, around *their* feelings not mattering, and feeling that their role was to support their wives. A couple of fathers also spoke about just needing to be practical and '*get on with things*', and again, I wondered if this meant that this way of talking about and reflecting on experiences may be quite different to what these fathers are used to.

A couple of fathers asked me questions during the interview like, '*I'm sure you've heard this before?*' and I got the sense that perhaps they were hoping for some validation and reassurance, and possibly hoping that others were going through similar experiences.

In hearing the fathers speak about their experiences, I was struck by some of the conflicting thoughts and feelings that arose in relation to considering the next steps, particularly, supported living. In thinking of my position and my own biases due to previous experience, I feel that my thoughts around these next steps were quite naïve, in that my assumption was that all fathers would be rooting for independent living, whereas the reality is a much more complex picture.

**Reflexive Box 1.** (Continued).

It was difficult hearing fathers speak about some of their challenges, particularly when I heard fathers question whether they were doing a good enough job. I noticed on a couple of occasions that I went into ‘rescue mode’ to try and make the situation feel better in some way. For example, after Brook shared his feelings of not being very good at making money, I responded by saying: “*yeah, I-I guess I don’t know how true that is, but I think we can only ever try do. . . do our best*” (line 1999). On reflection, this may have inadvertently shut down some of the thoughts and feelings they may have felt able to share had I been able to keep a more neutral stance.

Lastly, I was mindful prior to interviewing, of the impact that COVID-19 may have had on fathers’ experiences. However, overall, COVID-19 did not feature that frequently during the interviews. I wondered if that reflected the extent of what fathers already had going on at this time in considering this next stage of their son or daughter’s future. Or whether this was due to fathers not previously having opportunities to talk about their experiences of being a parent and therefore they had a lot of other things they wanted to say. Understandably, for a couple of fathers, COVID-19 has appeared to have had more of an impact, and therefore this did feature more during these interviews; however, this has been discussed in the relevant pen portraits above.

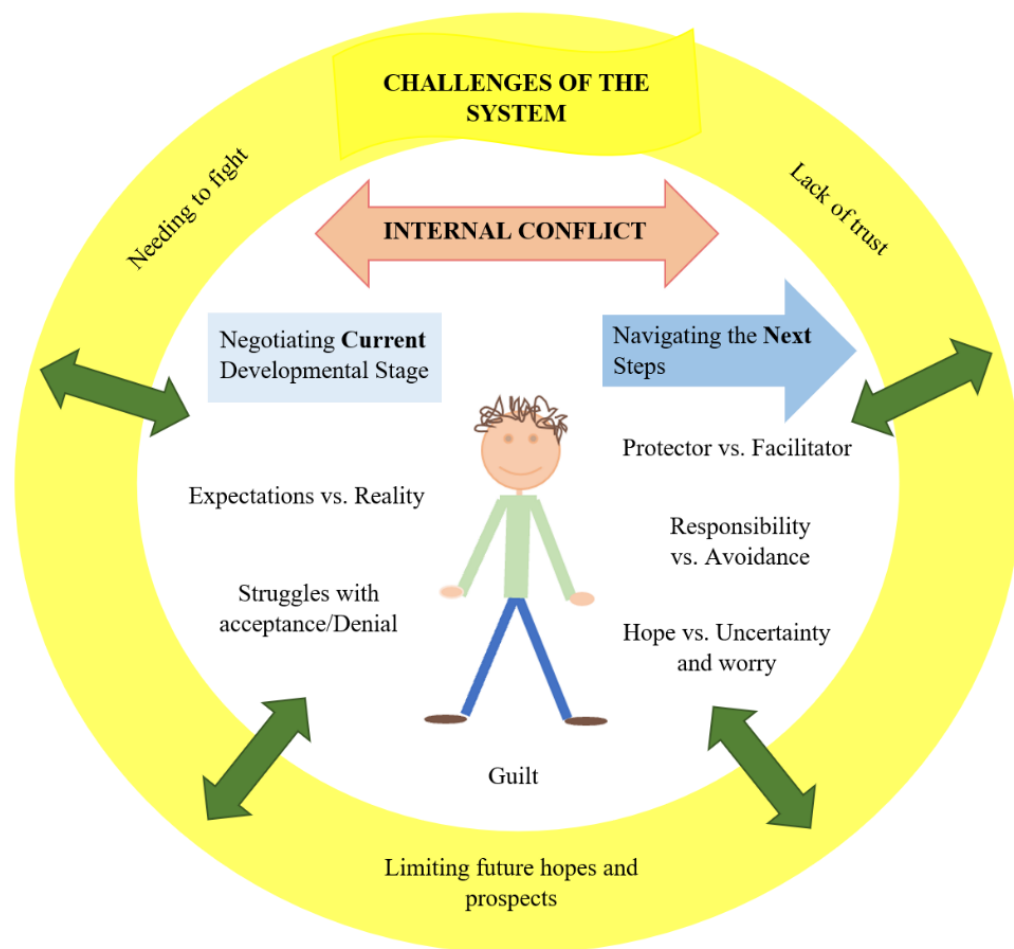
### Group Analysis

The following section presents the findings from the group analysis, which resulted in three superordinate themes and ten associated subordinate themes within these. The three superordinate themes are represented in bold and are as follows: **‘Internal conflict: negotiating current developmental stage’**, **‘Internal conflict: navigating the next steps’** and **‘Challenges of the system’**. The subordinate themes are represented by bold *italics* and are interconnected in a ‘circular’ relationship with one another. The superordinate themes are also interconnected, with ‘challenges of the system’ impacting on how fathers experience this current

developmental stage and perceive the ‘next steps.’ Additionally, fathers’ internal experiences impact on how they perceive the system around them.

Whilst the group analysis aims to capture the shared experience among participants, there were also differences within each of these themes in terms of the different factors that contribute to the various feelings of conflict and challenges within the system, and the extent to which different themes are present for different fathers. I have therefore tried to illustrate this in the write up to maintain a sense of the individual, whilst reporting on the shared experience.

The results of the group analysis are illustrated in a conceptual map in Figure 1.



**Figure 1: Conceptual map of fathers' experiences**

The bidirectional arrows within the map reflect how the superordinate theme of ‘**challenges of the system**’ impacts on the ‘**internal conflict**’ experienced by fathers and vice versa. For example, the system *limiting future hopes and prospects* for the family and the YA, through the lack of support post-education, and limited options for employment or supported living, amplifies the *expectations vs reality* conflict, by exacerbating fathers’ loss of expectations for these opportunities. Furthermore, this limits fathers’ *hope* and exacerbates the *uncertainty and worry* for the future. In addition, the system requiring families to ‘*fight*’ to ensure that the YA’s needs are met, heightens the *responsibility* that these fathers experience. Lastly, instances such as reported “horror stories” of residential care, that create a *lack of trust* in the system, amplify the *protector vs facilitator* conflict also experienced.

However, fathers are also likely to be more protective of the YA, in part due to the YA’s vulnerability, which understandably may make it harder for these fathers to ‘let go’ and trust the system. Furthermore, that fathers’ experience of *struggles with acceptance/denial* and experiencing a loss of expectations may also amplify fathers’ feelings that the system isn’t doing a good enough job.

There are also several circular relationships within the individual superordinate themes. Firstly, this developmental stage of the YA highlighting the conflict that fathers experience in terms of *expectations vs reality* appears to contribute to fathers’ *struggles with acceptance/denial*. This in turn, seems to fuel the feelings of *guilt* that fathers experience, which in turn seems to maintain the experience of fathers struggling to accept how things are for themselves and the YA.

Secondly, the *uncertainty and worry* that fathers experience in relation to the next steps of the YA’s journey seem to contribute to the *responsibility vs avoidance* conflict, as there are certain things that feel easier for the fathers to avoid. However, the act of *avoidance* seems to amplify the *uncertainty and worry* that is experienced by fathers, due to keeping some of the next steps at a distance. These experiences also seem to contribute to the conflict of *protector vs facilitator* as fathers navigate a desire to promote the next steps to independence whilst also keeping the YA safe, and recognising that the next steps are a significant jump.

Table 5 presents the superordinate and subordinate themes identified and reflects which participant experienced and reported each subordinate theme. The following section will provide more detail on each of these themes and include quotes to support how these themes have been developed.



**Table 5: Overview of the superordinate and subordinate themes for each participant**

		<b>Participants</b>								
<b>Superordinate Themes</b>	<b>Subordinate Themes</b>	<b>Jimmy</b>	<b>Brook</b>	<b>Robert</b>	<b>Benny</b>	<b>Harvey</b>	<b>John</b>	<b>Peter</b>	<b>William</b>	<b>Jon</b>
<b>Internal Conflict:</b>	Expectations versus Reality	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Negotiating Developmental Stage</b>	Guilt	✓	✓		✓		✓	✓		✓
	Struggles with Acceptance/Denial	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Internal Conflict:</b>	Protector versus Facilitator	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Navigating Next Steps</b>	Responsibility versus Avoidance	✓	✓	✓	✓	✓	✓	✓	✓	No avoidance
	Guilt	✓		✓		✓	✓		✓	

<b>Challenges of the System</b>	Hope versus Uncertainty and Worry	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Limiting Future Hopes and Prospects	✓	✓	✓		✓	✓	✓	✓	✓
	Needing to Fight					✓	✓	✓	✓	✓
	Lack of Trust					✓	✓	✓	✓	

---

### **Internal conflict: Negotiating Current Developmental Stage**

This first superordinate theme captures some of the conflicting thoughts and feelings that all fathers expressed towards their experiences of parenting since their son or daughter turned 18. One source of **internal conflict** appeared to be **negotiating the current developmental stage**. This appears to be a time when fathers are forced to confront any prior expectations versus the reality of parenting a YA with DS. It seems that alongside these conflicting thoughts and feelings, that fathers sometimes experience feelings of guilt. Furthermore, that the challenges of this developmental stage appear to make it difficult for fathers to have fully accepted things as they are.

This superordinate theme consists of three subordinate themes which captures these experiences: *'expectations versus reality'*, *'guilt'* and *'struggles with acceptance/denial'*.

#### **Expectations versus reality.**

The subordinate theme *'expectations versus reality'* relates to a shared experience amongst the group, whereby fathers described feelings of sadness and loss of original expectations, whilst also expressing feelings of pride and gratitude, in recognising how far their son or daughter has come. In reaching this period of 'young adulthood', fathers seem to be noticing the 'gap' increase between what their son or daughter can do in comparison to others of a similar age, as they witness their child's peers go off to university, move away from home, or acquire their first jobs.

The first father I interviewed, Jimmy, did not explicitly state what he would have expected to have happened at this point; however, he hinted that he had expected some change in what reflected disappointment, when telling me:

*"And unfortunately, not, not a great deal post-18." (line 2531).*

Jimmy also apologised several times during the interview that he did not think he would be much help as *"I can't think of much change"* (line 1649); however, I had not specifically asked what had *changed* since Richard had turned 18.

Some of the fathers spoke in their interviews about having to acknowledge that there are certain jobs that their son or daughter will never be able to do.

William: *“Well, he wants to be a jockey. He wants to be a pilot. He wants to be a fireman. He wants to do all the things that any, any eighteen-year-old would want to do. . .”* (line 901). *“. . . that’s the upsetting part about it. . . he won’t be able to realise some of his dreams.”* (line 913).

Brook: *“my expectations were probably a bit too great for her. . . I doubt that she’ll go to work and this sort of thing now.”* (line 1815).

Other fathers spoke explicitly about recognising that this period would usually be a time where their son or daughter would leave home, either to go to university, or to move out and live elsewhere.

Robert: *“I guess when we first were thinking of having children that’s kind of what the expectation was in our minds that our kids would grow up and leave home and go off to university...”* (line 2160)

John: *“It’s just the results at this stage are slightly wearing in that, you know, he’s not got to that place where he can fly yet and we don’t know if he ever will?”* (line 2604).

Robert had shared how having kids had been a later decision for him and his wife as they had been busy doing *“fun and exciting things”* (line 269). Thus, for Robert, there was a loss of expectations on both sides. Firstly, for Michael, and noticing that he will not be following in the footsteps of his peers, but also for Robert and his wife, in relation to having time back to make plans for themselves. Whereas John described that watching their younger son leave for university a couple of years prior had been the catalyst in realising how restricted things are for themselves and Frank.

Peter’s experience was slightly different, as Tamara had tried residential living; however, this had been unsuccessful.

Peter: *“Well I mean obviously we’ve tried to facilitate her living away, and instead she’s at home.”* (line 1204).

Whilst Peter shared this in quite a matter-of-fact way, his tone of voice reflected disappointment.

A couple of the fathers described certain events that stood out to them as a reminder that things were different, and not as they would have expected.

Harvey: *“e-r-r, er, I think er, his 18th was a bit funny, huh!” (line 1101)/ “we-we had a thing at a local pub. Er, and. . .you know father / son first pint. . .and he had a half, half of shandy and he’s like, ‘Yeah. I don’t like that. [chuckles] I’ll try that when I’m 19. . .” (line 1111).*

Jon: *“I think Thomas went to the toilet somewhere and ... just because it was a place that we didn’t know, I said I’ll wait outside. And you think ... Thomas is 24 ... and I’m waiting outside of ... some toilets for him!... it’s just a completely different life!” (1737).*

In both these interviews, neither Harvey or Jon appeared to spend a lot of time thinking about or focusing on what had been lost; however, these situations seemed to highlight how different things were.

One of the fathers, Benny, spoke about finding it difficult noticing Frankie’s academic ability stay the same.

Benny: *“it-it has been more as a young adult I’ve had more of those thoughts” (line 1395) . . . “I will think to myself, ‘Oh, you’re 21. . .you still can’t do that.’” (line 1408).*

Benny spoke about actively trying to balance these thoughts with recognising what Frankie has achieved, such as his ability to travel independently on public transport to college and being a great dancer.

Despite fathers talking about the discrepancy between their original expectations and the reality of how things have been since the young person has been 18, the reality was also that all fathers appeared to experience feelings of pride, gratitude and warmth towards their son or daughter.

During my interview with Jimmy, he told me: *“he’s using my phone now...talking to, one or two of the, of the friends that I feel like he’ll have for life.” (line 788)*

Some of the fathers spoke specifically about their relationship with their son, with the phrase *“good company”* coming up in several of the interviews.

Robert: *“I guess of all the things that I’m most pleased about with Michael is that he’s good company” (line 2660)*

Benny: *“. . .things still happen now that I think, ‘Oh, this is just amazing,’ you know. The relationship we have is just fantastic.” (line 1200).*

Others, whilst also describing positive relationships with their son or daughter, spoke about the YA’s personality and development.

John: *“I think em he’s just a thoroughly nice young man and that’s, that’s ... that’s the proudest bit I think for me.” (line 2524).*

Finally, fathers also shared feelings of pride in seeing their son or daughter get involved in activities and achieve certain milestones that would be ‘typical’ of this stage of development.

Harvey: *“. . .he’d just started working for er, half-a-day-a-week work experience in a restaurant” (line 1490). . . “you could see him getting taller every week, you know he absolutely loved it”. (line 1503).*

**Reflexive Box 2.** Reflections on the subordinate theme of ‘expectations versus reality.’

In writing up this subordinate theme, I was aware of trying to capture the range of fathers’ experiences and needing to highlight the positives as part of this conflict as well as some of the challenges. I was conscious of not wanting it to come across to the reader as though fathers’ experiences during this time were purely filled with loss and sadness for their son or daughter as this did not seem the case. I think that this was partly driven by a sense of responsibility that I felt as a researcher in presenting fathers’ experiences, given the controversial debate regarding termination if prenatal tests suggest that a baby might have Down’s syndrome. I was also aware that these fathers might feel upset, angry, or misled, if they read this research and I had not presented some of the highlights and joys of parenting their son or daughter.

## Guilt.

The subordinate theme of '*guilt*' also emerged for six out of the nine fathers interviewed.

### **Reflexive Box 3.** Reflections on the subordinate theme of 'guilt.'

In hearing fathers' experiences of parenting their son or daughter since they turned 18, fathers described feeling guilty for finding certain aspects of parenting challenging. They seemed to feel that they should not experience these difficulties or perhaps feared that in saying they were having difficulties meant that they loved their son or daughter less. Similarly, when fathers spoke about hoping to have some time back for themselves, it appeared that fathers felt that they should not be saying this as this might reflect negatively on their son or daughter and might suggest that they do not like having them around. Lastly, I felt that there was something about recognising this developmental stage which contributed to these feelings of guilt. It seemed that in recognising 'the gap' widen between what their son or daughter can do in comparison to their peers, that fathers began to question their role in this and doubt whether they have done enough to support their development.

Benny described a feeling of guilt for having some of these difficulties and sometimes wishing things were different.

Benny: *"even now, despite everything I've said, I wonder what life would've been like if he didn't have Down Syndrome. . .Er, and of course, those things are fleeting"* (line 1369)

Three fathers described feeling concerned that they had not done enough, or that they were not able to provide what was needed. For Jimmy and Benny, this was in relation to supporting the YA's academic learning and recognising where their learning needs were.

Jimmy: *"is it a skill that he needs? Don't know... I think reading is, but in terms of writing, will he need to write? I'm not really sure..."* (line 1433)

At this point in the interview Jimmy seemed to be caught up in his thoughts, trying to justify his decisions and priorities around where he has been placing his

focus. Similarly, Benny described feeling uncertain if he has done enough for Frankie:

Benny: *“It-I mean it’s not plain sailing in terms of my emotions. . .I still have times when I think, ‘Ohh, have we done enough?’” (line 2356).*

For Brook, there was a real sense of being caught in a battle of wanting to be more involved; however, feeling the pressure to earn more money, which he identified as being his responsibility as the father.

Brook: *“I’d like to be more involved with that er, but. . .I feel I need to earn more money, basically to support her.” (line 1947).*

Brook added: *“I’m not very good at it!” (line 1996).*

In addition to feeling this financial pressure, Brook spoke about not being able to do some of his old caring roles now that Elizabeth is 18. Thus, for Brook, it felt that this time brought about two sources of guilt: guilt for not being able to provide for Elizabeth in the way he had imagined, and guilt that his wife is now having to take on greater responsibility.

Brook: *“when they were younger, I could obviously go in and wipe her bottom and this sort of thing but now I can’t umm, because of the age she is. [Wife] has to do it all.” (line 1606).*

Lastly, it seemed that some fathers felt guilty for vocalising that it is nice or might be nice to have time back for themselves and relieve some of the pressure.

Jon: *“having more time is good. Em ... but also... doing more things with Thomas is also, you know, just as good!” (line 1280).*

### **Struggles with acceptance/denial.**

The final subordinate theme within the superordinate theme of ‘Internal Conflict: Negotiating Current Developmental Stage’ was labelled *‘struggles with acceptance/denial.’* During the interviews, it seemed that fathers were trying to vocalise having accepted things for how they are; however, perhaps they had not fully been able to accept, possibly due to some of the difficulties described, and this developmental stage highlighting some of what has been lost.



Several fathers used the phrase *'it's just different'* or *'everybody's different'* during their interviews as if they were trying to communicate that they had accepted the differences described. However, the way that fathers vocalised this and the language used indicated that perhaps there was an element of denial, and that they were still struggling to fully accept how things are.

Peter: *"Nah. It's just different. You don't really think about the others any less or any more." (line 1212) . . . "You still wonder, still worry about them going out driving and all this sort of stuff. And I guess that's just the same really." (line 1217).*

William: *"It doesn't bother me, the uncertainty, because everybody's different. And my two daughters are very different people, thank God." (line 1003).*

In speaking with Robert, he described how *"it does feel a little strange that you are also labelled as his carer"* (line 2103), but that:

Robert: *"now it does feel, much more, that that is the role that you have, in some ways it gets less because he can do more himself but at the same time the gap between what he can do and what other 18-year-olds can do has grown massively." (line 2118).*

It felt that due to the *'gap'* increasing between what Michael can do and *'other 18-year-olds can do'*, Robert is able to make more sense of being labelled Michael's *'carer'*, and perhaps become more accepting of this title; however, that this also brings up feelings of loss and upset in recognising the difference increasing, which makes it harder to accept.

In his interview, Brook said: *"it's what we've got, you know. . .we've got this house, we've got umm, the kids we've got each other er, and that's fine." (line 2258).*

It seemed that Brook felt he *should* vocalise feeling grateful and accepting how things are with Elizabeth, but that things are also hard, so it is difficult to be fully accepting of this. It is possible that this struggle feels even stronger for Brook, given all the additional health complications for Elizabeth at birth.

A couple of the fathers spoke about difficulties accepting how their son participates in social situations.

Harvey: *“er. . .so, it is a bit upsetting I think. Because you see [pause] Herbert just, yeah, not really getting involved with other pe-ople umm, he doesn’t. . .have friends as other people do umm, and that, that can be quite upsetting sometimes er, but he has friends on his terms” (line 1225).*

Whilst Harvey tries to make sense of Herbert’s actions and recognise that perhaps he *‘has friends on his terms’*, Harvey stated twice that it is quite *‘upsetting’* and added that it’s *“just different, I suppose” (line 1257)*, indicating that perhaps, he hasn’t fully been able to accept this.

Similarly, Jon shared his struggles with accepting how Thomas participates socially:

Jon: *“I think we’ve got used to it. . .you still want him to do more things but ... that’s just how he is! He . . .prefers to ... sort of watch on the side lines.” (line 1018).*

Jon added that *“it’s less frustrating than it used to be” (line 1014)*, suggesting that this is still frustrating to some extent and perhaps he has not completely *‘got used to it’* or accepted this difference.

