# A Grounded Theory Approach to Understand Paternal Adjustment to Parenting a Child with Down's Syndrome: Fathers' Roles, Satisfaction and Contributions to Family Functioning

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# *1. Introductory Chapter*

## Thesis overview

# 1. Thesis Overview

For most, becoming a parent is referred to as an overwhelming experience that requires the person to change their identity and lifestyle (Palkovitz, 2007). Although fathers' experiences are often overlooked, strong paternal relationships can not only benefit fathers, but also enhance children's development (Brown, Mangelsdorf & Neff, 2012). The past few decades have seen an increase in the active involvement of fathers in their children's care, attributed to changes in social circumstances and cultural values (Machin, 2015). However, there still remains a paucity of research focusing solely on paternal experiences.

A further neglected group are those who parent a child with an intellectual disability (ID). Historically, research has focused exclusively on maternal experiences, describing fathers as 'hard to reach' (Hastings, 2003). Although research highlights mothers of children with an ID experience distress), it is suggested that fathers' experiences differ (Bailey, Blasco & Simeonsson, 1992; Lanfranchi & Vianello, 2012).

The first paper presented within this thesis, a systematic review of paternal parenting experiences of a child with an ID, synthesises the results of the limited published literature. Eight papers are included in the review, with the majority being quantitative in nature and drawing conclusions from questionnaires completed by fathers. Moreover, several papers group fathers of children with ID together under one umbrella, where individual characteristics of different diagnostic groups might be lost (Cuskelly, 1999). For example, parents of children with Down's syndrome (DS) are believed to have different experiences to those parents of children with an ID of a different aetiology. It is suggested that parents experience a 'DS advantage', which is associated with lower stress levels and more positive views to parents of children with other IDs (Hartley, Seltzer & Abbeduto, 2012).

Down’s syndrome (DS) is a genetic condition, resulting from an extra chromosome 21 in each of the body’s cells, which leads to most children with DS having mild to moderate levels of ID (Dykens, Hodapp & Finucane, 2000).

Most studies which focus on fathers of children with DS highlight that, despite challenges particularly at the time of birth, fathers adapt positively (Bentley, Zvonkovic, McCarty & Springer, 2015; Henn & Piccinini, 2010; Herbert & Carpenter, 1994; Hornby, 1995). As noted earlier, most of these studies use quantitative methodology which fail to provide an in-depth understanding of experiences to the same extent as qualitative methods (Cuskelly, Hauser-Cram & Van Riper, 2008). Moreover, they specifically focus on different aspects of fathers’ experiences (e.g. psychological well-being/stress), rather than fathers’ adjustment overall and involvement in their child’s provision. The second paper within this thesis does just that, through exploring fathers’ lived experiences of parenting a child with DS.

Through the use of the analytic methodology of Grounded Theory (GT) (Strauss & Corbin, 1998), fathers’ accounts have contributed to a model of paternal adjustment to parenting a child with DS. Parenting a child with DS appears to be on a fluid trajectory, highlighting that the course of adjustment varies over time for each father. Three categories were identified which feed into this trajectory: ‘Accommodating the child’; ‘Adapting the parental/spousal role’; and ‘Adapting society’. Each of these categories captured the challenges fathers’ encounter that can hinder the adjustment process. Additionally, fathers discussed the deliberate strategies they use to overcome these challenges and shape their adjustment, which ultimately led to all 15 participants considering themselves to have achieved positive adjustment.

The two papers together highlight the need for society, most importantly services, to support *both* parents as equal, without disregarding the involvement and needs of fathers.

Fathers’ roles and experiences need to be openly explored and recognised, enabling support to be offered if and when fathers would most benefit. Future studies exploring paternal experiences following the birth of their child with DS would further add to the richness of the model presented here.

The empirical paper will be submitted to the Journal of Applied Research in Intellectual Disabilities. This journal brings together research in the area of ID and the author felt that the study’s aims and findings were appropriate to fulfil the journal’s scope and objectives.

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# *2. Chapter One*

## Fathers’ Experiences of Parenting a Child with an Intellectual Disability: A Systematic Review of the Literature

## 3. Abstract

**Background:** Traditionally, studies exploring parenting experiences have focused on mothers, leaving fathers' experiences and needs overlooked. Fathers of a child with an Intellectual Disability (ID) are further neglected. Existing reviews are outdated and often do not follow systematic protocols. The aim of this systematic review is to explore the literature regarding paternal experiences of parenting a child with an ID, recognising the positive and challenging aspects of their experiences.