Lastly, Jimmy and Benny vocalised that they would not change a thing about their experiences. However, this may be a reflection on both fathers *wanting* to have accepted how things are, as well as possibly feeling protective and defensive of their son’s and wanting to ensure they present them in a favourable light.

Jimmy: *“I can’t think of anything that, that I’d want to change in all 19 years of his life.” (line 1642).*

Benny: *“if you offered me a magic wand to take [chuckles] his Down Syndrome away [sighs] I’d absolutely say, forget that, you know” (line 2523) . . . “I wouldn’t want to change anything that would risk him, his personality changing.” (line 2526).*

### **Internal Conflict: Navigating the Next Steps**

This second superordinate theme captures what fathers articulated as being a second source of **internal conflict: navigating the next steps** in the YA's journey. There was a shared experience across fathers of being torn between the two roles of *protector versus facilitator*. Fathers also seemed caught between wanting to support the next steps and recognising that they were responsible for these; however, also wanting to protect the YA from harm and avoiding navigating some of these new challenges. Again, it seemed that alongside these conflicting thoughts and feelings that fathers experienced feelings of *guilt* as they try to navigate what is the right thing to do. Lastly, in addition to feeling conflicted about their role, nearly all fathers expressed conflicting thoughts and feelings of *hope versus uncertainty and worry* towards the future.

#### **Protector versus facilitator.**

This subordinate theme reflects the conflict that all fathers described in wanting to support the next steps and promote independence for the YA; however, also recognising the YA's vulnerability, and finding it difficult to let go of their father role as 'protector.'

The following statement by Peter reflects a shared view across all fathers interviewed:

Peter: *"So I think independence is a good thing for her, for us to try and organise for her."* (line 989).

However, despite all fathers recognising this, and describing wanting greater independence for their son or daughter, it seemed that this is difficult to consider due to fathers feeling protective and not ready to let go of their own roles and responsibilities.

Robert shared that, whilst he is hopeful to facilitate greater independence for Michael, and this is something that Michael is keen to achieve, that: *"it's that balance between that and, feeling that you're supporting your children [chuckles]."* (line 681).

Harvey described noticing how different this process feels in comparison to his younger daughters who are in their teens; however, that: *"we know other people*

*who are in that process, and-and the young adults love it so, er, I think we would have to let go a bit.” (line 2296).*

Many of the fathers shared how the ‘next steps’ associated with this developmental stage feel like a significant jump. In his interview, Jimmy recognises that Richard would benefit from independent living; however, this feels difficult to comprehend, and thus, is still only a “*thought*” at present.

Jimmy: *“this thought of...Richard moving into... sheltered accommodation, or whatever... I guess it’s something we’ll have to face some point...or, no, no something we ought to face. . .I imagine it’ll be a benefit to Richard...” (line 2216).*

Similarly, whilst Benny describes that, Frankie will ultimately “*have some sort of semi-independent life (line 1075)*”, he also clearly articulates how difficult this process is going to be for him.

Benny: *“the day when he does leave home, almost doesn’t bear thinking about for me because, first of all because. . .I feel he’s vulnerable. . .but also because of that relationship we have...I think [sighs] how would life be without Frankie being here every day which [sighs].” (line 1893).*

In addition to feeling protective, there appears to be some level of co-dependence that has also been created for some of the fathers, and the thought of no longer being with their son or daughter every day contributes to this conflict in facilitating the next steps to independence. Jimmy shared that:

Jimmy: *“I’m tempted to say, I couldn’t cope without him. . .obviously I’d have to. . . I would miss him tremendously.” (line 968).*

Likewise, whilst Jon’s son Thomas has already made the move to supported accommodation, Jon described how Thomas “*comes back home again at the weekends.*” (line 452). Furthermore, he described how “*it was quite a big wrench for him to go. He didn’t, he loved it there! He wanted to get, go. But it, it was bigger for us!*” (line 458).

The use of the word “*wrench*” to describe this process of letting go, really highlights this conflict, implying that Jon had to force himself to facilitate this

transition. However, it was also clear from Jon's description how much Thomas enjoyed this move, and the pride that Jon experienced in witnessing this.

For Brook, it felt that COVID-19 added an extra layer to this conflict, due to Elizabeth being generally susceptible to colds and flus. However, Brook's description of wanting Elizabeth to "fly" is an experience that many of the fathers vocalised in some way throughout the interviews, and really accentuates this dilemma that the fathers are experiencing.

Brook: *"she's going to college or supposed to be going to college on the 8th and they think she can fly there er. . .but her health wise, er, it's just a matter of whether to send her or not [chuckles]." (line 1157).*

For some fathers, handing over responsibility to someone else to look after their son or daughter appeared to be a significant contributing factor to this conflict in roles. This will be discussed more within the superordinate theme of '**Challenges of the System**' and within the subordinate theme of '**Lack of Trust.**'

Lastly, despite feeling protective and finding it difficult to hand over some of this caring responsibility, many of the fathers described recognising that facilitating the YA's independence was also important for them, acknowledging that it was not ideal for the YA to stay living at home forever. For example:

Harvey: *"I think er, f-for the short-term he'll stay at home but I don't think long-term that's viable. I don't think it'll be good for him. I don't think it'll be good for us." (line 2145).*

Thus, it was apparent from speaking to the fathers, that wanting to gain time back for self also contributed to the dilemma of '**protector versus facilitator.**' However, as John points out in his interview, this can become even more complicated due to the parents typically being responsible for facilitating the next steps.

John: *"In some ways you could say that. . .the right thing to do with him is actually the wrong thing to do with us because it would create more ... need for us to just go and drop him off places and do stuff with him." (line 2329).*

There was a real sense of frustration and disappointment when speaking with John, as he described being caught in a 'catch-22'-type situation, of wanting to try

and facilitate the best for Frank; however, also feeling the toll of the increased pressures and responsibilities that are placed on parents of YAs with DS after leaving college.

### **Responsibility versus avoidance.**

The subordinate theme of *'responsibility versus avoidance'* also emerged from the interviews. Most fathers also experienced feeling torn between being *responsible* for the next steps and *avoiding this responsibility* due to this feeling difficult and a significant jump in the journey for the YA. The only father who did not seem to be caught in this conflict was Jon. However, Jon's son Thomas was one of the eldest of the YAs at 24 years old, and the only YA at the time living away from home.

Fathers spoke about trying to ensure that their son or daughter was engaged in activities to ensure that they have a full and meaningful life.

Robert: *"I mean he really wants to do his acting and stuff so. . ." (line 2470)/ "if we can sort it out, he'll do some time at [name] as well." (line 2488).*

Peter: *"I think overall you want her to be happy, and if this makes her happy then that's great, so we should do our best to facilitate it." (line 1300).*

Whilst it seems quite typical for parents to want the best for their son or daughter, it was evident in the interviews that fathers recognised that the YA's hopes, and dreams were reliant on them facilitating them. The language used by Robert (*"if we can sort it out"*) and Peter (*"we should do our best"*) with an emphasis on the *'we'*, provides an illustration of this.

Furthermore, fathers were also concerned what would happen if they just let their son or daughter do whatever they wanted.

Jimmy: *"if he keeps on doing things, then he'll keep on learning... whereas, if, if we allowed him to just sit and do nothing... ermmm...then...you know, he would stagnate and...not have as a...full, and exciting life as I hope he does." (line 1730).*

There was also a shared experience across the fathers of needing to consider what happens next in the YA's journey. This can be seen in an extract from my interview with Harvey below:

Harvey: *"the bureaucracy changes, doesn't it. . . and also the question of 'What happens next?'" (line 1314).*

The phrase *"what happens next?"* was used by several fathers and seems to reflect the uncertainty of this next stage of life for the YA, and possibly contributes to fathers either avoiding some of these next steps or avoiding some of the feelings associated with this time. A few fathers shared that they hadn't had specific conversations about these 'next steps' with their wives. For example:

John: *"[Sighs] em ... I think it, it's... something that we're both aware the other thinks about from time to time but we don't openly discuss it, I don't think." (line 816).*

It seems that fathers are caught in this conflict of knowing that they need to be practical and consider what this next chapter looks like; however, are finding it difficult to think about it.

Benny: *"And in reality, when it happens it'll probably be a gradual process; it won't be a day where he's just not here all the time, but it's just unthinkable. It's. . .one of those things that I put aside thinking, oh, I don't want to think about that even though we have to be practical about it and prepared for it. . ."* (line 1928).

In William's description of navigating these next steps, he seems to manage this by focusing on the practicalities, but recognises that to do this, he avoids getting caught up in the associated thoughts and feelings.

William: *"Well, I suppose I don't dwell on it because I think I'd probably drive myself mad. . .But. . .we just have to put as much in place to protect him both financially and legally so that when me and [wife], fall off our perches, our daughters will have to take up some, but you know, they've got their own lives to lead... . so you can't put too much of a burden on them."* (line 466).

This responsibility of looking to the future and needing to consider what will happen when they are no longer around seemed to contribute to this conflict and

make it harder for fathers to avoid some of these next steps. Furthermore, fathers voiced recognising the impact on them as well as the YA if they were to continue parenting this way into older age.

Peter: *“She will always need help to live. . . so if we find something else that we can put in place in the future then that’s great we’ll do that. And if we can’t, um, at some point we are aware that we will be too old to look after Tamara. I mean it isn’t fair to expect Tamara to look after us.” (line 1052).*

However, despite recognising this responsibility to consider the future for Tamara, Peter acknowledges that this is something that has been pushed to the back of his mind for now.

Peter: *“It’s kind of at the back of my mind at some point is that we ought to, before she becomes unable to do sort of, you know, we ought to do something.” (line 1078).*



**Reflexive Box 4.** Reflections on the word *'burden'* used by some of the fathers during the interviews.

The word *'burden'* was used by both William and John in relation to concerns about the future and not wanting to place the responsibility that they carry onto the younger siblings. Whilst I know from speaking with these fathers and hearing the way that they spoke about their sons that they carry a lot of love and pride for them, I was initially worried about including extracts that used the word *'burden'* in case it painted young adults with Down's syndrome in an unfavourable light. I think the reason I felt uncomfortable about this relates to what I discussed in 'reflexive box 2' around the sense of responsibility that I carry as a researcher in presenting these experiences, given the debate around terminating a foetus if pre-natal tests indicate the baby has Down's syndrome. I took this dilemma to supervision and discussed with my supervisors why I felt uncomfortable, whilst recognising that it also did not sit comfortably to purposely omit something from the research. In having this discussion, I reflected on how important it is to allow these fathers to share these feelings as part of their experience, and that by including this in the research, I am giving voice to something that is difficult, and possibly allowing other fathers to feel that their experiences are also valid.

### **Guilt.**

The subordinate theme of *'guilt'* also emerged for just over half the fathers in relation to navigating the next steps.

William described that he and his wife have spoken about how he needs to try and support Gabriel to recognise that things should change as he moves into adulthood. He told me: *"I get accused of babying too much. I mean he still comes and sits on my knee" (line 187) . . . "he's done it forever" (line 208).*

It appeared that William felt guilty as he quite likes how things are but recognised that he needs to start thinking about what is best for Gabriel.

For Robert, he described feeling guilty in recognising that Michael is now 18 and being aware that he is not giving as much autonomy and independence as would usually be given at this age.

Robert: *“I do feel [sighs] a little . . . kind of, tricky saying to him as an 18-year-old, ‘No. It’s time for bed.’” (line 2011).*

*“I, I think. . . it’s always difficult giving people more independence and more freedom which makes it sound like, huh [chuckles]! We’re keeping him in prison!” (line 1763).*

Whilst Robert tried to normalise this and make a joke, I noticed that he felt uncomfortable about this.

Other fathers felt guilty for not doing enough in their role of ‘facilitator’ or recognising that perhaps they were holding back on the next steps.

John: *“And unless we significantly change our lifestyle and I can significantly reduce my earnings, then there’s sometimes not anyway I can get more involved. . . I should cook more with him. I should do all the practical things and his life skills with him more. . . but ... em ... the best intentions ... sometimes don’t happen right?” (line 2110).*

Harvey: *“sometimes you have to think about what Herbert can do with you. . . it’s quicker for me to do stuff on my own whereas maybe sometimes I should involve him.” (line 1961).*

In relation to Richard making his own drink, Jimmy said: *“it’s something I think I, I think I ought to do, but without actually doing it... A, After this conversation, I may well, er...I may well make him...” (line 1972).*

### **Hope versus uncertainty and worry.**

The final subordinate theme of *‘hope versus uncertainty and worry’* under the superordinate theme of **‘internal conflict: navigating the next steps’** seeks to capture how fathers seemed to be trying to balance feelings of hope alongside any worries and unknowns of the future. The only father who did not seem overly hopeful was John, who said at the end of the interview: *“I’m beginning to sound fairly pessimistic about all this. . . and that’s not the way it is at all! (line 2812) . . .*

*“it’s just concerning that you don’t, you know, you don’t know who’s going to look after him in the next 5 to 10 years? Or where he’s going to be and stuff?” (line 2819).*

However, earlier on in the interview, John did comment that:

*“If we could do something which would get him a job for a couple of days a week, you know at farm centre. . .then I think that’s the best we can hope for” (line 2253)*

Other fathers also spoke about being hopeful that their son or daughter would be able to acquire a job. However, again, there was a level of uncertainty with this.

Brook: *“we’d see how she developed in college and er. . .get her to umm-m-m, just progress into something. I don’t know what that is. Maybe working in a charity shop or er, I don’t know.” (line 2097).*

In interviewing Brook, it seemed that this felt quite far into the future for Elizabeth. Again, possibly in part due to COVID-19 impacting on Brook’s ability to see past the present. However, it was clear that he was trying to hold onto some hope for Elizabeth’s future, even though he was not sure if this would happen.

In contrast, whilst William seemed confident that Gabriel would be able to secure a job in the future; he struggled to discuss the possibility of Gabriel living semi-independently.

William: *“he could do quite a variety of jobs, even with limited language.” (line 969).*

*“I think there’ll always be some level of intervention, But, er. . .it’s so difficult to be able to see that far in the future. You’re asking me a question that I’m finding really quite difficult to answer.” (line 1368).*

The contrast in how William spoke about these future opportunities for Gabriel was quite stark. For William, it seemed that consideration of supported living options brings much greater uncertainty.

Both Harvey and Robert seemed to be trying to balance a sense of hope with the uncertainty that comes with exploring supported living.

Harvey: *“I’m sure it’ll-there’ll be a few bumps on the way, but we will find him the right place, umm. . . er, yes, and how long-term that’ll be, I don’t know.” (line 2351).*

Robert: *“his dream and he says this every, at every time we have an annual review, is that he wants to buy a house in [place] live in [place] and he’s gonna be an actor and he’s going to [name of theatre company] so, that’s kind of. . .where we’re at with things.” (line 2497). “but. . . umm, quite how that will pan out.” (line 2517).*

Whilst trying to sound hopeful, Harvey also expressed his doubt over whether supported living will work out long-term. Similarly, Robert seemed unsure how realistic it will be to meet his son Michael’s hopes and dreams.

In addition to discussing hopes and uncertainties regarding specific milestones or achievements, fathers also shared these thoughts and feelings more broadly.

Jimmy: *“one thing that [carer] said, was....you just... keep on learning, you know, that Richard will keep on learning, er, into adulthood... I mean...hopefully that’s true. . .it, it was an anecdotal story...” (line 1701).*

Jon: *“the more he does it and the better he. . .is at it, then. . .the more independent he is. And then he’s, so hopefully enjoying his life.” (line 1332).*

Whilst all fathers appear to be looking positively towards the future, there is also a suggestion of hesitation and uncertainty.

For some fathers, there was also a concern around how parenting might look for the future and how long they will be around.

Benny: *“I’m thinking in five years’ time wha-what will Frankie be doing and we worry because, you know I, I’m 58 and my wife’s 57 and you think well, as we’re getting older, you know we, we, first of all you think, well, are we always gonna be here for Frankie?” (line 1877).*

Therefore, the responsibility that fathers hold both in relation to the immediate future, and for thinking longer-term for their son or daughter, appears to be another source of uncertainty.

Lastly, for some fathers, trying to manage expectations of the future appeared to be a way of coping with this uncertainty.

Peter: *“I know some people have a life plan and want to get to a certain stage in life by a certain time. But I don’t think. . .that’s something that’s going to happen. So, we just take each step as we can sort of thing.”* (line 1336).

William: *“Well as far as I can, well I suppose the thing to recognise is that it’ll never be perfect. It’ll, it’ll be, you know, what is it? The best is the enemy of the good or something.”* (line 620).

### **The Experience of Being Caught Between the Areas of Internal Conflict**

Before presenting the final superordinate theme, it feels important to consider the experience of being caught between the conflicting areas illustrated above.

Firstly, my understanding is that the conflict of *‘expectations vs reality’* may bring about a feeling of disappointment for the fathers as they navigate this experience. However, that this conflict also creates a feeling of guilt for some fathers due to recognising the positives, and seeing their son or daughter surpass some expectations, whilst also experiencing the loss of others.

Secondly, the conflict of *‘protector vs facilitator’* appeared to evoke anxiety for the fathers as they try to navigate what the right thing is to do for the YA. However, again, my understanding is that this conflict may also bring about a feeling of guilt for some fathers as they recognise the role they play in the YA’s independence, and try to find the balance between promoting this and keeping the YA safe.

Thirdly, similarly to the conflict of *‘protector vs facilitator’*, the conflict of *‘responsibility vs avoidance’* seems to evoke anxiety and guilt for fathers. It appears to be the anxiety that fuels the avoidance; however, that some fathers then feel guilty for recognising that they are holding back on the YA’s independence.

Lastly, the experience of being caught between the conflict of *‘hope vs uncertainty and worry’*, appeared unsettling for fathers. It seemed that fathers were trying to find a middle ground, so as not to raise their expectations too high for the

YA and end up disappointed; however, were also trying to not let the worry and uncertainty take over and become a barrier to looking forward and considering the next steps in the YA's journey.

### **Challenges of the System**

This third superordinate theme reflects the **challenges of the system** that nearly all fathers described experiencing in some way. In discussing 'the system', I am referring to the wider context that fathers spoke about during their interviews, including schools, local authorities, providers of services, the legal system and accompanying processes. These challenges included the sense that most fathers felt that the system was *limiting future hopes and prospects*, for the YA. In addition, some fathers described *needing to fight* to get needs met and experiencing a *lack of trust* in the system. There was a real sense that for most of the fathers, these challenges were exacerbating the internal conflict that they were experiencing.

#### **Reflexive Box 5.** Reflections on naming this superordinate theme.

In naming this superordinate theme, I was torn between whether to name it 'Challenges of the System', or 'Failures of the System.' Part of me wanted to label it 'Failings of the System' due to the real sense that I got from fathers of being let down, and for some, how the system is failing them and their son or daughter. However, I was aware of this coming across as particularly blaming on the system, and in addition, not all fathers had named their 'challenges' with the system as explicitly as others. Therefore, it felt more appropriate to use the word 'challenges'; however, I wanted to acknowledge the real continuum of experiences within this superordinate theme, and to recognise that for some fathers it does seem as though they feel that the system has failed them.

#### **Limiting future hopes and prospects.**

The subordinate theme of '*limiting future hopes and prospects*' relates to a loss of hope for the YA's future described by nearly all fathers as result of difficulties experienced in relation to the system. The only father who did not

express any difficulties regarding the system limiting future avenues was Benny. However, Benny's son, Frankie, has been able to acquire a part-time job in a café, which may partly explain why he does not vocalise these limitations. Furthermore, Benny openly described that he is not yet ready to navigate the next steps to independent living for Frankie.

For some fathers, this loss of hope was experienced in relation to the education system and continued learning.

Jimmy: *“one thing that slightly disappoints me about the school was that, that they tailed off doing, doing writing.” (line 1323).*

William: *“My expectation was that school would continue trying to develop his speech and language. But to the contrary, his pathway is now that they don't do, or very limited speech and language because he's eighteen. . .But in fact, what he needs quite desperately and to a significant extent is the development of his speech and language.” (line 1429).*

Both William and Jimmy felt let down in relation to how the school curriculum was being run. Whilst Jimmy shared his disappointment, he did not elaborate much on this during the interview. However, William seemed angered and described his frustration that the school were not meeting Gabriel's needs.

Similarly, Brook expressed difficulties regarding resources not being age appropriate.

Brook: *“. . . we're trying to get things more into, er, perspective of her age. . .which is quite difficult because there are no books out there for anybody which are appropriate for her to read.” (line 1258).*

Other fathers expressed feeling disappointed and had difficulty in relation to finding suitable avenues for employment. Jon shared how Thomas has previously had work experience; however, this did not work out. From Jon's description it sounded as though the shop was not set up with the provisions of having someone to support Thomas working there.

Jon: *“we tried him at a local shop in which they gave him a sort of, a placement. It didn't work particularly well... he needs somebody to be with him, to help him and to motivate him.” (line 1404).*

William also spoke about recognising that Gabriel would need to have someone to supervise him if he were to be in a work environment.

William: *“if Gabriel got a job either in a farm, or in a factory, or whatever, um, the person that employs him has a duty of care, and I suspect that legally they won’t want to take on that responsibility.” (line 936). “So, you know, the avenues open to him are pretty limited.” (line 944).*

It seemed that William had almost admitted defeat in this becoming a reality, which contrasted with William’s hope described earlier when stating that Gabriel *“could do quite a variety of jobs.”*

Harvey’s experience of this was slightly different, in that Herbert had acquired a part-time job in a restaurant prior to COVID-19, in which he saw Herbert *“getting taller every week.”* However, this was placed on hold due to COVID-19, and as Harvey looks towards what work experience Herbert will gain through college, he feels disheartened about what is on offer.

Harvey: *“his college is trying to set up some work experience but that’ll probably be down the animal charity or something like that, which is, you know won’t-won’t be the same effect I think for him.” (line 1601).*

Fathers also spoke about limited opportunities for supported living for their son or daughter. Peter referred to the possibility that he and his wife would need to start considering how they can facilitate semi-independent living for Tamara and her friends, due to the likelihood that this will not be provided elsewhere.

Peter: *“Well I assume there won’t be some sort of magic solution that comes up, that Mencap don’t suddenly start running a home, or house, that she could take part in. So maybe it’s something that we can go back and address again.” (line 1094).*

For Brook, the limitation described was that the services on offer were not tailored for individuals of a similar age to Elizabeth, and Brook felt protective of Elizabeth possibly going into this setting.

Brook: *“We want her to be with people of her own age, you see if she goes into social care straightaway it’s with people of her own age and with older people too, which are er, they frighten her.” (line 1211).*



Lastly, a couple of fathers referred to concerns more generally. Whilst this was not stated explicitly, it appeared that the uncertainty of fulfilling Michael's ambitions is down to what services are on offer.

Robert: *"good that he's got the ability to look at those ambitions and to think that through and decide that. I have that natural concern that fulfilling them all . . . may not be possible."* (line 2548).

In contrast, John was very vocal about his views towards the "bureaucracy" that exists in the system, and the impact that this has on Frank, as well as him and his wife as they try to fulfil Frank's needs and find what provisions that exist.

John: *"It's a shame for him as well that he can't go off and do these things. . . There's not the support mechanisms to do it and even if there would be... it is either a) too expensive or, or b) the gatekeepers of those services refuse you to have the funds."* (line 953).

*"But as he finishes his course next year. . . then the onus falls on us to be able to provide things for him to do... and that, gets more difficult as you get older. . . but it's also trying to find some provision which actually exists!"* (line 1119).

### **Needing to fight.**

This subordinate theme seeks to capture the challenge that just over half the fathers expressed that suggested the '**need to fight**' to get their son or daughter's needs met. In addition, the system becoming more complicated and challenging since their son or daughter became 18.

As illustrated below, recognising that the systems are changing is something that Harvey was anticipating.

Harvey: *"Umm, we haven't had to do the money, the power of attorney thing yet. Umm, but that is in the pipeline; I think that is going to get quite complicated."* (line 1371).

For some fathers, the language used highlighted the challenge in navigating the systems in place to ensure the best for their son or daughter and to get the support in place to do so.

William: *“you just have to try and understand the processes and the systems in place and then, and then advocate in a way that gets the best out of it for him. Which might piss a few people off frankly, because it might not be running to their agenda, but you. . .have to be really thick skinned about it.”* (line 500) . . . *“if you have to take people to tribunals or take legal action, then that's what you have to do.”* (line 508).

John: *“We will always find a resolve to, to, to fight for, for what we need for him.”* (line 2908).

As illustrated in the examples above, there was a general sense from fathers that they would do whatever it takes to get the YA's needs met.

This seemed to be a view shared by Jon, who explained that getting Thomas into residential college and supported living took *“months and months and months! Hundreds of hours of ... lobbying and ... em ... us putting in lots. . .the reasons why it would be the best place for him. And em ... tribunals and things like that!”* (line 1549).

He also shared that: *“you have to sort of put things the right way but also have the ... perseverance to keep going and, yes, all by yourself. If someone says no, it doesn't mean no! It'll carry on until eventually you get the, the answer you need!”* (line 1701).

Jon expressed his concern for the YAs of families who may not be able to persevere in the same way they did.

Jon: *“I'm sure there's lots and lots of adults out there who ... their parents or their carers just aren't in that position to be able to do the same. . .And if you haven't got the perseverance then, you know, your child will miss out!”* (line 1604).

John shared during his interview, that he finds there is a *“hell of a lot of bureaucracy”* (line 2082) surrounding these processes and that his wife generally takes the lead on any writing needed as his *“language skills are not great”* (line 2083). Thus, providing support for Jon's concern that some people might miss out if they do not have the necessary skills.

There was a general sense from fathers of feeling let down by how challenging this can be. The following quote from Peter illustrates this experience.

Peter: *“Yeah, it’s just disappointing isn’t it? You always think that people would want to do the right thing, and it isn’t always obvious to them what is the right thing. So that’s why you have to be vocal and say what it is you want.” (line 1398).*

However, the following fathers did not express these difficulties during their interviews: Robert, Brook, Jimmy, and Benny. Whilst I have already discussed possible reasons for why Benny might have not experienced these challenges, it is possible that the age of the YA plays some part in explaining a lack of this experience for the other fathers, because, as Jon described, these processes appear to become more complicated after the age of 18, and the other three YAs were only 18 and 19 years old at the time of interview. It is also possible that these experiences may depend on where the family live and the systems that they navigate locally. Additionally, these differences may reflect fathers’ different coping mechanisms (i.e., it is possible that expressing anger at the systems surrounding them is easier for some fathers than feeling sad).

#### **Lack of trust.**

This last subordinate theme relates to the *‘lack of trust’* in the system which some of the fathers described, and which seemed to make it harder for these fathers to ‘let go’ of some of their parental ‘control’ and responsibility for their son or daughter.

As in the subordinate theme above, this was not an experience that was described by Robert, Brook, Jimmy, or Benny. Similarly, to what has been discussed previously, it is possible that this is a reflection on the age of the YA, as well as fathers’ thoughts and feelings surrounding their readiness to pursue the ‘next steps.’ Brook, Jimmy, and Benny all vocalised in their interviews a sense that they were not ready to think about their son or daughter moving out. Whilst Robert did speak about looking ahead and considering the next steps of supported living, it is possible that he has not experienced these difficulties yet, both due to Michael only being 18 years old, and the presence of COVID-19 complicating things during this

time. Lastly, it is not surprising that Jon did not share this experience as his son Thomas already lives in supported accommodation.

Two of the fathers spoke about being reluctant to consider supported living options due to reported challenges of residential care.

William: *“you see horror stories about residential care and stuff, and I think well I’m never going to put him into residential care because of harm that might come to him.” (line 404).*

Harvey: *“I mean it is a huge concern umm, because he’s so trusting and umm, there are some horrible stories out there.” (line 874).*

Furthermore, a couple of fathers expressed concerns that other professionals may not support their son or daughter in the way that they do.

John: *“who’s going to do it for him if he moves out? Who’s going to insist that he gets out of bed in the mornings and goes and does stuff if he does go and live with a few friends? Semi-independently? You know nobody is going to do it like Mum and Dad do!” (line 1494).*

Peter: *“They made her do her jobs and things like that, but they weren’t very consistent about it.” (line 640).*

Whilst John’s comment is a future-facing concern, Peter’s comment refers to his experience when Tamara tried living in residential care. However, both John and Peter seem to share the worry of placing their trust in staff members to ensure that their son or daughter is kept busy and motivated.

Lastly, there seemed to be a shared concern from William and Peter about placing their trust in other professionals. William described how he was in the process of taking legal action to ensure that they will be able to retain ‘control’ over what they perceive to be Gabriel’s best interests, as they do not feel that other professionals necessarily have this at heart. Whereas Peter alluded to a lack of trust in others to make wise decisions, by describing how they can avoid some of these difficulties by keeping Tamara living at home.

William: *“...but if we have a best interests meeting and we don’t think these other professionals are acting in Gabriel’s best interests and we’re his*

*parents, well how does that work then? Um, so we've taken the view that well we're going to get the legal protection so that you know, if push comes to shove and we have to advocate for Gabriel, we want to be in the strongest possible position, not be at the mercy of other people whose, who may have different agendas.” (line 251).*

*Peter: “I don't know why everybody thinks that there is some magic number that makes them into an adult, and that is one of the problems, particularly if she's living away. It's one of the problems that you avoid if she's living with us. But it's a factor in all sorts of things, when she walks into a bank and they just assume that she's able to control her own money and all the rest of it, that is quite a difficult thing.” (line 1413).*

**Reflexive Box 6.** Reflections on the superordinate theme of ‘challenges of the system.’

In hearing fathers speak about some of these challenges and hurdles experienced, I really felt their anger, frustration, and disappointment. It was upsetting to hear some fathers are not able to be very optimistic about aspects of their son or daughter’s future, and that that was down to what provisions are available, rather than the ability of their son or daughter.

I did wonder why some fathers seemed to experience a strong reaction towards ‘the system’ and the impact that it has had on them, whereas others only expressed more subtle challenges. My sense was that several factors might contribute to this. Firstly, that some fathers may not necessarily recognise the impact of the system, and instead may internalise their experiences as being down to them and the young adult’s capabilities. Secondly, for those young adults who were nearer the bottom of the age bracket at 18, 19-years old, I imagine that COVID-19 will have likely overshadowed a lot of difficulties experienced in relation to the system and navigating these next steps, whilst families were operating more in ‘survival mode.’ Thirdly, it can often be a bit of a ‘postcode lottery’ when it comes down to what provisions are available for families, and therefore this will likely have a significant impact on how any challenges are perceived.

## CHAPTER 4: DISCUSSION

This was an exploratory study that aimed to explore the experiences of fathers of YAs aged 18 – 25 with DS. The following research question was therefore proposed:

What are fathers' experiences of parenting a YA aged 18 – 25 with DS?

To address this research question, data was collected through individual semi-structured interviews with fathers and analysed using IPA.

This chapter will firstly summarise the main findings. The findings will then be considered in relation to relevant wider literature and psychological theory, including that discussed in the introduction. The extent to which there are findings that are particular to fathers, and findings that are particular to DS will then be summarised. A critical evaluation of the research study will then follow, discussing its strengths, limitations, and clinical implications. Avenues for future research will then be considered before offering conclusions and final reflections.

### Summary of Findings

Fathers' experiences of parenting a YA aged 18 – 25 with DS were presented as three superordinate themes. Two of these superordinate themes encapsulated the internal conflict that fathers seemed to experience during this time. Firstly, relating to the current stage of development for the YA, and secondly, in relation to the next steps. The third superordinate theme aimed to capture the challenges that nearly all fathers described experiencing in relation to the wider system. These superordinate themes were labelled: 'Internal conflict: negotiating current developmental stage', 'Internal conflict: navigating the next steps' and 'Challenges of the system'.

The superordinate themes were interconnected, and therefore the challenges of the system appeared to be exacerbating the internal conflict that fathers experienced. However, that fathers' internal experiences were also impacting on how they perceived the system. I will present an overview of these themes below.

### **Internal Conflict: Negotiating Current Developmental Stage**

Whilst each of the fathers' experiences were unique, there seemed to be a shared experience that this developmental stage evoked many conflicting thoughts and feelings. Fathers described a range of experiences, including a loss of expectations, and a sense of sadness towards how things were for their son or daughter, in addition to feelings of pride in noticing their son or daughter achieve certain milestones, and gratitude for the relationship they have. This conflict in experiences seemed to be highlighted by the 'gap' between what their son or daughter can do in contrast to previous expectations of this time, as well as witnessing other YAs they know go to university or move out of the family home.

It also seemed that this period brought about feelings of guilt for many of the participants. Fathers described a sense of guilt for vocalising some of their difficulties and challenges during the interview. In addition, fathers described feeling concerned or uncertain whether they had done enough. Again, it seemed that perhaps in recognising what other YAs can do at this stage, that some of these fathers were starting to question their own parenting and internalise some of the responsibility for their son or daughter's capabilities. Fathers also seemed to experience guilt in articulating relief in having acquired some time back for self, or conversely, looking forward to having some time back for self in the future.

Lastly, it seemed that even though fathers wanted to have accepted things for how they are, that this is made more difficult by the additional challenges and realisations that accompany this developmental stage.

### **Internal Conflict: Navigating the Next Steps**

Fathers also seemed to experience conflicting thoughts and feelings in relation to the next steps of the YA's journey. Part of this related to the conflict that fathers described experiencing in relation to their role as a parent. On one hand, fathers vocalised wanting to promote independence for their son or daughter and support the next steps of their journey, whereas on the other, fathers spoke about feeling incredibly protective of their son or daughter and recognising their vulnerability, which seemed to be making it harder for fathers to let go. However, fathers also described noticing that facilitating their son or daughter's independence



was also important to them, to allow time back for themselves. This seemed to further compound the conflict of ‘protector versus facilitator.’

Fathers also seemed to feel torn between recognising that they were responsible for initiating and planning the next steps, whilst also wanting to avoid thinking about this. They spoke about how contemplating the next steps feels particularly difficult due to potential changes representing a significant shift for the family and YA. In addition to feeling responsible for ensuring that their son or daughter has a full and meaningful life, fathers also described a responsibility for looking to the future and considering what will happen if they or their wife are no longer around.

In addition to experiencing guilt in relation to negotiating the current developmental stage, fathers also seemed to experience guilt when contemplating the next steps in the YAs’ journey. Fathers described recognising that perhaps things should change in terms of how they relate to their son or daughter and a sense of guilt in noticing that they had been holding back on encouraging their son or daughter to do more things independently, in part because this is also a big shift for them. Fathers also seemed to experience guilt for not devoting enough time to their role of ‘facilitator’, and for noticing how they parent their son or daughter in contrast to the freedom and autonomy that would usually be expected at this stage.

Lastly, fathers seemed to experience conflicting thoughts and feelings towards the future. There was a sense that fathers were trying to balance their worries and uncertainties with feelings of hope, and that for some, trying to manage their expectations was a way of coping with this uncertainty. Fathers’ experiences varied when discussing the future, or the prospect of their son or daughter acquiring a job or moving into semi-independent living. For example, some fathers expressed feeling optimistic in considering their son or daughter move into supported living, as they felt that this would be beneficial for the YA’s confidence and independence, as well as removing some of the responsibility from them as parents. For others, considering semi-independent living was a source of uncertainty and concern. Firstly, some fathers described not really knowing if there will be appropriate supported living options out there. For others, there was a worry associated with handing over the responsibility to someone else to look after their son or daughter,

or a concern because this is something the YA has previously tried but was unsuccessful. In addition to hopes and worries relating to their son or daughter's future, some fathers also spoke about a concern for how parenting might look in the future. For example, who will be continuing to look after their son or daughter as they get older, and what will this mean for the YA's quality of life as the parents are less able to meet the YA's needs and make their life meaningful.

### **Challenges of the System**

In addition to the conflict that fathers described, nearly all fathers vocalised experiencing challenges with the system. There was a sense from most fathers that the system was limiting future hopes and prospects for the YA. Fathers described a loss of hope in relation to the education system, options for residential living, and finding suitable avenues for employment.

Fathers also described needing to fight to get their needs met and experiencing a lack of trust in the system. There was the sense from fathers that the systems and processes become more challenging after the age of 18, and that perseverance and skill is required to secure what is needed for their son or daughter. Lastly, fathers expressed a lack of trust related to reported "*horror stories*" of residential living, as well as a concern about placing their trust in other professionals. For some fathers there was a worry that supported living staff may not be as invested in keeping their son or daughter occupied and motivated. For others, there was a concern around losing an element of 'control' and having other professionals try to make decisions that are not in their son or daughter's best interests.

### **Findings in Relation to Wider Literature**

The research findings will now be discussed in relation to psychological theory and the relevant wider literature on parenting experiences of YAs with DS, DDs, and IDs. Where possible, I will focus on fathers' experiences and YAs with DS. The following section will be structured in accordance with the subordinate themes: expectations versus reality, struggles with acceptance/denial, protector versus facilitator, responsibility versus avoidance, guilt, hope versus uncertainty and worry, the system limiting future hopes and prospects, needing to fight the system to

get needs met and lack of trust in the system. Finally, I will present a summary of findings that are particular to fathers, and findings that are particular to DS.

### **Expectations Versus Reality**

In the current study, all fathers expressed feelings of warmth, pride, and love, in addition to feelings of sadness and loss of expectations for their son or daughter. Whilst this did not emerge as a key finding in Docherty and Reid's (2009) study exploring the experiences of mothers of YAs with DS, Thackeray and Eatough (2018) who explored five fathers' experiences of parenting a YA with a DD did report this finding. Thackeray and Eatough found that certain events, such as watching another son or daughter load their car in preparation for leaving home highlighted feelings of loss and served as a reminder of how life could have been. One of the fathers in the present study acknowledged that seeing his younger son leave for university had been the catalyst in realising how different things were. Other fathers spoke about having to acknowledge that there are certain jobs that their son or daughter will never be able to do. Interestingly, these fathers also had other children who did not have any disabilities, and the YA that the fathers were referring to were all the youngest, which perhaps invites a natural comparison of what this new 'chapter' could or 'should' look like.

Numerous developmental frameworks exist that can help us try to understand the processes that individuals within a family go through at different life transitions. As discussed in the introduction, Arnett's (2000) theory of 'Emerging Adulthood' was developed to capture the period between the ages of 18 and 25, which he proposed was a distinct developmental stage, different to both 'adolescence' and 'young adulthood.' However, whilst Arnett proposes that this age bracket typically represents a time of frequent change, greater independence, and increased possibilities for the individual, this was not the experience that fathers in the present study reported of their son or daughter. In contrast, these fathers described how being confronted with various 'typical milestones' reiterates the various opportunities for their son or daughter that have been lost.

However, whilst Arnett's theory of emerging adulthood has been utilised by many, it has also received criticism. In their conceptualisation of life transitions, Hendry and Kloep (2007; 2010) suggest how the transitions between developmental

stages may not be as smooth as Arnett (2000) proposes. Furthermore, they highlight how different individuals may reach different stages at different points and recognise that development through the stages is nonlinear and reversible (Baltes, 1987, 1997). An example of this can be seen in Peter's account of how his daughter Tamara tried living semi-independently; however, moved back home with the family when this did not work out. This suggests that Arnett's theory of emerging adulthood does not sufficiently account for the experiences in families where there is a YA with a disability. Furthermore, Arnett's theory has been criticised for being ethnocentric and not recognising how other factors such as social class, ethnicity and gender contribute to the options available to individuals in society (Côte, 2014; Hendry & Kloep, 2007; 2010).

However, as was reported in the present study, Thackeray and Eatough (2018) noted how fathers were at their most animated when speaking about the joy and happiness that their son or daughter brings into their lives. Thus, despite navigating these challenges and difficulties, fathers still report positive experiences with their son or daughter. This supports the finding of Goff et al. (2016) who looked at parents of children with DS at different life span ages. They found that in addition to challenges experienced, such as, adjusting to their son or daughter's current development stage, parents of YAs over the age of 18 with DS may also be able to recognise and describe their son or daughter's achievements.

Another related finding in the present study, was a sense from some fathers of a loss of their own expectations relating to the future. As discussed in the introduction, Family System's Theory (Turnbull, Turnbull, Erwin, Soodak & Shogren, 2011) can be useful to understand the whole family, and the impact of different developmental stages in the family life cycle. In considering this theory, the transition from adolescence to adulthood may be a time whereby parents look towards their own future beyond parenting and start to make plans for retirement. This finding is echoed within the wider literature that has explored experiences of parents who have a YA with an ID or DD transition to adulthood (Dyke, Bourke, Llewellyn & Leonard, 2013; Todd & Shearn, 1995; Wong, Ruble & Brown, 2020; Young et al., 2017). However, the vision of retirement as an opportunity to connect

with one's own interests and have some time back for self may be a product of westernised culture.

### **Struggles with Acceptance/Denial**

During the interviews, fathers' responses suggested that even though they wanted to have accepted things for how they are, there were still difficulties in coming to terms with the new challenges that accompany their son or daughter's diagnosis during this developmental stage. Research has suggested that the transition to adulthood for individuals with disabilities is experienced by parents as "the second shock" and parallels the transition of receiving a diagnosis (Hanley-Maxwell, Whitney-Thomas & Pogoloff, 1995). Thus, given the magnitude of this time for parents, it is not surprising that fathers may be struggling to accept, or experiencing an element of denial.

One way of understanding the loss that fathers seem to be experiencing during this developmental stage, may be to consider Kübler-Ross' (1969) model of grief. This proposes five common stages that individuals go through in their process of grieving: denial, anger, depression, bargaining, and acceptance. It does not stipulate a time frame to go through these stages, and individuals can move back and forth through the stages at any point. Whilst acceptance signifies coming to terms with the 'new reality', denial is often a way of coping in which individuals choose to deny the difficulties experienced in front of them. For example, despite vocalising certain challenges across Richard's development, Jimmy stated: *"I can't think of anything that, that I'd want to change in all 19 years of his life."* However, despite this model offering a possible understanding of fathers' experiences in the present study, it is important to acknowledge that this model has been criticised for its lack of empirical evidence, conceptual clarity, and its proposition that everyone experiences these stages in their process of grief (Stroebe, Schut, Boerner, 2017).

Some similarities in this struggle for acceptance have been reported by Goff et al. (2016). Goff et al. found that parents of YAs with DS over the age of 18 described having accepted their son or daughter's diagnosis; however, that it is still a source of sadness. These parents described having periods of grief in recognising their child's limitations and missed opportunities. However, like the fathers reported in this study, parents described that it is *'just different'* and that this is who they are.

Finally, it is also important to recognise that it might have been difficult for fathers to be completely honest about how they are feeling. There was a sense from a couple of fathers that they felt they *should* be grateful and have accepted how these things are. Part of this may relate to an element of ‘social desirability bias’ (Edwards, 1957) whereby individuals choose to respond in a way they feel is considered most acceptable. It may be that to some extent, fathers in the current study were worried about how it might come across if they did not express fully accepting their son or daughter as they are. However, vocalising that they have accepted things as they are may also be a way of trying to minimise any feelings of guilt that some fathers seemed to experience for describing some of their difficulties.