**Methods:** A systematic search of four electronic databases was conducted utilising terms relating to ID and fathers' experiences and adjustment. A total of 4287 articles were considered as part of the identification process and after de-duplication and application of exclusion criteria, eight studies were included in the final review.

**Results:** The methodological quality of studies exploring the effects of parenting a child with an ID varied greatly, and although all studies recognised the impact on fathers' psychological wellbeing, results were inconsistent. Various themes were identified as influencing fathers' experiences: demographics; spousal relationships; coping; support; and personality.

**Conclusions:** The results highlight the challenges and positives of parenting a child with an ID. Methodological limitations, clinical implications and recommendations regarding future research are discussed.

**3.1 Keywords:** Paternal, experiences, parenting, intellectual disability, systematic review

## 4. Introduction

Becoming a parent is described by many as an overwhelming experience that requires the person to change their identity and lifestyle (Palkovitz, 2007). Prior to the birth of the child, parents start to create and develop expectations of their children (Stern, 1995).

The early work of Bowlby and Ainsworth which focused on the core relationships for children's attachment, focused exclusively on mothers (Ainsworth, 1969; Bowlby, 1969). Most subsequent research also neglected fathers who were perceived to take the culturally prescribed role of economic provider (Sansiriphun, Kantaruksa, Klunklin, Baosuang & Liamtrirat, 2015).

The relationship between a father and his child is unique and separate to that of mother and child (Machin, 2015). Fathers can contribute positively to their child's development and any mental health challenges experienced by fathers can negatively impact on their partner and child. Thus, the study of fathers' experiences and needs are relevant for the wider family and society at large (Ramchandani et al., 2013).

Bartlett (2004) noted that many fathers make emotional, physical and psychological adjustments prior to their children's birth, with some fathers referencing the stress and weariness that comes with caring for a new baby. Over time, attachment increases and fathers' safeguarding and protective instinct becomes stronger, alongside their child's needs becoming prioritised (Fagerskiold, 2008).

Fathers' roles have been slowly changing over the years and now a growing body of evidence is becoming concerned with their experiences, recognising the importance of fathers' involvement in child development (Chanfreau et al., 2011). Many women now work outside the home which has made it necessary for fathers to take a more active role in childcare and household maintenance tasks (Machin, 2015).

Despite the growing evidence base, a number of studies which aim to explore fathers' experiences rely on indirect responses from mothers and do not often see fathers as a worthy topic of study in their own right (Machin, 2015).

### 4.1 Parenting a Child with an Intellectual Disability

A further group of fathers, that remain under-researched, are those of children with an Intellectual Disability (ID). Although the impact of a child's ID on the family is well-documented, research primarily focuses on mothers. Despite fathers' increasing involvement, less is known about their psychological wellbeing when parenting children with ID (Ricci & Hodapp, 2003).

As outlined earlier, many parents attest that becoming a parent can be a stressful event. When parents have a child diagnosed with an ID, this stress is believed to increase exponentially (Hastings & Taunt, 2002). Moreover, a revision of parents' expectations and preconceptions take place which can have positive and negative effects (Seltzer et al., 2009).

An ID may be diagnosed soon after birth, for example when the child has chromosomal abnormalities, or later when the child's development is realised and appears to be delayed. Several studies have explored parents' reactions to receiving a diagnosis for their child and the way the diagnosis is given by health professionals is suggested to be a key facilitator of initial parental adaptation (Graungaard & Skov, 2007). Parents' reactions to diagnosis are often framed within the theoretical context of attachment by suggesting that for some the diagnosis can be experienced as a loss or trauma which affects parental representations of their child (Bowlby, 1980; Marvin & Pianta 1996). Although studies highlight the difficulties parents have in adapting to their child's diagnosis, others indicate parents can still experience positive emotions which restore their coping resources (Hastings & Taunt, 2002).

Families of children with ID often experience stressors that families of children with typical development (TD) do not (Baker, Blacher, Crnic & Edelbrock, 2002). Stressors may be predicted by: the parents' age, the child's age; caring for multiple children with disabilities and the wellbeing of their spouse (Baker et al., 2002; Frey, Greenberg & Fewell, 1989; Hartley, Seltzer, Head & Abbeduto, 2012; Hauser-Cram et al., 2001; Lanfranchi & Vianello, 2012).