### **Protector Versus Facilitator**

Fathers described experiencing conflicting thoughts in relation to their role as a parent to the YA and wanting to protect their son or daughter and keep them safe, whilst also wanting to facilitate greater independence and promote the next steps to adulthood. This conflict in role seems similar in some ways to that described by Docherty and Reid (2009) who explored mothers’ experiences of parenting this population. Mothers described recognising their son or daughter’s current abilities and needing to challenge their natural intuitions to protect them and keep them at home and try to find the right balance towards encouraging change. Similar findings were reported by Young et al. (2017) and Codd and Hewitt (2020) who found that parents experienced a tension between desiring independence for their son or daughter with an ID, whilst also not wanting to place them at risk and recognising their vulnerability. The conflict that these parents experience, may be partly explained by the value that western cultures place on goals such as independence and self-fulfilment. It is important to note that participants in Docherty and Reid, Young et al., and Codd and Hewitt’s studies also inhabit societies that place value on individualism and independence. It would be interesting to note if this conflict still exists in cultures that place greater value on interdependence.

However, in the current study there appeared to be additional factors contributing to this conflict in role. For some fathers, the thought of being separated from their son or daughter and not being with them daily seemed to amplify this conflict. Fathers spoke about how they would miss the young person tremendously

and questioned how they would cope if the YA were to move out. This finding emerged during Thackeray and Eatough's (2018) interviews with fathers of YAs with a DD, with one father describing how terrified he was of letting go of his son because he would "*miss him terribly*" and that he will "*have to bite the bullet.*" This description of having to force himself to facilitate this transition, is also similar to Jon's description in the present study when explaining that it was "*quite a big...wrench*" when his son moved into supported living. To better understand these fathers' experiences, it can be helpful to consider some of the changes that tend to occur in the family system during the period of adolescence where the young person is TD (McGoldrick, Carter & Garcia-Preto, 2014). For example, during this time, adolescents tend to place greater demands for independence, which in turn creates structural shifts within the family, and a renegotiation of roles to facilitate some of these changes. Furthermore, these demands can sometimes be a source of conflict between the adolescent and the parent (McGoldrick et al., 2014). For fathers in the present study, they may not have been met with some of the same demands for independence that may occur where the young person is TD, and resultantly, may not have experienced the same conflict in their relationship with the young person. In addition, due to the nature of having DS and the YA likely being more dependent on parents to take them to activities or to socialise with friends, there may not have been the same gradual decrease in attachment that may otherwise occur as adolescents typically start to spend less time with their parents. Therefore, it seems that for many fathers in the present study, they are caught between recognising the typical transitions that can occur at this age, and therefore wanting to support the next steps towards independence; however, are battling with their own feelings of attachment to their son or daughter.

For a couple of other fathers in the present study, the thought of handing over responsibility to someone else to look after their son or daughter also served to heighten any anxiety and exacerbate this conflict. This will be discussed in more detail under 'lack of trust in the system'; however, this was not a finding that seemed to emerge in either Docherty and Reid's (2009) study or discussed explicitly in Thackeray and Eatough's (2018) study. However, in both Thackeray and Eatough's and Codd and Hewitt's (2020) studies, parents spoke about difficult interactions with services, and therefore it is possible that these experiences, in

conjunction with recognising their son or daughter's vulnerability does contribute to this conflict.

Lastly, despite fathers feeling protective of their son or daughter, many fathers interviewed recognised that facilitating their son or daughter's independence was also important for them in terms of gaining time back for themselves. However, as pointed out by John, this may not be as straightforward as it sounds because generating greater independence for his son, typically means greater involvement from them as parents. Erikson's theory of psychosocial development (1950) can be used to understand the conflict that may be occurring for fathers at this age. According to Erikson, individuals move through eight psychosocial stages across the lifespan, and conflict is experienced at each stage. According to these stages, all fathers except one in the present study, would fit into the stage of 'middle adulthood' (40 to 65 years). Erikson proposes that the conflict experienced at this stage relates to 'generativity versus stagnation.' 'Generativity' refers to the process of promoting the wellbeing of the next generation and can typically be achieved by raising children and guiding them towards autonomy. Whereas 'stagnation' refers to a feeling of disconnectedness and feeling unable to contribute to society. Given that it may be harder to fulfil these acts of 'generativity' when parenting a YA with DS, it is understandable that fathers may be feeling more in conflict during this time when hoping to gain some time back for themselves and their own future. However, due to the nature of parenting a child with DS and family life often needing to revolve around the young person, fathers may also feel a sense of stagnation in terms of their own personal productivity, heightening the 'generativity versus stagnation' conflict. As with other stage theories, Erikson's theory has been critiqued for suggesting that these stages occur discretely. Furthermore, whilst it gives an overview of social and emotional development, it does not elaborate on the causes that underlie each developmental stage (Shaffer, 2009).

### **Responsibility Versus Avoidance**

Most fathers seemed to be conflicted in recognising their responsibility for considering the next steps for their son or daughter, whilst also wanting to avoid these changes, or the difficult feelings associated with this time. A similar finding of needing to anticipate the next steps and remain ahead was found in Docherty and



Reid's (2009) study of mothers' experiences. The mothers in this study also spoke about needing to guide and motivate the YA, which is an experience that fathers in the current study also spoke about. Jimmy expressed concern that his son would "*stagnate*" if they "*allowed him to just sit and do nothing.*" Furthermore, the mothers in Docherty and Reid's study described their role in organising their son or daughter's activities and knowing what is available for the YA. The findings of the current study echo this; however, whilst fathers discussed taking on some of the organisational responsibility, many fathers shared that their wife also took a significant role in this. Similar experiences have also been reported in the wider literature looking at this transition period for parents who have a YA with an ID or DD. For example, parents are required to play an active role in organising post-secondary education, employment, social participation, and residential living (Chambers, Hughes & Carter, 2004; Cheak-Zamora, Teti & First, 2015; Dyke, Bourke, Llewellyn & Leonard, 2013; Leonard et al., 2016; Stewart et al., 2010, 2014; Young et al., 2017).

Fathers also spoke about a responsibility for thinking about when they are no longer around, or how parenting might look in older age, and the impact on this for them and their son or daughter. Again, this finding also emerged from Docherty and Reid's (2009) study whereby mothers expressed worries about ageing and how their son or daughter would cope. Mothers also described not wanting other siblings to have to take on the responsibility for care in the future. This was something that a couple of fathers also spoke about in the current study, with William describing how he would not want to "*put too much of a burden*" on his other daughters. Again, this is a finding that has consistently been replicated in the wider literature exploring experiences of parenting a YA with an ID or DD during this time (Leonard et al., 2016; Goff et al., 2016; Wong, Ruble & Brown, 2020; Young et al., 2017).

However, whilst there appear to be many similarities in the literature regarding the additional responsibility that fathers describe experiencing, the conflict that fathers seem to experience between responsibility and avoidance does not seem apparent in the studies described that have focused on mothers' experiences or parenting experiences generally where the sample is biased towards mothers. Interestingly, in Thackeray and Eatough's (2018) study that explored fathers'

experiences of parenting a YA with a DD, they found that fathers appeared to avoid difficult emotions and tried to resist fully engaging in conversations which evoke anxiety. Thackeray and Eatough suggested that this may be a coping mechanism that fathers employ to prevent themselves from experiences that are potentially overwhelming. The finding that men are more likely to rely on avoidance as a coping strategy, both in terms of repressing difficult emotions, as well as avoiding difficult situations is supported in the wider literature (Pelchat et al., 2009); however, Mahalik et al. (2005) suggests that consequently, other people, especially family members, may interpret this as men being emotionally distant. Considering that several of the fathers in the present study shared that they had told me things that they had not told their wives, it would be interesting to know how this action has been interpreted.

## **Guilt**

### **Negotiating current developmental stage.**

Another finding was that for many of the fathers, this current developmental stage also seemed to bring about feelings of guilt.

One father spoke about feeling that he is not able to provide for his daughter in the way he would have liked. He described how he would like to be more involved; however, it was his responsibility to earn enough money to provide for the family. As discussed in the introduction, according to Identity Theory (Stryker & Burke, 2000), our identities are influenced by society, and how individuals see themselves in different roles will impact on their thoughts, feelings, and behaviour in that role. Similar identification with traditional masculine identities were found in Thackeray and Eatough's (2018) study. Although there was variation in how fathers were involved in parenting their son or daughter, two of the fathers specifically spoke about adopting a breadwinner identity.

The tendency to reduce masculinity to certain key traits stems from the assumptions underpinning sex role theory; that disparities between the sexes result from an individual's biologically determined sex. Based on this concept, Robert Brannon (1976) summarised the four key traits of masculinity: 'no sissy stuff' (i.e., avoiding any characteristics associated with femininity); 'be a big wheel' (i.e., masculinity is measured by success and power); 'be a sturdy oak' (i.e., to be

masculine means being tough and self-reliant); and ‘give ‘em hell’ (i.e., men must take risks to ‘become the big wheel’), highlighting how ‘the male script’ has been socially constructed. However, the assumption that masculinity can be reduced in this way has been widely critiqued (e.g., Connell, 1995; Liu, 2016; Mahlik, 2014). One such critique is that the concept of masculinity has typically been constructed using convenience samples of white, western males. However, research needs to consider various aspects of intersectionality, such as: ethnicity, class, age, sexual orientation, rather than make generalisations (Gough, Robertson & Robinson, 2016; Liu, 2016).

Traditional parental roles that place fathers as the ‘breadwinner’ are built upon these masculine identities. However, as can be seen in the present study, trying to keep up to these masculine ideals, in conjunction with modern expectations of fatherhood can be stressful if fathers feel they are falling short. This is a finding that has been repeatedly found in the literature (O’Neill, 2008). This added pressure that fathers may experience because of this conflict may be increased in families where there is a child with a disability, particularly if they are not able to meet the higher financial demands that typically occur (Dobson, Middleton & Beardsworth, 2001). Previous research has found that parents of YAs with a DD vocalised concerns that the transition to adulthood would create additional financial pressure if funding did not cover what was needed (Leonard et al., 2016).

Two other fathers described feeling uncertain whether they had done enough for their sons as they recognised their son’s current level of academic ability. A similar finding emerged in Wong, Ruble and Brown’s (2020) study that looked at parents’ adaptation process during this time when parenting a YA with ASD. It is important to note that out of the 13 parents interviewed, only three were fathers; however, they reported how several parents described feeling guilty towards their son or daughter because they felt they could have done better. Unfortunately, the authors of this study did not provide any further information regarding this. In considering the expanded family life cycle proposed by Carter and McGoldrick (1999), it is possible that in witnessing their son or daughter’s peers complete education and consider the next steps in their journey, that fathers may start to question their own role in their YAs’ progress. As a result, fathers may feel guilty as

they question whether they have ‘done enough.’ Additionally, societal expectations can influence how an individual sees themselves, and defines what is important (Gergen, 1991). Therefore, the focus on academic ability may be in part a product of living in a westernised society that generally places value on personal success and independence, whereby academic success may be seen as a marker for these achievements.

For two other fathers, there was a sense of guilt in describing the difficulties experienced or sharing that they had moments of wondering what life might be like if their son did not have DS. It seemed that the conflict in sharing many positive experiences with their sons as well as recognising the strength of their current relationship partly contributes to this feeling of guilt. The guilt that fathers in the current study seem to experience because of these conflicting thoughts and feelings towards the YA may be partly understood by considering Festinger’s (1957) cognitive dissonance theory. According to the theory, all individuals have an inner desire to find harmony amongst their attitudes and behaviours. As a result, any inconsistency in thoughts and behaviours creates dissonance, and individuals will typically try to avoid this discomfort by taking steps to minimise this dissonance. It may be that in highlighting the difficulties created by the wider system, this serves to minimise some of the guilt by making sense of their difficulties.

However, it is also important to recognise the impact that the wider system has on the experiences of an individual and their families. Considering Bronfenbrenner’s Ecological Systems Theory (1977) can support with this. For example, it may be that if there were increased opportunities and services available for the YA in the area which they live (i.e., the microsystem), that fathers’ experiences may feel slightly easier as there might be less pressure on them to find ways to occupy the YA’s time. This may then partly reduce this feeling of guilt for experiencing or expressing these difficulties. However, changes at the level of the microsystem would also rely on change at the macrosystem to make society more inclusive and would require increased funding to be placed into supporting people with disabilities to have equal opportunities. Similarly, if the opportunities for the YAs increased and pressures on fathers were reduced, fathers may gain some time

back for themselves which may reduce the need for fathers to express this wish, and in turn, minimise the guilt experienced.

Recognising the impact of the wider system on parents' emotional experiences has been discussed in previous literature. Green (2007) explored mothers experiences' of parenting a child with a variety of disabilities and identified a range of both positive and negative experiences. Many of the mothers in their study perceived that their 'burden of care' was a result of restrictions and limitations placed on them by society, rather than emotional distress.

### **Navigating the next steps.**

Many fathers also seemed to experience feelings of guilt as they considered the next steps towards adulthood for their son or daughter. For some, this was related to a sense that things *should* change now the YA had reached 18 years, or a discomfort in recognising some of the limitations that they are currently placing on their son or daughter. In their review of the literature relating to the developmental and social constructions of adulthood for young people with ID, Redgrove, Jewell and Ellison (2016) discuss how adulthood and 'emerging adulthood' have not been conceptualised for young people with ID. It is possible that this lack of clarity about how 'emerging adulthood' might look for a YA with an ID may contribute to fathers experiencing guilt as they struggle to navigate this non-normative transition for their son or daughter with little guidance as to how this next phase might look. This may be even more challenging, as in the current study, where families also have, or have had YAs that are TD and whose experiences may align more closely with those described by Arnett (2000).

For other fathers, these feelings of guilt seemed to be brought about by recognising that they were holding back on the next steps or not dedicating enough time to facilitate the next steps as much as they feel they should. It seems that as fathers start to notice and compare how their son or daughter is doing in comparison to other YAs of this age, that this may bring about feelings of guilt as fathers start to doubt whether they are doing enough to facilitate the next steps. However, as discussed previously, the wider system may also be contributing towards some of these feelings of guilt. John spoke specifically about how he would like to be supporting his son to develop life skills and cooking; however, that he is not able to

become more involved unless he can significantly reduce his earnings. In considering Bronfenbrenner's Ecological Systems Theory (1977), if changes were to be made at the macrosystem which were to reduce the need for parents to earn more money to support their family, this may reduce some of the pressure these parents face. Thus, the findings suggest that some fathers may be caught between wanting to be more involved in facilitating the next steps but feel unable to due to the additional pressures that the wider system places on these families to meet the YA's needs.

### **Hope Versus Uncertainty and Worry**

All fathers seemed to be trying to hold onto feelings of hope, whilst also describing navigating the uncertainty of the next steps. This finding partially echoes that of Goff et al. (2016) who found that parents of YAs with DS experienced additional challenges, including: concerns towards the future, financial worries, a fear about what will happen when they are no longer around, and concerns about the YA's living arrangements long-term. Furthermore, in Docherty and Reid's (2009) exploration of mothers' experiences, their superordinate theme of 'Identifying stages of development: What's the next stage?' suggests some uncertainty as mothers describe trying to anticipate the next stages in their child's development. The unpredictability of the next steps and the sudden worry that accompanies this was reported in Codd and Hewitt's (2020) exploration of parents' experiences as their son or daughter with an ID transitions to adulthood. Codd and Hewitt reported that one of the mothers stated: "*I'm still not sure what we were transitioning from and to*", highlighting the confusion that parents seem to be experiencing during this non-normative transition. It is important to recognise that only three out of the ten parents interviewed were fathers, and only three of the YAs had DS; however, it replicates the finding that this period of time brings about additional uncertainty and worry for parents. Furthermore, highlighting the complexity of parenting a YA with DS during this developmental stage when the transition is non-normative.

Whilst not specifically focusing on fathers, experiences of both hope and uncertainty that map closely onto those discussed by fathers in the present study have been documented in the wider literature for parents who have a YA with DS, ID or DD. For example, parents describing feeling hopeful that their son or daughter has acquired a job or might acquire a job, whilst also expressing doubt and

uncertainty in relation to the YA's future or worries about when they are no longer around (Hudnall, 2014; Wong, Ruble & Brown, 2020; Young et al., 2017). Leonard et al. (2016) found that parents expressed uncertainty around what opportunities are available and the need to establish new routines following school, whilst also describing feeling hopeful that this next stage of life would bring about new chances that would allow their son or daughter to lead a full and meaningful life. However, because these authors grouped parents' experiences together, rather than presenting them individually, it is not possible to determine if the uncertainty and hope reported in these studies is experienced in conflict as was found in the current study.

Whilst most of the fathers interviewed seemed to describe a balance between hope and uncertainty, John vocalised that he knew he was sounding "*fairly pessimistic.*" In speaking with John, there was the sense that as a family, they were right in the middle of thinking about the future and trying to get things in place for his son, Frank. In noticing the age of the YAs of the fathers interviewed, Frank falls in the middle at aged 22 years, whereas most of the other YAs fall at either end of the age bracket interviewed, either 18, 19 years old or 24 years old. It is possible that there is perhaps more hope early on as fathers start to consider these next steps, and again, later down the line if the YA has been able to secure a part-time job, or a place in supported accommodation.

Lastly, for a few of the fathers, there was the sense that they were trying to manage their uncertainty by taking things one day at a time and try not to have too high expectations for their son or daughter's future. Therefore, whether intentionally or unintentionally, this may be another coping strategy that the fathers have employed to deal with the challenges of this transition period. There are some similarities in what fathers describe in the current study in comparison to what has been found in research on bracing and performance. Shepperd, Ouellette and Fernandez (1996) found that students lowered their predictions for upcoming exam scores nearer to receiving their grade. It has been suggested that lowering expectations can serve to minimise disappointment if negative outcomes occur due to lowered expectations acting as the reference point for evaluating the outcome (Shepperd et al., 1996; Carroll, Sweeny & Shepperd, 2006). Whilst these situations are very different, and fathers in the current study were discussing predictions

regarding their son or daughter's future, rather than their own, it may be that a similar strategy is being employed as a means of trying to avoid future disappointment if fathers' hopes are not met.

### **The System Limiting Future Hopes and Prospects**

All but one of the fathers in the current study seemed to experience a loss of hope that was related to the provisions in the wider system. For some fathers, this was experienced in relation to the education system and noticing that they had stopped doing tasks such as writing or focusing on speech and language that the YA still needed, due to their age. This finding did not emerge in either Docherty and Reid's (2009) or Thackeray and Eatough's (2018) studies; however, Wong, Ruble and Brown (2020) reported a similar finding in their exploration of parents of YAs with ASD. In this study, it was reported that parents expressed frustration that schools were not trying to adapt their curriculum to appropriately meet the YA's needs in relation to greater support with social skills.

Despite some of the difficulties experienced within schools, there was the sense from some fathers that the YA leaving school brings a different set of challenges as the responsibility then falls on parents to navigate what services are available to fill the YA's time. This finding is repeatedly discussed in the wider literature of both parents of YAs with DS (Goff et al., 2016) and parents of YAs with an ID (Codd & Hewitt, 2020; Leonard et al., 2016) with parents reporting how services seem to stop when the young person reaches adulthood. In the present study, John spoke explicitly about the "*bureaucracy*" that exists in the system and there was a real sense of lost hope as he described trying to find appropriate activities to fulfil his son Frank's needs and the barriers in securing the funds to do so. Similar frustrations and loss of hope emerged in Thackeray and Eatough's (2018) interviews of fathers of YAs with a DD. Fathers described how services were "*making an already difficult situation considerably worse*" and described experiences of the social care system as trying to minimise costs rather than putting the YA at the centre.

Fathers also vocalised concerns and disappointment relating to finding appropriate employment and accommodation for their son or daughter. Robert described how his son, Michael, has very clear visions of where he wants to live and



what he wants to do for his career; however, there was the sense that Robert recognised this may not be possible due to what provisions exist to accommodate this. In Hudnall's (2014) study exploring parents' views regarding what resources are needed to achieve their dreams for their YA with DS, 'barriers to success' emerged as a theme from the qualitative data. Parents described a lack of adequate and affordable housing options for the YA and vocalised a wish for increased job opportunities and job supports for YAs with DS. These findings have also been replicated in parents of YAs with ID (Dyke, Bourke, Llewellyn & Leonard, 2013; Young et al., 2017). Furthermore, Young et al., described how some parents had reported to have been promised funding for housing for their son or daughter, only for it later to be denied. The potential negative impact of a loss of hope on the fathers and families is significant. Seligman's (1972) concept of 'learned helplessness' explains how, if individuals are repeatedly made to feel they have no control over a situation, they will eventually just give up. However, this would likely have a significant impact on the quality of life for the father, their family, and the YA. Interestingly, in Blacher, Kraemer and Howell's (2010) study, they found that most parents of YAs with DS expected that their child would continue to live in the family home. However, it is possible that this discrepancy in findings is related to a societal shift that places greater focus on trying to promote independence for YAs with disabilities.

In making sense of fathers' experiences here, it is also useful to consider the Social Model of Disability (Oliver, 1983). The Social Model of Disability was introduced as a way of viewing the world that seeks to change attitudes towards people with disabilities. According to the model, individuals are disabled by the barriers in society, rather than due to any difference or impairment. Furthermore, the model advocates for society to remove these barriers to enable equal opportunities for people with a disability. In hearing fathers' experiences, it is apparent that there are still numerous limitations that society places on the young person, which in turn, impacts on fathers' experiences. For example, the appropriateness and availability of employment options and independent living options, or the level of educational input given post-18. In limiting these opportunities for YAs with DS at a societal level, this in turn influences fathers' beliefs and expectations relating to their son or daughter's future. Thus, also contributing to the conflicting experiences of

‘expectations versus reality’ and ‘hope versus uncertainty and worry’ discussed earlier on.

### **Needing to Fight the System to Get Needs Met**

Over half the fathers interviewed suggested the need to fight to get the YA’s needs met. Jon, whose son had already moved into supported accommodation, described how this process took “*months and months and months! Hundreds of hours of ... lobbying.*” Another father William also spoke about his role in advocating to get the best for his son, including an expectation that he might need to “*piss a few people off*” as it “*might not be running to their agenda.*” It seemed that fathers would do whatever it takes but felt disappointed and let down that this was necessary. A similar finding emerged from Thackeray and Eatough’s (2018) study, whereby three out of the five fathers interviewed described similar challenging interactions with providers of health and social care. One father vocalised that you “*have to be strong in order to fight it.*” It seems that in a similar manner to fathers in the current study, fathers felt the need to maintain vigilant to ensure that their child’s best interests are met.

In Docherty and Reid’s (2009) study, ‘needing to fight’ did not emerge as a key finding; however, mothers spoke about needing to educate themselves to ensure that they are aware of their rights to access resources. Thus, whilst perhaps expressed in a more subtle manner than in fathers’ descriptions in the current study, it seems that the complexities of navigating the system are shared amongst mothers and fathers. These findings are also supported in the wider parenting literature exploring parents’ experiences with a YA with ID. Codd and Hewitt (2020) found that parents of a YA with an ID described “*battling against services*” and reported that services don’t seem to “*make it that friendly in many ways.*” Other similar findings include political lobbying and being a strong parent advocate (Dyke, Bourke, Llewellyn & Leonard, 2013), as well as descriptions of the system as lacking in transparency and efficiency in decision making (Young et al., 2017).

In the current study, Jon raised a valid concern as to what this might mean for other parents who are not in the position to persevere or do not have the skills to navigate the processes in place. This concern was echoed in Codd and Hewitt’s (2020) study with one father reportedly describing interactions with professionals as

a “minefield if you don’t know what you’re doing.” Again, considering the concept of learned helplessness (Seligman, 1972), it is worrying how much perseverance is required, as families who have less support in place, or who are less resilient to setbacks, may understandably give up. As discussed previously, this could have a huge impact on the family, in terms of increased dependence and ongoing responsibility for the parents, and what this might mean for their quality of life. Whilst at the same time, limiting the likelihood of increased independence and opportunities for meaningful activity and involvement for the YA.

However, the resilience shown by the fathers in the current study does highlight a limitation of Bronfenbrenner’s Ecological Systems Theory (1977). Whilst Bronfenbrenner’s theory can provide a useful insight into the different environmental systems that surround an individual and can impact an individual, it has been critiqued for not explaining how individuals might thrive if placed in a difficult environment (Christensen, 2016; Engler, 2007). Engler argues that Bronfenbrenner’s theory should have an additional dimension of ‘resilience’ to account for an individual’s capacity to overcome such challenges and adversities. The perseverance and resilience shown by fathers in this study certainly provide support for this suggestion.

### **Lack of Trust in the System**

Some fathers vocalised that they were not yet ready to think about their son or daughter moving out. However, for those who seemed to be contemplating this next step, it seemed that a lack of trust in the wider system and providers of services was making this feel more challenging. A couple of the fathers interviewed expressed anxieties around reported “*horror stories*” in residential services. For example, William shared the following: “*as a parent, if he, if he got abused, how would you live with yourself?*” (line 426). Two other fathers shared concerns relating to handing over the care to other professionals and trusting that they will keep their son or daughter motivated and engaged in activities. This finding also emerged in Hudnall’s (2014) study when exploring parents’ views regarding their dreams for their YA with DS. In Hudnall’s study, one of the parents expressed how the options are “*basically nursing homes*” and “*you look at the type of people that are taking care of these people in nursing homes and it’s horrific.*”

This lack of trust in the system did not seem to emerge in Docherty and Reid's (2009) exploration of mothers' experiences. In their study, mothers appeared to speak quite optimistically about supported living, and any concerns about this transition did not appear to be related to a lack of trust in the system and services involved in the next steps. However, as previously described, three of the fathers interviewed in Thackeray and Eatough's (2018) study did vocalise experiencing challenges in their interactions with health and social care, and descriptions of the system as "*uncaring*" indicated that some of these fathers may also have experienced a lack of trust.

Finally, a lack of trust has also been reported in other areas of the system in the wider literature. For example, in their exploration of parents of YAs with ASD, Wong, Ruble and Brown (2020) described that the difficulties and tension that parents described experiencing with schools led to one parent recording all their meetings "*because of what [the school] were doing*". However, the authors did not provide any further details as to what this was. Furthermore, Codd and Hewitt (2020) found that parents of a YA with an ID described lacking trust in services and viewed professionals as lacking in competence. There was also a concern from one of the parents about professionals not respecting the families' wishes, and therefore resorting to best interest meetings to protect the YA and family's identity. These concerns echo those raised by William and Peter in the present study, with William describing how he was currently taking legal action to try and maintain "*control*" over his son's best interests.

Before discussing the strengths and limitations, I will first summarise the findings that are particular to fathers and those that are particular to DS.

### **Findings that are Particular to Fathers**

Firstly, whilst the literature would suggest that mothers of parents of YAs with DS also report feeling responsible for 'the next steps' of the YAs journey, and planning activities and finding out what is available for their son or daughter (Docherty & Reid, 2009), the conflict of '*responsibility vs avoidance*' that fathers in the present study experienced does not seem apparent in the literature reporting on mothers' experiences. A suggestion offered is that this may be a coping strategy that

fathers utilise, consciously or unconsciously, to navigate difficult experiences and feelings.

Secondly, several fathers in the present study seemed to experience guilt. Whilst the reasons for this guilt varied, for some fathers, this guilt appeared to be driven by a pressure to earn more money, and a feeling that this was the role of the father. Thus, it appears that fathers may experience added pressure due to the gender role conflict (O'Neill, 2008), and trying to balance modern expectations of fatherhood, alongside the traditional stereotypes of the 'breadwinner father.'

Thirdly, a couple of fathers spoke about not networking as much as the 'mothers' and asked me if I had heard of certain experiences before. It seems that this may contribute to the uncertainty and worry that fathers experience, in addition to any difficulties navigating the system, if fathers do not have these forms of informal support/networking opportunities.

### **Findings that are Particular to DS**

Firstly, a couple of fathers spoke about difficulties accepting how the YA participates in social situations. Given that individuals with DS are typically stereotyped as being very sociable, and having 'good people skills' (Down, 1866; Dykens, 2007; Fidler, Most & Philofsky, 2008), this may lead parents of individuals with DS to have these expectations, whereas research shows that individuals with DS can experience difficulties in developing interpersonal relationships (Cebula, Moore & Wishart, 2009; Wishart, Cebula, Willis & Pitcairn 2007). However, several fathers did speak of the strength of their relationship with the YA, and the YA's personality and sense of humour as one of the proudest qualities in their son or daughter.

Secondly, whilst experiencing challenges within the system is not unique to parenting a YA with DS and has been reported in the wider literature of parents of YAs with ASD and ID (e.g., Wong, Ruble & Brown, 2020; Codd & Hewitt, 2020), fathers in the current study did describe challenges that relate to DS specifically. A couple of fathers described feeling disappointed regarding the YA's continued education, and school/college not meeting the specific needs of YAs with DS regarding their speech and language needs.

Thirdly, several fathers appeared feeling guilty for experiencing difficulties, and sharing these with me during the interview. Again, given the claim of some researchers of a 'DS advantage' (Hartley, Seitzer, Head & Abbeduto, 2012; Ricci & Hodapp, 2003; Smith, Ronski, Sevcik, Adamson, & Barker, 2014), this may contribute to parents of individuals with DS feeling guilty for their experiences, and a feeling that they *'should'* feel grateful for how things are.

Lastly, whilst the conflict of *'protector vs facilitator'* has been found in the wider literature of parenting a YA with an ID (Codd & Hewitt, 2020; Young et al., 2017), it may be that due to associated health conditions being more common in individuals with DS (Perkins, 2017; Ram & Chinen, 2011; Roizen et al., 2014), that this conflict may be amplified where the YA has a DS diagnosis.

## **Strengths and Limitations**

### **Strengths**

One of the key strengths of this research is that it utilised a qualitative methodology to explore fathers' experiences. This is valuable as previous parenting research has tended to focus on mothers' experiences, despite fathers now being more involved than in previous decades. Thus, this research has provided the opportunity to give fathers a voice. Furthermore, conducting semi-structured interviews has enabled rich and meaningful data to be collected which is important given that Boyd et al.'s (2019) review identified that there are fewer qualitative studies in this area. I interviewed nine fathers for this research, which was at the upper end of what I had hoped to recruit. Whilst the intention in conducting IPA research is not to generalise the findings, this has meant that I have been able to hopefully gather a more accurate representation of fathers' experiences during this stage, whilst still respecting and capturing the individual experience.

Another key strength is that it solely looked at fathers' experiences of parenting a YA with DS. A significant limitation of previous research is that DDs have often been grouped together, which creates less homogeneity and risks losing experiences that relate to specific DDs. Whilst homogeneity of the sample is important in IPA research, it also felt important to explore parenting within the DS population due to less research being conducted in this area. Therefore, by only

interviewing fathers who had a YA with DS, it has been possible to gain a more accurate account of fathers' experiences within this population. This is particularly important given that families are offered non-invasive prenatal tests during pregnancy to screen for conditions such as DS. Whilst recognising that the current study only reflects the experiences of nine fathers, gathering more information of what it might be like parenting a child or adult with DS is also crucial to help parents make more informed choices around what this might look like.

It is also a strength of this research that the fathers included were recruited from different locations across the UK. Again, whilst there is no intention to generalise the findings, it does mean that the results are not only representative of one pool of fathers who may access the same services or support systems. This is important to recognise and adds weight when considering the clinical implications in understanding that these experiences and systemic challenges do not appear to be localised to one geographical location.

Lastly, the quality checks recommended by Yardley (2000) and Elliot, Fischer and Rennie (1999) were used throughout this study. Details of the steps taken to address these guidelines were discussed in chapter two.

### **Limitations**

Despite recruiting nine fathers to the study, which was at the upper limit of what I had hoped to recruit, this is still a small sample of participants, and therefore it is not possible to generalise the results. However, this was not the aim of the current study. In contrast, the aim was to meet the gap in the literature by conducting an exploratory study that captures rich and meaningful data about fathers' experiences of parenting this population.

Whilst the recruitment process proved successful, and I was able to stick to 'plan A' in terms of the inclusion criteria, there was still some heterogeneity introduced into the sample. Firstly, the inclusion criteria did not stipulate gender of the YA, and it is possible that there are differences between parenting male and female YAs with DS. However, because of the sample size and the methodology employed, it was not possible to explore if there were any experiences that were unique to parenting either a male or female YA with DS. Furthermore, though not diagnosed, according to their fathers, both female YAs were on the autistic

spectrum, thus increasing the heterogeneity in the sample. In addition, despite, all YAs falling within the age bracket of 18-25 years old, the findings suggest that there is quite a lot of variability in what YAs with DS might be doing in this period of time. However, including a relatively small range of ages has allowed for a broader picture of what fathers and YAs might be doing during this stage of life.

In addition, whilst not part of the inclusion criteria, all fathers self-reported to be 'white', 'white/British' or 'White/Caucasian' and appeared to be from relatively middle-class backgrounds. Furthermore, they were all married to the mother of the YA discussed in the interview, and all had at least one other child. On one hand, this can be seen as a strength in terms of increasing the homogeneity of the sample, on the other, this possibly represents a self-selection bias. It is important to recognise these demographics when considering the experiences of the fathers in this study and recognise that these experiences may look different for fathers from different socio-economic backgrounds, ethnicities, and family structures. Whilst not within the scope of the current study, it would be useful for future research to explore experiences of fathers from a variety of backgrounds to ensure we can gain a more detailed picture of fathers' experiences and that any additional support needs or recommendations for services are captured.

Despite implementing several of the quality checks recommended by Yardley (2000) and Elliot, Fischer and Rennie (1999), there were a couple of limitations to this. Firstly, whilst I shared full and part transcripts and sections of data with my supervisors at numerous time-points throughout the study, I did not share my analysis with the fathers interviewed. This would have been a helpful quality check and illustrated if the identified themes had face value to the participants. Unfortunately, this was not possible due to time constraints. Secondly, it needs to be acknowledged that whilst the parent consultants involved in this study may have some similar experiences to parents of YAs with DS, there may also be some differences. As discussed previously, the involvement of the parent consultants was extremely valuable; however, if future research is conducted in this area, it may want to consider involving fathers of YAs with DS in this process.

Lastly, in writing up the results, I wondered whether I should have captured specific information about the YA's ability and level of communication. Whilst this



information tended to come up informally at some point during the interview, it was not something that I asked specifically about. However, I wondered if this would have been useful information for the reader to contextualise the findings further.

### **Clinical Implications**

I will now discuss the implications of these research findings. It is recognised that the focus of this study was on the individual experience, and that the findings represent the experiences of only nine fathers. Therefore, it is recommended that any potential considerations for services are taken using a person-centred approach with respect for the diversity and intersectionality that individuals and families bring. The key implications for this research are presented below:

- Given the implications regarding prenatal testing and prospective parents being offered the opportunity to terminate their baby if abnormalities are detected, it is highly important to add to the literature to illustrate what it might be like to parent someone with DS. Furthermore, to ensure that research is inclusive of parenting experiences into adulthood now that individuals with DS are living longer.
- Hearing fathers in the current study speak about their son or daughter highlights the potential that can be achieved for a YA with DS. It is important that these positive experiences of parenting are captured to provide hope and optimism for these families.
- Despite fathers describing many positive interactions and experiences with their son or daughter, the results do also support previous findings that the transition to young adulthood can be a challenging time (Docherty & Reid, 2009; Goff et al., 2016). It is concerning to reflect on the extent to which fathers' experiences appear to be exacerbated due to the current system and provisions available for the YA. The findings highlight how the limited availability of appropriate supported accommodation, employment opportunities and facilities post-education place increased responsibility and pressure on fathers and families of YAs with DS. This seems to limit fathers' hopes and expectations for the YA's future and appears to fuel feelings of

guilt. This is concerning for two reasons: Firstly, the direct impact on fathers' ability to cope and maintain their own quality of life. Secondly, the limits that are placed on the YA's opportunity for growth and some form of semi-independent living. This highlights the need for providers of health and social care and relevant stakeholders to consider increasing the funding that is going into providing such services for this population. In addition, for services to consider whether they can offer respite care to families during this time – recognising that for other parents, the responsibility may have decreased, whereas for fathers and families of YAs with DS, the responsibility is amplified once the young person leaves the education system.

- The findings also highlighted how difficult these fathers described the process of 'letting go.' This indicates that it is important for services to work with families and try to engage fathers to better understand how they can be supported at this time given this non-normative transition. It may be helpful if relevant services engage the family in an extended transition process that facilitates discussion around 'the next steps', as well as providing an opportunity for fathers to develop the trust and relationships with services that currently seems to be lacking. Fathers may also benefit from a forum to discuss and ask questions about how to facilitate this process where the transition is non-normative. Trying to support this process will be key, not just for the fathers, but also to support the YA to ensure that families are not inadvertently holding back on the YA's independence due to their own worries and uncertainties of the future.
- In speaking to these fathers, it seemed as though many did not seem to know or speak to other fathers who were in a similar situation. Fathers may also benefit from more informal options of support, such as a support group for dads to connect with other fathers who also parent a YA with DS. This could provide a space for fathers to share some of their experiences (if they wanted), provide support, and perhaps share knowledge and ideas during this process.
- Lastly, fathers' experiences of accessing and interacting with services highlighted the additional barriers that fathers face in trying to get the YA's

needs met. This is another concern, firstly for the parents engaging in this process, and the time and energy that appears to be needed to secure funding or access to services. Secondly, for the YAs who do not have a parent or guardian who is equipped with the skills, knowledge, or perseverance to secure the opportunities to enable them to have a full and meaningful life. Relevant services may want to consider the accessibility and ease of the current processes in place.

### **Future Research**

The focus of the present study was to explore the experiences of fathers parenting a YA with DS. Given that this does not appear to be an area that has been researched before, this study has provided useful insight into fathers' experiences of parenting during this stage of development and provides a starting point for future research. Whilst IPA was best placed to answer the research question in the current study, future researchers should consider using both quantitative and qualitative methodologies, as well as widening the sample criteria as discussed within the limitations section. This will be helpful in increasing understanding into fathers' experiences and further understand any support needs or challenges experienced. This may result in additional recommendations to services to better meet the needs of these families. Some specific areas for future research are suggested below.

- It would be interesting for future research to consider having a follow-up element to their study. Whilst the present study captured fathers' hopes and wishes for their YA's future, it would be beneficial to learn whether certain aspirations for future jobs or transitions to semi-independent living for the YA take place and the consequential impact on the psychological well-being of fathers if this did or did not happen.
- It could also be useful to hear from fathers of YAs who are slightly older. Due to the sampling method used in the present study, there were greater numbers of YAs in the sample closer in age to the lower end of the bracket (18 and 19 years old), and only two YAs near the top end at 24 years old. However, given that YAs with DS finish school and attend college slightly later than children who are TD, some of the changes and considerations

around jobs and supported living inevitably seem to occur at a slightly later age. Hearing from more fathers who are in the middle of these processes would be helpful.

- It could also be helpful for studies to explore in more detail fathers' experiences of parenting a YA with DS at specific ages, to enable researchers and clinicians to find out more about key times of support. Linked with this, to gather more specific information regarding fathers' experiences within various parts of the system, including aspects that they feel has gone well, in addition to any challenges or barriers to accessing support or getting needs met.
- Additionally, it could be helpful to hear from fathers of younger children with DS at different non-normative developmental stages. As highlighted in the literature review, current research that has focused on fathers' experiences of parenting a child with DS has tended to include children from a wide variety of ages (e.g., 3-30 years of age). This makes it harder to interpret the results due to the differences that occur for both the child and the parent at different stages of the life cycle.
- It was noticed that unintentionally, all fathers recruited to the present study had a least one other child and no siblings had any DDs. Following one of the interviews, a father emailed me to say that I did not explore the wider impact on siblings of having a family member with special needs, and how that affects parents, specifically fathers. It would be interesting to understand more about this and to find out, if, and how, having another child impacts on fathers' experiences and siblings' experiences - positively or negatively.
- Lastly, as well as conducting further research with fathers, it would be useful to find out more about other perspectives within the system (i.e., schools, SENCOs, local authorities, local charities, and providers of services). Gathering information from a wider perspective would hopefully elucidate areas that seem challenging and perhaps bridge the gap in trying to understand each other's needs and consider what can be done to make the system more accessible to these families.

## Conclusion

In conclusion, this piece of research explored fathers' experiences of parenting a YA, aged 18-25 with DS. Fathers' experiences were captured as three superordinate themes: 'Internal conflict: negotiating current developmental stage'; 'Internal conflict: navigating the next steps'; and 'Challenges of the system'. A group analysis of the data was conducted due to fathers sharing similarities in their experiences as well as differences.

Fathers seemed to experience a range of conflicting thoughts and feelings relating to negotiating this current developmental stage and navigating the next steps in the YA's journey. This conflict seemed to be brought about, in part, by recognising this stage as non-normative, in addition to the limitations placed on the YA by the wider system. Nearly all fathers described experiencing challenges in the system, and this appeared to exacerbate the internal conflict that fathers seemed to experience.

The resultant themes had both similarities and differences with previous research that have explored parenting experiences of YAs with DS, IDs, and DDs. Some of the key similarities relate to this developmental stage highlighting a loss of expectations, increased responsibility, uncertainty of the future, and challenges of the system. However, whilst the current study suggests that fathers may use avoidance as a coping strategy, this finding did not emerge when looking at mothers' experiences of parenting this population.

The findings suggest that providers of health and social care and relevant services consider what support is available for fathers and their families during this time, and what opportunities exist for the YA. Further research is needed to explore the experiences of fathers from different socio-economic backgrounds, ethnicities, and family structures. It is also suggested that future research is conducted within the wider system (e.g., schools, providers of services), to support in trying to understand how to better meet the needs of these families.

### **Final Reflections**

Despite finding this a challenging process to undertake, I have also found it to be extremely rewarding. Hearing fathers speak about their experiences of parenting a YA with DS has been a real privilege, and I truly hope that I have done them justice in analysing and writing up this research. I am aware of the current difficulties within the systems we inhabit and know that some of the fathers interviewed may feel that certain changes within the system are unlikely; however, I do hope that in shining a light on these fathers' experiences, this research may strengthen the argument for increased funding and services for these fathers and their families.

## REFERENCES

- Ahlborg, T. & Strandmark, M. (2001) The baby was the focus of attention – first-time parents’ experiences of their intimate relationship. *Scandinavian Journal of Caring Sciences* 15, 318–325.
- Alexander, M., Petri, H., Ding, Y., Wandel, C., Khwaja, O. & Foskett, N. (2016). Morbidity and medication in a large population of individuals with Down syndrome compared to the general population. *Developmental Medicine and Child Neurology*, 58, 246–54.
- Allen, S. M., & Hawkins, A. J. (1999). Maternal gatekeeping: Mothers’ beliefs and behaviors that inhibit greater father involvement in family work. *Journal of Marriage & the Family*, 61, 199–212.
- Arnett, J. J. (2000) Emerging adulthood: a theory of development from the late teens through the twenties. *American Psychologist* 55, 469–480.
- Armijos-Yambay, K. & Sierra, J. A. J. (2019). Fathers matter too! Lived experience of pedagogical hope in raising children with Down syndrome. *Journal of Intellectual Disability Research*. doi: 10.1111/jir.12689.
- Altintas, E., & Sullivan, O. (2017). Trends in fathers’ contribution to housework and childcare under different welfare policy regimes. *Social Politics*, 24, 81–108. <https://doi.org/10.4054/DemRes.2016.35.16>.
- Azar, M., & Badr, L. K. (2010). Predictors of coping in parents of children with an intellectual disability: Comparison between Lebanese mothers and fathers. *Journal of Pediatric Nursing*, 25, 46–56. <https://doi.org/10.1016/j.pedn.2008.11.001>.
- Baltes, P. B. (1987). Theoretical propositions of life-span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology*, 23, 611–626.
- Baltes, P. B. (1997). On the incomplete architecture of human ontogenesis: Selection, optimisation, and compensation as foundations of developmental theory. *American Psychologist*, 52, 366–381.