Past research has focused on mothers' experiences of stress, however evidence suggests that fathers also experience stress when parenting a child with a disability (Dabrowska & Pisula, 2010; Hartley et al., 2012).

One study indicated that fathers experience less stress compared to mothers (Bailey, Blasco & Simeonsson, 1992). Although, other research demonstrates that this may be associated with different coping strategies; in particular, fathers may contain their emotions to protect their partners (Barak-Levy & Atzaba-Poria, 2013; Lanfranchi & Vianello, 2012; Locock & Alexander, 2006).

Some research also notes that the sources of fathers' stress differ to those of mothers, for example fathers' stress may be associated with their child's acceptability, finances and long-term support provision (Keller & Honig, 2004; Lanfranchi & Vianello, 2012).

Recent studies have suggested that paternal experiences are impacted upon by the ID aetiology of their child. Fathers of children with Down's Syndrome (DS), for example, described a 'DS advantage' whereby they reported less stress and more positive views of care-giving compared to those parents of children with other IDs (Lanfranchi & Vianello, 2012; Hartley et al., 2012) .

It is important to note however that a number of these studies are made up of samples that predominantly feature mothers and it is therefore difficult to separate fathers' experiences exclusively.

Importantly, many studies exploring fathers' roles and experiences include a wide range of developmental disabilities such as autistic spectrum conditions (ASC) (referred to in studies as autistic spectrum disorder [ASD]) under the umbrella term of learning or intellectual disability (Carpenter & Towers, 2008; Macdonald, Hastings & Fitzsimons, 2009; Saloviita, Italinna & Leinonen, 2003). A significant proportion of children with ASC also have an ID, but not all do (Fombonne, 2003).

Moreover, some children with ASC may exhibit behaviour which challenges such as biting, spitting, non-compliance and self-injurious behaviours possibly due to sensory needs or as a result of the child experiencing stress or anxiety (Emerson, 1995). These behaviours and differences in temperament and personality can understandably contribute to divergent parenting experiences and challenges, differentially affecting psychological wellbeing (Bostrom, Broberg & Hwang, 2009; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011). For example, child behaviour problems, as opposed to intellectual functioning, have been shown to be a strong predictor of parental stress (Baker et al., 2002). Thus, the presence of comorbid behaviour problems in children with ASC might be an important contributor to poor parental psychological wellbeing. Furthermore, children with ASC might have greater variability in developmental areas compared to children with IDs, impacting upon the availability of support which might influence fathers' experiences of stress (Rodrigue, Morgan & Geffken, 1990).

Research specifically focusing on mothers has also reported that mothers of children with an ASC report more stress than mothers of children with other additional needs (Bouma & Schweitzer, 1990; Rodrigue et al., 1990).

It is also important to recognise that there might be differences concerning the attachment relationships children with an ASC develop, due to impairments in communication and social functioning, although this is often impacted upon by parenting style and requires more research (Perry & Flood, 2016).

The most recent review of literature regarding fathers' experiences of parenting a child with ID was written over twenty years ago. Lillie's (1993) paper highlighted the roles fathers played in families and how fathers expressed more interest in the needs of their children than often acknowledged in the literature. Prior to this, Hornby (1992) reviewed fathers' experiences highlighting the variation and recognising the challenges and positives that fathers encountered. Price-Bonham and Addison (1978) conducted a similar review which is limited due to the inclusion of mothers in the sample and the date of publication.

## 4.2 Review Objectives

Due to studies using a variety of methodologies and mixed samples, there remain inconsistencies within research in this area. It would therefore prove confusing, unmanageable and overwhelming to follow recommendations suggested from each individual paper to inform clinical practice. A systematic review is therefore necessary to synthesise literature to inform clinical practice and also to identify gaps in the literature.

The three previous reviews, outlined earlier, that focus on fathers' experiences of parenting a child with an ID are now outdated, with the last review conducted over 20 years ago (Lillie, 1993). Additionally, two of these studies provide limited evidence of systematic searches (Hornby, 1992; Price-Bonham & Addison, 1978). Furthermore, Hornby (1992) solely focused on individual experiences and neglected studies with larger samples. Finally, the most recent of these reviews could not be accessed and therefore the quality could not be assessed, despite the current author's attempted contact with the review's author and contact with other libraries (Lillie, 1993).