- Barclay, L., & Lupton, D. (1999). The experiences of new fatherhood: A socio-cultural analysis. *Journal of Advanced Nursing*, *29*, 1013–1020.
- Barak-Levy, Y., & Atzaba-Poria, N. (2013). Paternal versus maternal coping styles with child diagnosis of developmental delay. *Research in Developmental Disabilities*, *34*, 2040–2046. <https://doi.org/10.1016/j.ridd.2013.02.026>.
- Barnes, C. (1997). Theories of disability and the origins of the oppression of disabled people in Western society. In L. Barton (Ed.), *Disability & society* (pp. 43–60). London: Longman.
- Baron, S., Riddell, S. & Wilson, A. (1999). The secret of eternal youth: identity, risk and learning difficulties. *British Journal of Sociology of Education* *20*, 483–499.
- British Association for Supported Employment (2020). Employment Rates for People with Disabilities 2019/20. Retrieved from: <https://www.base-uk.org/employment-rates>
- Bearss, K., Johnson, C., Handen, B., Smith, T., & Scahill, L. (2013). A pilot study of parent training in young children with autism spectrum disorders and disruptive behavior. *Journal of autism and developmental disorders*, *43*(4), 829-840.
- Beighton, C. & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: a systematic review and narrative synthesis. *Journal of applied research in intellectual disabilities*. *32*, 1255 – 1279.
- Belsky, J., & Pensky, E. (1988). Marital change across the transition to parenthood. *Marriage and Family Review*, *12*, 133–156.
- Bentley, G. E., Zvonkovic, A., McCarty, M., & Springer, N. (2015). Down syndrome and fathering: An exploration of ambiguous loss. *Fathering*, *13*, 1–17. <https://doi.org/10.3149/fth.1301.1>.
- Beresford, B. (1994). Resources and Strategies: How Parents Cope with the Care of a Disabled Child. *Journal of Child Psychology and Psychiatry*, *35*, 171-209.



Berger, J. & Cunningham, C. C. (1981). Development of eye contact between mothers and normal versus Down syndrome infants. *Developmental Psychology, 17*, 678-689.

Blacher, J., Kraemer, B. R. & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in mental health and learning disabilities, 4*, 3- 16.

Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging, 19*, 668–675.

Bostrom, P., & Broberg, M. (2014). Openness and avoidance—A longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 58*, 810–821. <https://doi.org/10.1111/jir.12093>

Bourke-Taylor, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Australian Occupational Therapy Journal, 57*, 127–136. <https://doi.org/10.1111/j.1440-1630.2009.00817.x>

Boyd, M. J., Iacono, T., McDonald, R. (2019). The perceptions of fathers about parenting a child with developmental disability: a scoping review. *Journal of Policy and Practice in Intellectual Disabilities*. doi: 10.1111/jppi.12287.

Bradley, E., Mackenzie, M., & Boath, E. (2004). The experience of first-time fatherhood: A brief report. *Journal of Reproductive and Infant Psychology, 22*, 45–47.

Brannon, D. (1976) The male sex role: our culture's blueprint for manhood and what it's done for us lately. In: David, D. Brannon, R. (Eds) *The Forty-Nine Percent Majority: The Male Sex Role*. Reading, MA: Addison-Wesley.

Bretherton, I. (2010). Fathers in attachment theory and research: A review. *Early Child Development and Care, 180* (1–2), 9–23.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Bromley, J., Hare, D. J., Davison, K. & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health

status and satisfaction with services. *Autism: The International Journal of Research & Practice*, 8(4), 409–423.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32, 513-531.

Capone, G., Goyal, P., Ares, W. & Lannigan, E. (2006). Neurobehavioral disorders in children, adolescents, and young adults with Down syndrome. *American Journal of Medical Genetics*. 142C, (3), 158–172.

Carter, E. & Mc Goldrick, M. (1999). The family life cycle and family therapy: an overview. In E. Carter & M. McGoldrick (Eds.). *The family life cycle: A framework for family therapy*. (pp.3-20) New York: Gardner Press, Inc.

Carroll, P., Sweeny, K., & Shepperd, J. (2006). Forsaking optimism. *Review of General Psychology*, 10, 56 –73

Carvajal, F. & Iglesias, J. (2000). Looking behavior and smiling in Down syndrome infants. *Journal of Nonverbal Behavior*, 24, 225-236.

Cebula, K. R., Moore, D. G. & Wishart, J. G. (2009). Social cognition in children with Down's syndrome: challenges to research and theory building. *Journal of Intellectual Disability Research*, 54, (2), 113-134.

Centers for Disease Control & Prevention. (2020). Facts about Developmental Disabilities. Retrieved from:  
<https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>.

Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, 39, 79–94.

Cheak-Zamora, N.C., Teti, M. & First, J. (2015). Transitions are scary for our kids, and they're scary for us': Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of applied research in intellectual disabilities*. DOI:10.1111/jar.1215.

Chin, R., Hall, P. & Daiches, A., (2011). Fathers' experiences of their transition to fatherhood: a metasynthesis. *Journal of Reproductive and Infant Psychology*, 29, 4–18.

Christensen, J. (2016). A critical reflection of Bronfenbrenner's development ecology model. *Problems of Education in the 21st Century*, 69, 22–28.

<https://doi.org/10.13140/RG.2.1.2959.7681>

Coad, J., Kaur, J., Ashley, N., Owens, C., Hunt, A., Chambers, L. & Brown, E. (2015). Exploring the perceived met and unmet need of life-limited children, young people and families. *Journal of Paediatric Nursing*, 30, 45–53.

Codd, J. & Hewitt, O. (2020). Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective. *British Journal of Learning Disabilities*, 49, 39–51. <https://doi.org/10.1111/bld.12327>

Collacott, R. A., Cooper, S. A. & McGrother, C. (1992). Differential rates of psychiatric disorders in adults with Down's syndrome compared with other mentally handicapped adults. *British Journal of Psychiatry*. 161 (5), 671–674.

Condon, J. (2006). What about dad? Psychosocial and mental health issues for new fathers. *Australian Family Physician* 35, 690–692.

Connell, R. (1995). *Masculinities*. Sydney: Polity Press

Cooper, S. A. & Collacott, R. A. (1994). Clinical features and diagnostic criteria of depression in Down's syndrome. *British Journal of Psychiatry*, 165, 399–403.

Corrice, A. M., Glidden, L. M. (2009). The Down syndrome advantage: Fact of fiction? *American Journal on Intellectual & Developmental Disabilities*, 114, 254-268. doi:10.1352/1944-7558-114.4.254-268.

Côté, J. (2014). 'The Dangerous Myth of Emerging Adulthood: An Evidence-Based Critique of a Flawed Developmental Theory.' *Applied Developmental Science*. 18 (4):177-188

Cowan, C. P., & Cowan, P. A. (1995). Interventions to ease the transition to parenthood: Why they are needed and what they can do. *Family Relations*, 44, 412–423.

Cowan, P. A., & Cowan, C. P. (1988). Changes in marriage during the transition to parenthood: Must we blame the baby? In G. Y. Michaels & W. A.

Goldberg (Eds.). *The transition to parenthood: Current theory and research* (pp. 114–154). New York: Cambridge University Press.

Cowan, P. A., & Cowan, C. P. (1998). New families: Modern couples as new pioneers. In M. A. Mason, A. Skolnick, & S. D. Sugarman (Eds.), *All our families: New policies for a new century* (pp. 169–192). New York: Oxford University Press.

pCox, M. J., Paley, B., Burchinal, M., & Payne, C. C. (1999). Marital perceptions and interactions across the transition to parenthood. *Journal of Marriage and the Family*, *61*, 611–625.

Crohan, S. E. (1996). Marital quality and conflict across the transition to parenthood in African American and White couples. *Journal of Marriage and the Family*, *58*, 933–944.

Crowe, T. K., & Florez, S. I. (2006). Time use of mothers with school age children: A continuing impact of a child's disability. *The American Journal of Occupational Therapy*, *60*, 194–203.

Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2008). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice*, *97*, 1–10. <https://doi.org/10.3104/reviews/2079>.

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Davern, M., & Reddihough, D. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health & Development*, *36*, 63–73. <https://doi.org/10.1111/j.1365-2214.2009.00989.x>

Davys, D., Mitchell, D., & Martin, R. (2017). Fathers of adults who have a learning disability: Roles, needs and concerns. *British Journal of Learning Disabilities*, *45*(4), 266–273. doi:10.1111/bld.12205.

D'Haem, J. (2008). Special at school but lonely at home: An alternative friendship group for adolescents with Down syndrome. *Down Syndrome Research & Practice*, *12*, 107–111.

DiNuovo, S. & Buono, S. (2011). Behavioral phenotypes of genetic syndromes with intellectual disability: Comparison of adaptive profiles. *Psychiatry Research*, *3*, 440–445

Deave, T. & Johnson, D. (2008). The transition to parenthood: What does it mean for fathers? *Journal of Advanced Nursing*, 63, 626–633.

Demo, D. H., & Cox, M. J. (2000). Families with young children: A review of research in the 1990s. *Journal of Marriage and the Family*, 62, 876–895.

Dobson, B., Middleton, S. & Beardsworth, A. (2001). The impact of childhood disability on family life. Retrieved from:  
<https://www.jrf.org.uk/report/impact-childhood-disability-family-life>

Docherty, F. & Dimond, R. (2018). 'Yeah that made a big difference!': The importance of the relationship between health professionals and fathers who have a child with Down Syndrome. *Journal of Genetic Counseling* 27 (3), 665-674. 10.1007/s10897-017-0171-y file.

Docherty, J. & Reid, K. (2009) 'What's the next stage?' Mothers of young adults with down syndrome explore the path to independence: a qualitative investigation. *Journal of Applied Research in Intellectual Disabilities* 22, 458–467.

Dollahite, D. C. (2004). A narrative approach to exploring responsible involvement of fathers with their special-needs children. In R. D. Day & M. E. Lamb (Eds.), *Conceptualizing and measuring father involvement* (pp. 109–127). Mahwah, NJ: Erlbaum.

Down, J. L. H. (1866). Observations on an ethnic classification of idiots. *London Hospital Clinical Lecture Reports*, 3, 265–262.

Down's Syndrome Association. (2016). About Down's Syndrome: FAQs. Retrieved from: <https://www.downs-syndrome.org.uk/about/general/>

Down's Syndrome Association. (2020). Screening, diagnosis and support. Retrieved from: <https://www.downs-syndrome.org.uk/wp-content/uploads/2020/09/25.08.2020-Screening-diagnosis-support-final-1.pdf>

Durmaz, A., Cankaya, T., Durmaz, B., Vahabi, A., Gunduz, C., Cogulu, O. ... Ozkinay, F. (2011). Interview with parents of children with Down syndrome: their perceptions and feelings. *The Indian Journal of Pediatrics*, 78(6), 698-702.

Dyer, W. J., McBride, B. A., & Jeans, L. M. (2009). A Longitudinal examination of father involvement with children with developmental delays. *Journal of Early Intervention, 31*(3), 265–281.

Dyke, P., Bourke, J., Llewellyn, G. & Leonard, H. (2013) The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability, 38* (2), 149–162.

Dykens, E. M. (2007). Psychiatric and behavioral disorders in persons with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 272–278.

Dykens, E. M. & Kasari, C. (1997). Maladaptive behavior in children with Prader-Willi syndrome, Down syndrome and non-specific mental retardation. *American Journal of Mental Retardation, 102*, 228–237.

Dykens, E. M., Shah, B., Davis, B., Baker, C., Fife, T. & Fitzpatrick, J. (2015). Psychiatric disorders in adolescents and young adults with Down syndrome and other intellectual disabilities. *Journal of Neurodevelopmental Disorders, 7*, 1–8.

Elliot, R., Fischer, C. T. & Rennie, D. L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215 – 229.

Engler, K. (2007). *A look at how the ecological systems theory may be inadequate*. A Capstone project, Winona State University.

Edwards, A. (1957). *The social desirability variable in personality assessment and research*. New York: The Dryden Press.

Erikson, E. H. (1950). *Childhood and Society*. New York: Norton.

Evans, D. W. & Gray, F. L. (2000). Compulsive-like behavior in individuals with Down syndrome: Its relation to mental age level, adaptive and maladaptive behavior. *Child Development, 71*, 288–300.

Fägerskiöld, A. (2008). A change in life as experienced by first-time fathers. *Scandinavian Journal of Caring Science, 22*, 64–71.

Farkas, L., Cless, J. D., Cless, A. W., Nelson Goff, B. S., Bodine, E., & Edelman, A. (2019). The ups and downs of down syndrome: A qualitative study of positive and negative parenting experiences. *Journal of Family Issues, 40*(4), 518–539. <https://doi.org/10.1177/0192513X18812192>

Festinger, L. (1957). *A Theory of cognitive dissonance*. Stanford, CA: Stanford University Press.

Fidler, D. J. (2005). The emerging Down syndrome behavioral phenotype in early childhood: Implications for practice. *Infants and Young Children, 18*, 86–103.

Fidler, D. J., Most, D. E. & Philofsky, A. D. (2008). The Down syndrome behavioural phenotype: Taking a developmental approach. *Down Syndrome Research and Practice, 37–44*.

Finnbogadottir, H., Svalenius, E. & Persson, E. (2003). Expectant first-time fathers' experiences of pregnancy. *Midwifery 19*(2), 96–105.

Fleming, S.A., Fickenscher, C. Guditis, L. Bell, E. & Hultquist, A.K. (2013). Fathers' experiences after their child has been diagnosed with down syndrome: A phenomenological study. Dissertation Abstracts International: Section B: *The Sciences and Engineering, 74* (11-B(E)). ISSN: 0419-4217; ISBN: 978-1-303-24087-4.

Flouri, E., & Buchanan, A. (2004). Early father's and mother's involvement and child's later educational outcomes. *British Journal of Educational Psychology, 74*, 141–153.

Foley, K. R., Bourke, J., Einfeld, S. L., Tonge, B. J., Jacoby, P. & Leonard, H. (2015). Patterns of depressive symptoms and social relating behaviors differ over time from other behavioral domains for young people with Down syndrome. *Medicine 94*, 710. doi: 10.1097/MD.0000000000000710.

Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., . . . Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: Care, Health and Development, 39* (6), 789–80.

Fox, G. L., Nordquist, V. M., Billen, R. M., & Savoca, E. F. (2015). Father involvement and early intervention: Effects of empowerment and father role identity. *Family Relations*, *64*, 461-475. doi:10.1111/fare.12156

Franco, F. & Wishart, J. G. (1995). The use of pointing and other gestures by young children with Down syndrome. *American Journal of Mental Retardation*, *100*, 160–182.

Gatrell, C.J., Burnett, S., Cooper, C. L. C. & Sparrow, P. (2015) The Price of Love: The Prioritisation of child care and income earning among UK fathers. *Families, Relationships and Society*, doi.org/10.1332/204674315X14321355649771.

Gergen, K. (1991). *The saturated self: Dilemmas of identity in contemporary life*. New York: Basic Books

Glaser, B., & Strauss, A., (1967). *The Discovery of Grounded Theory*. Aldine Publishing Company, Hawthorne, NY.

Glasson, E., Dye, D. & Bittles, A. (2014). The triple challenges associated with age-related comorbidities in Down syndrome. *Journal of Intellectual Disability Research* *58*, 393–8.

Glenn, S., Dayus, B., Cunningham, C. & Horgan, M. (2001). Mastery motivation in children with Down syndrome. *Down Syndrome Research and Practice*, *7* (2), 52–59.

Glidden, L., Billings, F., & Jobe, B. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, *50*, 949–962. <https://doi.org/10.1111/j.1365-2788.2006.00929.x>.

Goff, B. S. N., Monk, J. K., Malone, J., Staats, N., Tanner, A. & Springer, N. P. (2016). Comparing parents of children with Down syndrome at different life span stages. *Journal of Marriage and Family* *78*, 1131–1148.

Gough, B., Steve, R. & Robinson, M. (2016) Chapter 8: Men, ‘masculinity’ and mental health: critical reflections. In J. Gideon (Ed). *Handbook on Gender and Health* (pp 134–147). DOI: <https://doi.org/10.4337/9781784710866.00018>.



Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, *56*, 631–642.

Green, S. E. (2007). “We’re tired, not sad”: benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, *64*, 150–63.

Hackel, L. S., & Ruble, D. N. (1992). Changes in the marital relationship after the first baby is born: Predicting the impact of expectancy disconfirmation. *Journal of Personality and Social Psychology*, *62*, 944–957.

Hall, W. A. (1992) Comparison of the experience of women and men in dual-earner families following the birth of their first infant. *Journal of Nursing Scholarship* *24*, 33–38.

Hall, W. A. (1994) New fatherhood: myths and realities. *Public Health Nursing* *11*, 219–228.

Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A qualitative study of parents’ perspectives and needs during their child’s transition from school to adult life. *Research and Practice for Persons with Severe Disabilities*, *20*, 3–15. <https://doi.org/10.1177/154079699502000102>

Hartley, S. L., Seltzer, M. M., Head, L., & Abbeduto, L. (2012). Psychological well-being in fathers of adolescents and young adults with Down syndrome, Fragile X syndrome, and Autism. *Family Relations*, *61*, 327–342. <https://doi.org/10.1111/j.1741-3729.2011.00693.x>.

Hatzmann, J., Maurice-Stam, H., Heymans, H. S., Grootenhuis, M. A. (2009). A predictive model of health-related quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system. *Health and Quality of Life Outcomes*, *7* (72), 9.

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping and future expectations. *Journal of Developmental and Physical Disabilities*, *14*, 159–171.

Hendry, L. B., & Kloep, M. (2007). Conceptualizing emerging adulthood: Inspecting the emperor’s new clothes? *Child Development Perspectives*, *1*, 74–79.

Hendry, L. B. & Kloep, M. (2010) How universal is emerging adulthood?

An empirical example, *Journal of Youth Studies*, 13, 2, 169-179, DOI: 10.1080/13676260903295067

Hill, C. M., Evans, H. J., Elphick, H., Farquhar, M., Pickering, R. M., Kingshott, R., .... Gringras, P. (2016). Prevalence and predictors of obstructive sleep apnoea in young children with Down syndrome. *Sleep Medicine*, 27–28, 99–106

Hodgson, A. R., Freeston, M. H., Honey, E., & Rodgers, J. (2017). Facing the unknown: Intolerance of uncertainty in children with autism spectrum disorder. *Journal of applied research in intellectual disabilities*, 30 (2), 336-344.

How, B., Smidt, A., Wilson, N.J., Barton, R., Valentin, C. (2018). “We would have missed out so much had we terminated: What fathers of a child with Down syndrome think about current non-invasive prenatal testing for Down syndrome”. *Journal of Intellectual Disabilities*, 1-20. doi: 10.1177/1744629518787606.

Huang, Y. P., Tsai, S. W., & Kellett, U. (2012). Fathers of children with disabilities: Encounters with health professionals in a Chinese context. *Journal of Clinical Nursing*, 21, 198–206. <https://doi.org/10.1111/j.1365-2702.2011.03826.x>

Hudnall, J. E. (2014). Parents' Dreams for Their Young Adults with Down syndrome: What Resources are Needed to Achieve Them?.(Master's thesis). Retrieved from: <https://scholarcommons.sc.edu/etd/2584>

Karmiloff-Smith, A., Al-Janabi, T., D'Souza, H., Groet, J., Massand, E., Mok, K., ...Strydom, A. (2016). The importance of understanding individual differences in Down syndrome. doi: 10.12688/f1000research.7506.1. PMID: 27019699; PMCID: PMC4806704.

Kayfitz, A. D., Gragg, M. N., & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities*, 23 (4), 337-343.

Kepreotes, E., Keatinge, D., & Stone, T. (2010). The experience of parenting children with chronic health conditions: A new reality. *Nursing and Healthcare of Chronic Illness*, 2, 51-62.

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing*, 51, 456–64.

Kleop, M., & Hendry, L. B. (2010). Letting go or holding on? Parents' perceptions of their relationships with their children during emerging adulthood. *British Journal of Developmental Psychology*, 28, 817-34.

Kluwer, E. S. (2010). From partnership to parenthood: A review of marital change across the transition to parenthood. *Journal of Family Theory and Review*, 2, 105–125.

Kneips, L. J., Walden, T. A. & Baxter, A. (1994). Affective expressions of toddlers with and without Down syndrome in a social referencing context. *American Journal of Mental Retardation*, 99 (3), 301–312.

Kowlessar, O. (2012). A qualitative exploration of men's transition to fatherhood and experiences of early parenting (Doctoral dissertation). University of Manchester, Manchester.

Kübler-Ross, E. (1969). *On Death and Dying*. Routledge. ISBN 0-415-04015-9.

Ladden, M. & Damato, E. (1992). Parenting and supportive programs. *Clinical Issues in Perinatal and Women's Health Nursing*, 3, 174–187.

Lamb, M. E. (2000). The history of research on father involvement: An overview. *Marriage and Family Review*, 29, 23 –42.

Lamb, M. E. (2010). *The role of the father in child development*. New Jersey: John Wiley and Sons, Inc.

Landsman, G. (2003). Emplotting children's lives: Developmental delay vs. disability. *Social Science & Medicine*, 56, 1947–1960.

Legerstee, M. & Fisher, T. (2008) Coordinated attention, declarative and imperative pointing in infants with and without Down syndrome: Sharing experiences with adults and peers. *First Language*, 28, 281-312.

Legerstee, M. & Weintraub, J. (1997). The integration of person and object attention in infants with and without Down syndrome. *Infant Behaviour and Development*, 20, 71–82.

Leonard, H., Foley, K., Pikora, T., Bourke, J., Wong, K., McPherson, L., ... Downs, J. (2016). Transition to adulthood for young people with intellectual disability: The experiences of their families. *European Child and Adolescent Psychiatry*, 25, 1369–1381.

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.

Liu, W. M. (2016). Masculinities on the verge: An editorial. *Psychology Of Men & Masculinity*, 17(1), 1-2. doi: 10.1037/men0000020.

Lopez, S., McWhirter, A. C., Rosencrans, M.t, Giuliani, N. R., & McIntyre, L. L. (2019). Father involvement with children with developmental delays. *Global Education Review*, 6 (1), 40-62.

Lowit, D. & Averill, M. B. (2014). Fathers Reflect on Their Experiences of the Receipt of a Postnatal Diagnosis of Down Syndrome or Trisomy 21. *Journal of Prenatal & Perinatal Psychology & Health*. 28 (3), 174-197.

Ludlow, A., Skelly, C., & Rohleder, P. (2012). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of health psychology*, 17 (5), 702-711.

Maatt, T., Tervo, Maatta, Taanila, A., Kaski, M. & Ilvanainen, M. (2006). Mental health, behavior and intellectual abilities of people with Down syndrome. *Down Syndrome Research and Practice*, 11, 37–43.

Mahalik, J. R. (2014). Both/and, not either/or: A call for methodological pluralism in research on masculinity [Commentary]. *Psychology of Men & Masculinity*, 15, 365–368. <http://dx.doi.org/10.1037/a0037308>

Mahalik, J.R., Talmadge, W.T., Locke, B.D. & Scott, R.P.J. (2005). Using the Conformity to Masculine Norms Inventory to Work with Men in a Clinical Setting. *Journal of Clinical Psychology*, 61, 6, 661-674.

Mason, C. F. (2002). *Biology of freshwater pollution*. Pearson Education.

Marshak L. E., Lasinsky E. E. & Williams C. (2018) Listening to fathers: personal impacts of raising children with Down syndrome. *Journal of Intellectual Disabilities*. 1– 7. <https://doi.org/10.1177/1744629518801112>

McAndrew, I. (1976). Children with a Handicap and their Families. *Child: Care, Health, and Development*, 2, 213-237.

McBride, B. A., Brown, G. L., Bost, K. K., Shin, N., Vaughn, B., & Korth, B. (2005). Paternal identity, maternal gatekeeping, and father involvement. *Family Relations*, 54, 360–372.

McBride, B. A., Curtiss, S. J., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J. & Kern, J. (2017). Father involvement in early intervention: Exploring the gap between service providers' perceptions and practices. *Journal of Early Intervention*. 39 (2), 71–87. <https://doi.org/10.1177/1053815116686118>.

McBride, A. B. & Shore, C. P. (2001) Women as mothers and grandmothers. *Annual Review of Nursing Research* 19, 63–85.

McCarron, M., McCallion, P., Reilly, E., Mulryan, N. (2014). A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*, 58, 61–70.

McGoldrick, M., Carter, B. & Garcia-Preto, N. (2014). *The Expanded Family Life Cycle. Individual, Family, Social Perspectives*. Fourth Edition. Harlow, Essex: Pearson Education Limited.

McKeever, P., & Miller, K.-L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine*, 59, 1177–1191.

Meadan, H., Stoner, J. B., & Angell, M. E. (2015). Fathers of children with autism: perceived roles, responsibilities, and support needs. *Early Child Development and Care*, 185, 1678–1694. <https://doi.org/10.1080/03004430.2015.1019876>

Miller, T. (2011). Falling back into gender? Men's narratives and practices around first-time fatherhood. *Sociology*, 45, 6, 1094-1109.

de Montigny, F. & Lacharite, C. (2004). Fathers' perceptions of the immediate postpartal period. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 33, 328–339.

Mundy, P., Sigman, M., Kasari, C. & Yirmiya, N. (1988). Nonverbal communication skills in Down syndrome children. *Child Development*, 59, 235–249.

Murphy, N., Christian, B. J., Caplin, D., Young, P. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, 33, 180-187. doi:10.1111/j.1365-2214.2006.00644.x.

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders*, 3 (3), 670-684.

National Down Syndrome Society (n.d.). What is Down Syndrome? Retrieved from <https://www.ndss.org/about-down-syndrome/down-syndrome/>

Naerland, T., Bakke, K. A., Storvik, S., Warner, G., & Howlin, P. (2017). Age and gender-related differences in emotional and behavioural problems and autistic features in children and adolescents with Down syndrome: a survey-based study of 674 individuals. *Journal of Intellectual Disability Research*, 61, 594–603.

Nystrom, K., Ohrling, K. (2004). Parenthood experiences during the child’s first year: literature review. *Journal of Advanced Nursing*, 46, 319– 30.

O’Brien, M. (2005). Shared Caring: Bringing Fathers into the Frame. Equal Opportunities Commission Working Paper Series number 18. Equal Opportunities Commission. Available at: <https://dera.ioe.ac.uk/5299/>

Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: Macmillan.

Olsson, P., Jansson, L. & Norberg, A. (1998). Parenthood as talked about in Swedish ante- and postnatal midwifery consultations. *Scandinavian Journal of Caring Sciences* 12, 205–214.

O'Neill, J. (2008). Summarizing 25 years of research on men's gender role conflict using the gender role conflict scale: New research paradigms and clinical implications. *The Counseling Psychologist*, 36 (3), 358-445

Office for National Statistics (2020). Divorces in England and Wales: 2019. Retrieved from:

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/divorce/bulletins/divorcesinenglandandwales/2019#number-of-divorces-and-rates>

Office for National Statistics (2021a). Employment, unemployment and economic inactivity by age group (seasonally adjusted). Retrieved from:

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/employmentunemploymentandeconomicinactivitybyagegroupseasonallyadjustedada05sa>

Office for National Statistics (2021b). Families and households. Retrieved from:

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/datasets/familiesandhouseholds>

Pacholok, S., & Gauthier, A. (2010). Non-participant fathers in time-use studies: Uninvolved or data artifact? *Social Indicators Research*, 96 (2), 249–66.

Pancer, S. M., Pratt, M., Hunsberger, B., & Gallant, M. (2000). Thinking ahead: Complexity of expectations and the transition to parenthood. *Journal of Personality*, 68, 253–280.

Parke, R. D. (2002). Fathers and families. In M. Bornstein (Ed.), *Handbook of parenting: Vol. 3. Being and becoming a parent* (2nd ed., pp. 27–73). Hillsdale, NJ: Erlbaum.

Patti, P. J. & Tsiouris, J. A. (2006). Psychopathology in adults with Down syndrome: Clinical findings from an outpatient clinic. *International Journal on Disability and Human Development*, 357–364,  
<https://doi.org/10.1515/IJDHD.2006.5.4.357>.

Pelchat, D., Lefebvre, H. & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of child health care*, 7 (4), 231 – 247.

Pelchat, D., Levert, M. & Bourgeois-Guerin, V. (2009). How do mothers and fathers who have a child with a disability describe their adaptation/ transformation process? *Journal of Child Health Care*, 13(3), 239-259.

Perkins, A. (2017). The lowdown on Down syndrome. *Wolters Kluwer Health*, 15(2), 40-46 doi: 10.1097/01.NME.0000511841.85763.77

Petch, J. & Halford, W. K. (2008). Psycho-education to enhance couples' transition to parenthood. *Clinical Psychology Review*, 28, 1125–1137. doi: 10.1016/j.cpr.2008.03.005.

Potter, C. A. (2017). “I received a leaflet and that is all”: Father experiences of a diagnosis of autism. *British Journal of Learning Disabilities*, 45 (2), 95-105.

Potter, J. & Wetherll, M. (1987). *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.

Premberg, A., Hellström, A., & Berg, M. (2008). Experiences of the first year as father. *Scandinavian Journal of Caring Science*, 22, 56–63.

Priestley, M. (2003). *Disability: A life course approach*. Cambridge (UK): Polity Press.

Public Health England (2021). New Operational Guidance for NIPT screening within the NHS. Retrieved from: <https://phescreening.blog.gov.uk/2021/04/26/new-operational-guidance-for-nipt-screening-within-the-nhs/>

Ram, G. & Chinen, J. (2011). Infections and immunodeficiency in Down syndrome. *Clinical and Experimental Immunology*, 164, 9–16.

Rane, T. R., & McBride, B. A. (2000). Identity theory as a guide to understanding fathers' involvement with their children. *Journal of Family Issues*, 21, 347–366.

Read, J. (2000). *Disability, the family and society*. Buckingham (UK): Open University Press.

Redgrove, F. J., Jewell, P., & Ellison, C. (2016). Mind the gap between school and adulthood for people with intellectual disabilities. *Research and Practice*



in *Intellectual and Developmental Disabilities*, 1-9. doi:  
10.1080/23297018.2016.1188671.

Ricci, L. A., & Hodapp, R. M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: Perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47(4-5), 273–284. <https://doi.org/10.1046/j.1365-2788.2003.00489.x>.

Ridding, A. & Williams, J. (2019). Being a dad to a child with Down's syndrome: Overcoming the challenges to adjustment. *Journal of Applied Research in Learning Disabilities*. 32, 678 – 690.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 44 (7), 1609-1620.

Rodgers, R. H., & White, J. M. (1993). Family development theory. In W. J. Doherty, P. G. Boss, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Sourcebook of family theories and methods* (pp. 225–257). New York: Plenum.

Rogan, F., Shmied, V., Barclay, L., Everitt L. & Wyllie, A. (1997). 'Becoming a mother' – developing a new theory of early motherhood. *Journal of Advanced Nursing* 25, 877–885.

Roizen, N. J., Magyar, C. I., Kushner, E. S., Sulkes, S. B., Druschel, C., van Wijngaarden, E., ...Hyman SL. (2014). A community cross-sectional survey of medical problems in 440 children with Down syndrome in New York state. *Journal of Pediatrics*, 164, 871–5.

Rosen, N. O., & Knäuper, B. (2009). A little uncertainty goes a long way: State and trait differences in uncertainty interact to increase information seeking but also increase worry. *Health communication*, 24 (3), 228-238.

Sarkadi, A., Kristiansson, R., Oberklaid, F., & Bremberg, S. (2008). Fathers' involvement and children's developmental outcomes: A systematic review of longitudinal studies. *Acta Paediatrica*, 97, 153– 158. <https://doi.org/10.1111/j.1651-2227.2007.00572.x>.

Scott, M., Foley, K. R., Bourke, J., Leonard, H., & Girdler, S. (2014). I have a good life: The meaning of well-being from the perspective of young adults with Down syndrome. *Disability and Rehabilitation*, *36*, 1290–1298.  
doi:10.3109/09638288.2013.854843

Seligman, M. E. P. (1972). Learned Helplessness. *Annual Review of Medicine*, *23*, 407-412. <https://doi.org/10.1146/annurev.me.23.020172.002203>

Shaffer, D.R. (2009). *Social and Personality Development*. (6th ed.). USA: Wadsworth Cengage Learning.

Sheldon, K. P., Oliver, M. & Yashar, B. M. (2020): Rewards and challenges of parenting a child with Down syndrome: a qualitative study of fathers' perceptions, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2020.1745907.

Shepperd, J. A., Ouellette, J. A., & Fernandez, J. K. (1996). Abandoning unrealistic optimism: Performance estimates and the temporal proximity of self-relevant feedback. *Journal of Personality and Social Psychology*, *70*, 844–855.

Siegel, M. S. & Smith, W. E. (2010). Psychiatric features in children with genetic syndromes: Toward functional phenotypes. *Child and Adolescent Psychiatric Clinics of North America*, *19* (2), 229–261.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage.

Smith, A. L., Ronski, M., Sevcik, R. A., Adamson, L. B., & Barker, R. M. (2014). Parent stress and perceptions of language development: Comparing Down syndrome and other developmental disabilities. *Family Relations*, *63*, 71–84.  
doi:10.1111/fare.12048.

Sobey, C. G., Judkins, C. P., Sundararajan, V., Phan, T. G., Drummond, G. R., Srikanth & V. K. (2015). Risk of major cardiovascular events in people with Down syndrome. *PLoS One*, <https://doi.org/10.1371/journal.pone.0137093>

Startin, C. M., D'Souza H., Ball, G., Hamburg, S., Hithersay, R., Hughes, K. M, O., ...Strydom, A. (2020). Health comorbidities and cognitive abilities across the lifespan in down syndrome. *Journal of Neurodevelopmental Disorders*, *12*, 1–13.

Startin, C. M., Hamburg, S., Hithersay, R., Davies, A., Rodger, E., Aggarwal, . . . Strydom, A. (2016). The LonDownS adult cognitive assessment to study cognitive abilities and decline in Down syndrome. *Wellcome Open Res, 1*, 11.

Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., ... Guenther, S. (2010). The transition to adulthood for youth with disabilities: Evidence from the literature. In J. H. Stone & M. Blouin (Eds.), *International encyclopedia of rehabilitation* (pp. 1–25). Buffalo, NY: Center for International Rehabilitation Research Information and Exchange, University at Buffalo.

Stewart, D., Law, M., Young, N., Forhan, M., Healy, H., Burke-Gaffney, J., & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: Person–environment interactions. *Disability and Rehabilitation, 36*, 1998–2004. <https://doi.org/10.3109/09638288.2014.885994>

St John, W., Cameron, C. & McVeigh, C. (2005) Meeting the challenges of new fatherhood during the early weeks. *Journal of Obstetric, Gynecologic, and Neonatal Nursing 34* (2), 180–189.

Stoneman Z. (2007). Examining the Down syndrome advantage: Mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research, 51*, 1006-1017.

Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning health care professionals: Bereaved persons are misguided through the stages of grief. *OMEGA—Journal of Death and Dying, 74*, 455–473. <https://doi.org/10.1177/0030222817691870>

Stryker, S. & Burke, P. J. (2000). The Past, Present, and Future of an Identity Theory. *Social Psychology Quarterly. 63*(4). 284-297.

Swedish Institute. (2016). <https://Sweden.Se/Quick-Facts/Parental-Leave>.

Takataya, K, Yamazaki, Y. & Mizuno, E. (2016). Perceptions and feelings of fathers of children with Down syndrome. *Archives of Psychiatric Nursing 30*(5): 544–551. DOI: 10.1016/j.apnu.2016.04.006

Tamis-LeMonda, C. S., & Cabrera, N. (1999). Perspectives on father involvement: Research and policy. Social Policy Report: *Society for Research in Child Development*, 13(1), 1–32.

Taunt, H. M. & Hastings, R.P. (2002). Positive impact of children with developmental disabilities on their families: a preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities*. 27 (4), 410 – 420.

Thackeray, L. & Eatough, V. (2018) ‘Shutting the world out’: an Interpretative Phenomenological Analysis exploring the paternal experience of parenting a young adult with a developmental disability. *Journal of Applied Research in Intellectual Disabilities*, 31, (2), 179-190. ISSN 1360-2322.

Todd, S., & Shearn, J. (1995). *Family Secrets and Dilemmas of Status: Parental management of the disclosure of ‘learning disability’*. Cardiff: Welsh Centre for Learning Disabilities Applied Research Unit.

Tong, A., Lowe, A., Sainsbury, P., Craig, J. C. (2008). Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*, 121 (2), 349–360.

Towers, C. (2007). Let’s not forget about fathers. *Learning Disability Today* 7(2), 15–21.

Turnbull, A., Turnbull, R., Erwin, E., Soodak, L., & Shogren, K. (2011). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (6th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

Tyerman, E., Eccles, F. & Gray, V. (2017). The experiences of parenting a child with an acquired brain injury: A meta-synthesis of the qualitative literature. *Brain Injury*, 31(12), 1553–1563. <https://doi.org/10.1080/02699052.2017.1341999>.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-hill education (UK).

Wiseman, F. K., Al-Janabi, T., Hardy, J., Karmiloff-Smith, A., Nizetic, D., Tybulewicz, V. L... Strydom, A. (2015). A genetic cause of Alzheimer disease: mechanistic insights from Down syndrome. *Nature Reviews Neuroscience*, 16, 564–74.

Wishart, J. G., Cebula, K. R., Willis, D. S. & Pitcairn, T. K. (2007) Understanding facial expressions of emotion in children with intellectual disabilities of differing aetiology. *Journal of Intellectual Disability Research*, 51, 551-563.

Wong, V., Ruble, L. & Brown, L. (2020) “We are mama and papa bears”: A qualitative study of parents' adaptation process during transition to adulthood. *Research in Autism Spectrum Disorders*, 79, <https://doi.org/10.1016/j.rasd.2020.101650>

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215–228. doi:10.1080/08870440008400302.

Young, R. A., Marshall, S. K., Stainton, T., Wall, J. M., Curle, D., Zhu, M., ... Zaidman-Zait, A. (2017). The transition to adulthood of young adults with IDD: Parents' joint projects. *Journal of Applied Research in Intellectual Disabilities*, 31, 224–233. <https://doi.org/10.1111/jar.12395>

## APPENDIX

### Appendix A: Interview Topic Guide and Verbal Consent Script



UNIVERSITY OF LEEDS

#### Topic Guide

*Script if verbal consent is to be sought:*

*Thank you for agreeing to take part in this interview today. As we have already discussed I am conducting this research as part of my Doctorate in Clinical Psychology at the University of Leeds. As you know, the purpose of the study is to explore fathers' experiences of parenting a young adult (aged 18 -25) with Down's syndrome.*

*This involves an interview which will take approximately 45 – 90 minutes.*

*I will start by summarising the main points covered in the participant information sheet. I will then go through the consent form and ask for your verbal consent in participating in this study.*

*A summary of the participant information sheet is as follows:*

- *Both your personal information and your interview will be kept strictly confidential. However, it is our duty of care to inform appropriate services if you disclose that you or others are at risk of harm.*
- *Your interview will be audio recorded and will be deleted following transcription of the data.*
- *Any personal or identifiable information will be changed.*
- *You can withdraw your data up to one week after the interview.*
- *Results of the study may be published in a journal article, but you will not be identified in any report or publication.*

*Do you have any questions?*

*In order to gain your verbal consent to participate in the project, it is also necessary to audio record our discussion of this. This is where I will talk through the consent form and ask you if you agree.*

*Are you happy for me to start audio recording our conversation? (set up audio recording)*

*Okay, the conversation is now being audio recorded.*

Project title	Document type	Version #	Date
Fathers' experiences of parenting a young adult with Down's Syndrome.	Topic Guide	3	13/06/20


**UNIVERSITY OF LEEDS**

*Do you confirm that you have read and understood the information sheet (V4) dated 13/06/20) explaining this project, and that you have had the opportunity to ask questions about the project?*

*Do you agree that the data collected from yourself will be stored at The University of Leeds for 3 years?*

*Do you understand that relevant sections of the data collected during the study may be looked at by auditors from the University of Leeds or from regulatory authorities where it is relevant to your taking part in this research? Do you give permission for these individuals to have access to your data?*

*Do you give your consent for audio recordings of the interview to be made? Do you understand that this is for the purposes of analysing the information you provide in the interview to allow for the anonymous reporting of the information? Do you understand that the people hearing the recording (only the researcher and the transcriber) will keep the information confidential, and that recordings will be stored securely?*

*Do you understand that where any direct quotes are used from the interview, that any identifiable information will be removed to preserve your anonymity?*

*Do you understand that you can withdraw from the project up to one week after the interview, and that you do not have to give a reason? However, after a week, it is not possible to withdraw interview data as analysis will have started.*

*Finally, do you agree to take part in the research project discussed?*

*Will you also inform me if your contact details change during the project, and if necessary, afterwards?*

*Thank you very much.*

*If there are any questions in the interview that you would rather not answer, then please let me know.*

<i>Project title</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
Fathers' experiences of parenting a young adult with Down's Syndrome.	Topic Guide	3	13/06/20



UNIVERSITY OF LEEDS

*I will start the interview now.*

#### **‘Warm up’ Questions**

- I’m interested to hear about what attracted you to take part in the project.
- Have you always known you wanted to be a father?
- Can you remember what it was like finding out you were going to be a father to ‘x’?
  - How were you feeling? Was it expected?
  - At what point did you find out that ‘x’ had Down’s syndrome?
  - Was he/she your first child, or do you have any other children?

#### **Topic Areas**

- Father’s experiences when ‘x’ was born.
  - What do you remember about when ‘x’ was born?
  - Are there any thoughts that have stayed with you? Can you remember what you were feeling? What was that like? What did it mean to you?
- Father’s experiences in between birth and young adulthood.
  - Have there been any particular events/milestones that stand out for you as a father to ‘x’? *(try to get specific events and times, whilst keeping the ‘what’s it been like for you?’ focus.)*
  - Examples of possible significant events as prompts: going to school, leaving school, health (any medical events), holidays, friendships, relationships.
  - In what ways has ‘x’ contributed to family life?

<i>Project title</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
Fathers’ experiences of parenting a young adult with Down’s Syndrome.	Topic Guide	3	13/06/20





## UNIVERSITY OF LEEDS

- Does he or she do anything that is unique to the family? Can you tell me a bit more about that? What is that like? What does that mean for your relationship?
- Father's experiences as 'x' has become a young adult.
  - How has it been parenting 'x' since he/she turned 18?
  - How has that been similar or different? Can you give me any examples?
  - Is there anything that you would change about your experience during this time?
  - What was that like? What did you do? How did that feel?
  - What difference would that make? What would that mean to you?
- Father's experiences of their role as 'x' has become a young adult.
  - How would you describe your current role as a father to 'x'?
  - What does this mean to you?
  - Any contrasts/similarities with prior expectations of fatherhood at this age?
- Father's thoughts toward the future.
  - What do you think 'x' might be doing?
  - What are your thoughts/ feelings towards their future?

### Closing Interview Questions

- Is there anything else you feel is important to say that you've not had chance to say yet?
- Have you got any questions for me?

<i>Project title</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
Fathers' experiences of parenting a young adult with Down's Syndrome.	Topic Guide	3	13/06/20



**Demographics Information** (to complete any unanswered questions with participant at the end)

Father

- Age
- Race/ethnicity
- Occupation
- Marital status
- Number of children
- Living arrangements (e.g. partner/any other children)? If partner, is this the mother to 'x'?

The young adult – 'x'

- Age
- Race/ethnicity
- Occupation
- Marital status
- Number of children
- Living arrangements (If 'x' lives away from home, how long have they done this for?)

<i>Project title</i>	<i>Document type</i>	<i>Version #</i>	<i>Date</i>
Fathers' experiences of parenting a young adult with Down's Syndrome.	Topic Guide	3	13/06/20

## Appendix B: Ethics Approval Confirmation Email

Rachel De Souza [Medicine]

Mon 13/07/2020 13:14

To: Rebecca Piclet  
Cc: Tom Cliffe; Tracey Smith  
Dear Becky

MREC 19-73 - Fathers' experiences of parenting a young adult with Down's syndrome

***NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.***

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and on behalf of the Chair, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

***Please retain this email as evidence of approval in your study file.***

***PLEASE NOTE:*** Prior to using the Participant Information Sheet the committee has requested that the typographical error in the second sentence under the heading 'Electronic data' is rectified

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see <https://leeds365.sharepoint.com/sites/ResearchandInnovationService/SitePages/Amendments.aspx> or contact the Research Ethics Administrator for further information ([FMHUniEthics@leeds.ac.uk](mailto:FMHUniEthics@leeds.ac.uk)) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

***Please note:*** You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes

Rachel

*On behalf of Dr Naomi Quinton and Dr Anthony Howard, co-Chairs, SoMREC*

~~~~~

**Rachel de Souza, Lead Research Ethics & Governance Administrator**, The Secretariat, Room 9.29,  
Level 9, Worsley Building, Clarendon Way, University of Leeds, LS2 9NL, Tel: 0113  
3431642, [r.e.desouza@leeds.ac.uk](mailto:r.e.desouza@leeds.ac.uk)

## Appendix C: Participant Information Sheet



UNIVERSITY OF LEEDS

### Participant Information Sheet

#### 'Fathers' experiences of parenting a young adult with Down's Syndrome'

My name is Becky Piclet, and I am a second year Psychologist in Clinical Training at The University of Leeds. As part of my studies for the Doctorate in Clinical Psychology training course, I am undertaking a piece of research that aims to explore fathers' experiences of parenting a young adult with Down's syndrome.

You will be reading this information sheet because you have expressed some interest in the project. Before you decide whether you would like to take part or not it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### What is the purpose of the project?

This research is interested in understanding fathers' experiences of parenting a young adult (aged 18 -25) with Down's syndrome.

Whilst previous research has explored mothers' experiences of parenting a young adult with Down's syndrome, fathers' experiences in this area have not been explored. It is important to gather fathers' experiences directly as the research demonstrates that mothers and fathers can differ in both their parenting experiences and coping strategies.

#### Why have I been chosen?

You have been chosen as you are a father of a young adult (aged 18 - 25) with Down's syndrome. We hope to recruit between 6 – 10 fathers in total, who parent a young adult with Down's syndrome.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to give either verbal or written consent prior to the interview.

#### What will happen to me if I take part?

You will be asked to take part in an interview to talk about your experiences of being a father to a young adult with Down's syndrome.

You will only be asked to meet on one occasion, and we can decide which location might feel best for you (either at home, or if you would prefer to travel to The University of Leeds). If you do travel to the University of Leeds for the interview, you will be reimbursed for your travel expenses. If you live a significant distance from the University of Leeds, or if necessary due to COVID-19 restrictions, we can also discuss having the interview over the phone or via video conferencing (such as: skype, zoom). It is hoped that we can arrange a time between us that is mutually convenient.

The interview will take approximately 45 - 90 minutes to complete.

All interviews will be recorded and stored securely to enable the interview to be transcribed later.

2

| <i>Project title</i>                                                  | <i>Document type</i>          | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Participant Information Sheet | 4                | 13/06/20    |



## UNIVERSITY OF LEEDS

The questioning style will mainly involve open-ended questions about your experiences. The questions have been designed to only be used as a guide. It is hoped that the interview will feel more like a 'conversation' that enables you to talk in some detail about your experiences as a father to the young person.

If for whatever reason you need to terminate the interview early and wish to continue at another time, we can arrange another time to complete the interview.

If after reading this information sheet, you still wish to take part, you can contact me (Becky Picket) via the following email address to confirm and we can discuss suitable dates for the interview: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk).

If I have not heard from you after one week, I will send a follow-up email to check in and see if you are still interested.

The research itself is being carried out between May 2020 and end of September 2021.

### Can I withdraw from the project if I have already signed up?

Yes. You can withdraw from the project up to one week after the interview. After this point, transcription will have started, and the data anonymised. If you do change your mind and wish to withdraw your contribution to the project, you can email me to express your decision and do not have to give a reason. Email address is as follows: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk).

### What are the possible disadvantages and risks of taking part?

There is always the possibility that discussing topics relating to potentially difficult experiences might cause you to become upset during an interview. If you do become upset, breaks will be offered, or the opportunity to resume at a later point if you wish to continue at another time.

If you do feel like you would like to talk to someone about how you are feeling, you can always go to your local GP surgery, or you can call the Samaritans 24 hours a day on 116123.

### What are the possible benefits of taking part?

In the short-term, people may benefit from having the opportunity to share and reflect on their experiences.

Furthermore, in both the short and medium-term, you are being given an opportunity to contribute to an area of research that is currently under-researched and often misunderstood.

### Use, dissemination and storage of research data

This piece of research will be written up to form my thesis, which is necessary to complete the requirements for the Clinical Psychology Doctorate. I will present the project and discuss the findings at a conference presentation and the thesis will be made available online that other students will be able to access. In addition, if you would like, I will also send you a summary of the research findings. Lastly, it is hoped that this piece of work may also be published in academic journals in the future to enable others to read about the research. If the research is published, you will not be identified in any report or publication.

2

| <i>Project title</i>                                                  | <i>Document type</i>          | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Participant Information Sheet | 4                | 13/06/20    |





## UNIVERSITY OF LEEDS

### What will happen to my personal information?

Any personal information shared during the interview (or given prior to the interview) will only be only seen by the researcher and the transcriber. In addition, any contact information that we collect about you during the course of the research will be kept strictly confidential and stored separately from the research data.

The only limit to confidentiality, would be if something was shared during the interview that involved risk to yourself or someone else. In this situation only, this information would have to be shared with the researcher's supervisors to decide how to appropriately manage the situation for the safety of you or others around you.

Direct quotes from participants will be included in the write up of the research. However, any identifiable information will be removed, and a pseudonym will be used instead of your real name, ensuring that the data is still anonymised.

#### *Electronic data*

As mentioned, all recordings will be stored securely. Only the transcriber and I will be able to listen to the recording. The interview will be transferred from the recording device as soon as possible to a secure computer and then deleted from the recording device. All identifying features will be anonymised when transcribed. For those transcriptions that will be done by someone else, the transcriber will sign the programme's transcriber confidentiality form. Recordings will be shared securely according the University policy. Other electronic data (such as: demographic information) will also be stored in a secure space. Any files that include personal information relating to the project will be deleted 3 years from the completion of the project by the Research coordinator.

For more information on the University Privacy Notice, please see: <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>.

I will thus adhere to the University Information Protection Policy and the DClinPsychol Policy on Safeguarding Sensitive Data.

### Ethical Approval

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

### Contact for further information

#### Primary Researcher

Rebecca Piclet

Email address: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk)

#### Secondary Contacts

Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor)

Telephone: 0113 1234567

Address: Clinical Psychology, Level 10, Worsley Building, University of Leeds, Clarendon Way, LS2 9NL

Email addresses: [T.D.Cliffe@leeds.ac.uk](mailto:T.D.Cliffe@leeds.ac.uk) [T.E.Smith@leeds.ac.uk](mailto:T.E.Smith@leeds.ac.uk);

Thank you for taking the time to read through this information.

2

| <i>Project title</i>                                                  | <i>Document type</i>          | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Participant Information Sheet | 4                | 13/06/20    |

## Appendix D: Recruitment Documents



**UNIVERSITY OF LEEDS**

**Father's experiences of parenting a young adult with Down's syndrome**



**Are you a father to a young adult with Down's syndrome, aged 18 -25 years old?**

Traditionally, parenting research has tended to focus on mothers' experiences. However, we know that men and women can differ in both their parenting experiences and coping strategies. Therefore, we feel it is important to listen to fathers speak about their experiences of parenting.

**Can you help?**  
You are eligible to take part if:

- You are a father to a young adult with Down's syndrome (aged between 18 – 25). Fathers may be biological fathers to the young person, or any male who assumes a paternal parenting role to a young adult with Down's syndrome.

**AND**

- You are in contact with the young person and can understand and speak English as a first or second language.

**What does taking part involve?**

An individual interview lasting approximately 1 hour either in your home, at The University of Leeds or by phone or Skype. The interview would discuss your personal experiences of parenting a young adult with Down's syndrome.

**If you would like to find out more, please contact:**  
Becky Piclet (Psychologist in Clinical Training) [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk)

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

| <i>Project title</i>                                                  | <i>Document type</i> | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|----------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Recruitment Flyer    | 1                | 10/03/20    |

Recruitment for this project will be taking place between May 2020 and September 2021.  
The poster will be removed by....(date to be added after discussion with the charity/group).





UNIVERSITY OF LEEDS

Recruitment information for newsletters

**Fathers' experiences of parenting a young adult with Down's syndrome.**

Becky Piclet, a second year Psychologist in Clinical Training at The University of Leeds is undertaking a piece of research as part of her Doctorate in Clinical Psychology course. The research aims to explore fathers' experiences of parenting a young adult with Down's syndrome.

**Why is research in this area important?**

Firstly, research has suggested that the transition to adulthood for a young person with Down's syndrome is a significant period that typically brings along new challenges for both the young person and their families.

Secondly, parenting research has tended to focus on mothers' experiences, despite evidence suggesting that fathers are more involved in childcare than in previous decades.

Thirdly, because research has demonstrated that men and women can differ in both their parenting experiences and coping strategies, it is important to listen to fathers speak about their experiences in this time period.

**Can you help?**

You are eligible to take part if:

- You are a father (of any age) to a young adult with Down's syndrome (aged between 18 – 25). Fathers may be biological fathers to the young person, or any male who assumes a paternal parenting role to a young adult with Down's syndrome.

AND

- You are in contact with the young person and can understand and speak English as a first or second language.

**What does taking part involve?**

An individual interview lasting approximately 1 hour either in your home, at The University of Leeds, or by phone, or video conferencing (such as: skype, zoom). The interview would discuss your personal experiences of parenting a young adult with Down's syndrome.

**How to find out more, ask questions, or express your interest?**

Please contact Becky Piclet (Psychologist in Clinical Training) via email on: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk).

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

| <i>Project title</i>                                                  | <i>Document type</i>                    | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-----------------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Recruitment Information for Newsletters | 2                | 10/04/20    |



Recruitment information for Facebook post

**'Fathers' experiences of parenting a young adult with Down's syndrome'**

Hi,

My name is Becky, and I am a second year Psychologist in Clinical Training at The University of Leeds. As part of my Clinical Psychology Doctorate training, I am undertaking a piece of research that aims to explore fathers' experiences of parenting a young adult, aged 18 – 25, with Down's syndrome.

**Are you a father to a young adult with Down's syndrome, aged 18 -25 years old?**

Traditionally, parenting research has tended to focus on mothers' experiences. However, we know that men and women can differ in both their parenting experiences and coping strategies. Therefore, we feel it is important to listen to fathers speak about their experiences of parenting.

**Can you help?**

You are eligible to take part if:

- You are a father to a young adult with Down's syndrome (aged between 18 – 25). Fathers may be biological fathers to the young person, or any male who assumes a paternal parenting role to a young adult with Down's syndrome.

AND

- You are in contact with the young person and can understand and speak English as a first or second language.

**What does taking part involve?**

An individual interview lasting approximately 1 hour either in your home, at The University of Leeds or by phone or video conferencing (such as: skype, zoom). The interview would discuss your personal experiences of parenting a young adult with Down's syndrome.

**How to find out more, ask questions, or express your interest?**

Please contact Becky Piclet (Psychologist in Clinical Training) via email on: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk).

If you are not eligible to take part, but know others who might be eligible and interested, please do forward this message on or let them know!

| <i>Project title</i>                                                  | <i>Document type</i>                      | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-------------------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Recruitment information for Facebook post | 2                | 10/04/20    |

**UNIVERSITY OF LEEDS**

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

| <i>Project title</i>                                                  | <i>Document type</i>                      | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|-------------------------------------------|------------------|-------------|
| Fathers' experiences of parenting a young adult with Down's Syndrome. | Recruitment information for Facebook post | 2                | 10/04/20    |



Recruitment Email 1 from Researcher following interest

Subject of email: Research study – Fathers’ experiences of parenting a young adult with Down’s syndrome.

Dear xxx

Thank you for agreeing to be contacted in relation to the above study.

I am undertaking the research as part of my Doctorate in Clinical Psychology. The research aims to explore fathers’ experiences of parenting a young adult with Down’s syndrome.

It will involve participating in an interview that will last between 45 and 90 minutes. I will ask you to talk about various experiences which have been important to you at different times.

Please find attached a participant information sheet for further information. If you have any questions or concerns, please do not hesitate to contact me on the details provided below. If you would like to arrange an interview, please send me an email.

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

I look forward to hearing from you.

Many thanks,

Becky Piclet (Psychologist in Clinical Training)

Clinical Psychology,

Worsley Building

University of Leeds

Clarendon Way

Leeds LS2 9LJ

[umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk)

| <i>Project title</i>                                                  | <i>Document type</i> | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|----------------------|------------------|-------------|
| Fathers’ experiences of parenting a young adult with Down’s Syndrome. | Recruitment Email 1  | 1                | 10/03/20    |



UNIVERSITY OF LEEDS

Recruitment Email 2 from Charity/Group Leader/Administrator to mailing list

Subject of email: Research study – Fathers’ experiences of parenting a young adult with Down’s syndrome.

Dear xxx

I am emailing on behalf of Becky Piclet, a second year Psychologist in Clinical Training at The University of Leeds, who is undertaking a piece of research as part of her Doctorate course. The research aims to explore fathers’ experiences of parenting a young adult with Down’s syndrome.

Research is being carried out in this area for several reasons. Firstly, research has suggested that the transition to adulthood for a young person with Down’s syndrome is a significant period that typically brings along new challenges for both the young person and their families. Secondly, parenting research has tended to focus on mothers’ experiences, despite evidence suggesting that fathers are more involved in childcare than in previous decades. Thirdly, because research has demonstrated that men and women can differ in both their parenting experiences and coping strategies, it is important to listen to fathers speak about their experiences in this time period.

Taking part in the research will involve participating in an interview that will last between 45 and 90 minutes. You will be asked to talk about various experiences which have been important to you at different times.

You are eligible to take part in the research project if you are:

- A father to a young adult with Down’s syndrome.
- The young adult must be between the ages of 18 and 25.
- Fathers may be biological fathers to the young person, or any male who assumes a paternal parenting role to a young adult with Down’s syndrome.
- In contact with the young person.
- Able to understand and speak English as a first or second language.

If you have any questions about taking part in the project, or would like to express your interest, you can contact Becky directly on the following email address: [umrmp@leeds.ac.uk](mailto:umrmp@leeds.ac.uk).

Becky will then be able to email across or post out a copy of the participant information sheet. This will provide further information which you can read through in your own time to help you make an informed decision before deciding whether or not you would like to take part in this study.

This study is supervised by Dr Tom Cliffe (Lecturer in Clinical Psychology) and Dr Tracey Smith (Clinical Tutor) and has been approved by the University of Leeds School of Medicine (SoMREC) Ethics Committee (reference number: MREC 19-73 date: 13/07/2020).

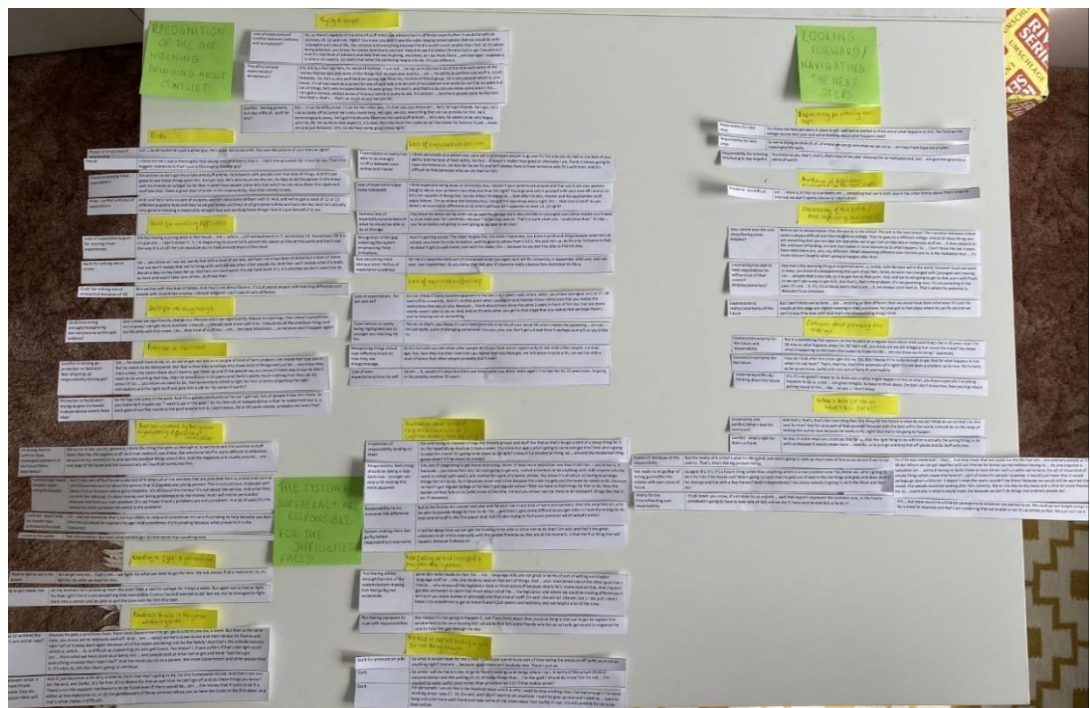
| <i>Project title</i>                                                  | <i>Document type</i> | <i>Version #</i> | <i>Date</i> |
|-----------------------------------------------------------------------|----------------------|------------------|-------------|
| Fathers’ experiences of parenting a young adult with Down’s Syndrome. | Recruitment Email 2  | 1                | 10/03/20    |



## Appendix E: Initial Noting of Individual Transcript

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| <p>Participant no: 2</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | <p>Pseudonym: Brook and Elizabeth</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |  |
| <p><b>B: yeah. Yeah</b></p> <p><b>I: okay</b></p> <p><b>B: I think so. Yes. Yeah. Yeah. So, er, yeah, it's umm . . . it-it's hard</b></p> <p><b>I: mmm</b></p> <p><b>B: being a, a father for umm, a kid with Down Syndrome. It's really hard</b></p> <p><b>I: would you, yeah, would you be able to expand on that at all Brook?</b></p> <p><b>B: I-er, yeah, when she, when they were younger, I could obviously go in and wipe her bottom and this sort of thing but now I can't umm, because of the age she is. [Wife] has to do it all and this sort of thing and cause her arms are too short to reach her bottom</b></p> <p><b>I: mmm. Yeah</b></p> <p><b>B: and er, we've tried to get her to use, er, pieces of equipment we've bought for her to try and wipe her bottom</b></p> <p><b>I: okay</b></p> | <p><i>'I think'- unsure. Quieter, hesitant. Carer role/responsibility – having to make assumptions/decision on behalf of their child.</i></p> <p><b>Being a dad to a child with DS is hard. Repetition of 'hard' to emphasise this. Voice slowed down, and quieter. 'Kid' – doesn't see Elizabeth as grown up either.</b></p> <p><b>Wishing he could help more. Not able to do as much now she is a young adult and a female. Feels inappropriate.</b></p> <p>Does this add to the feeling of not doing enough? Not being a good enough dad as his wife does it all. Sounds like he would like to be able to do more. Sounds frustrating.</p> <p><b>Attempts to help with toilet independence. 'Tried' – hasn't been successful. Losing hope for independence?</b></p> |  |

## Appendix F: Example of Individual Theme Map



Appendix G: Steps Taken During the Group Process