In summary, given the methodological limitations of the previous reviews, the time elapsed since they were published and a recent resurgence of interest in this area, there is a need for a new systematic review to be published.

The aim of the present research is to conduct a systematic review of the published literature to investigate fathers' experiences of parenting a child with an ID. The review aims to answer the following question: how do fathers experience parenting a child with an ID?

# 5. Method

## 5.1 Eligibility Criteria

In accordance with the previously outlined research, studies with only fathers of children with an ASC within the sample were excluded. Although it can be argued that a significant proportion of children with ASC also have an ID, the behavioural presentation of children with ASC might lead to different parenting experiences and stressors, compared to other IDs (Fombonne, 2003; Hartley et al., 2011). Due to the limited amount of research in this area, if the study included a mixed sample and the results (i.e. non-ASC ID experiences) could be identified and separated, the studies were included in this review.

For explorative purposes and due to the limited amount of research within the area of fathers' experiences and ID, it was deemed appropriate to include both quantitative and qualitative studies. The study inclusion criteria were therefore as follows:

- Participants who were fathers (including biological and non-biological) of a child with an ID
- Studies which focussed on the experience of parenting a child with an ID. The following aspects were considered 'experience', although this list is not exhaustive: adjustment, adaptation, coping, hope, satisfaction, psychological symptoms (e.g. stress) and marital relationships.
- Publication in a peer-reviewed journal; and
- Published in English

## 5.2 Search Strategy

The initial step of the review included a systematic literature search of the following electronic databases for existing academic journal articles and reviews: Web of Science, Medline, PsycINFO and CINAHL. Databases were searched for studies from inauguration to April 2016.

Search terms were chosen following a PICo framework (Cherry, Perkins, Dickson & Boland, 2014). The abbreviation refers to the **P**opulation (e.g. fathers), phenomenon of **I**nterest (e.g. the experiences of fathers) and the **Co**ntext (e.g. fathers of children with an ID). The most commonly-used terminology within research and clinical contexts and relevant synonyms were entered in three stages to ensure relevant papers were discovered. Search terms are presented in the table below (Table 1). Each stage was separated by the Boolean operator ‘AND’. The papers identified included these terms in the title, abstract or keywords attached to the article**.**

Table 1
*Search Strategy Stages and Terms*

| | |
|---|---|
| 1. | ‘father* OR dad* OR paternal*’ |
| | **AND** |
| 2. | ‘learning disab* OR intellectual disab* OR mental* retard*" OR developmental* disab* OR intellectual* impair* OR mental* handicap*" OR learning diff*’ |
| | **AND** |
| 3. | ‘impact* OR effect* OR adjust* OR consequence* OR psych* OR well being* OR experience* OR parent* OR attitude*’ |

The reference lists of the two reviews which could be obtained (Hornby, 1992; Price-Bonham & Addison, 1978) and also the reference lists of the papers chosen for the review were cross-checked and examined. Duplicate studies were identified and removed through auto and hand-searching.

Two independent reviewers identified and selected eligible studies. Initially, this involved screening potentially relevant papers by the title and abstract of the article. This was followed by more in-depth consideration of full-text articles. Both reviewers were in agreement regarding the final articles included in this review.

### 5.3 Quality Assessment

Due to the studies being diverse, a tool which integrated quality indicators for both quantitative and qualitative studies and demonstrated good reliability and validity was deemed necessary. Therefore, the Quality Assessment Tool for Studies of Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2012) was utilised to assess quality.

Despite the implications and limitations acknowledged of employing a general tool to assess study quality, the QATSDD enabled cross-comparisons to be made between differing methodologies.

Two independent reviewers also completed the quality assessment and disagreements were resolved through discussion to reach a consensus. The QATSDD scoring guidance notes are set out in Table 2.

### 5.4 Data Extraction

The data extracted from the final studies included: the focus of each study, participant details, measures used to assess fathers' experiences and the main findings.

## 6. Results

A total of 4287 records were initially yielded through electronic database searches. One further paper was identified through hand searching. The previous literature reviews conducted did not yield any additional relevant studies.

Through electronic and manual removal of duplicates 2542 titles and abstracts were reviewed and 28 of these were eligible for full-text assessment. The search process and reasons for exclusion are outlined in Figure 1 below. Overall, eight studies were identified in the analysis. Of these, five employed quantitative methodologies, two employed qualitative methodologies and one was a mixed-method study which employed both.

*Figure 1.* Identification of included studies

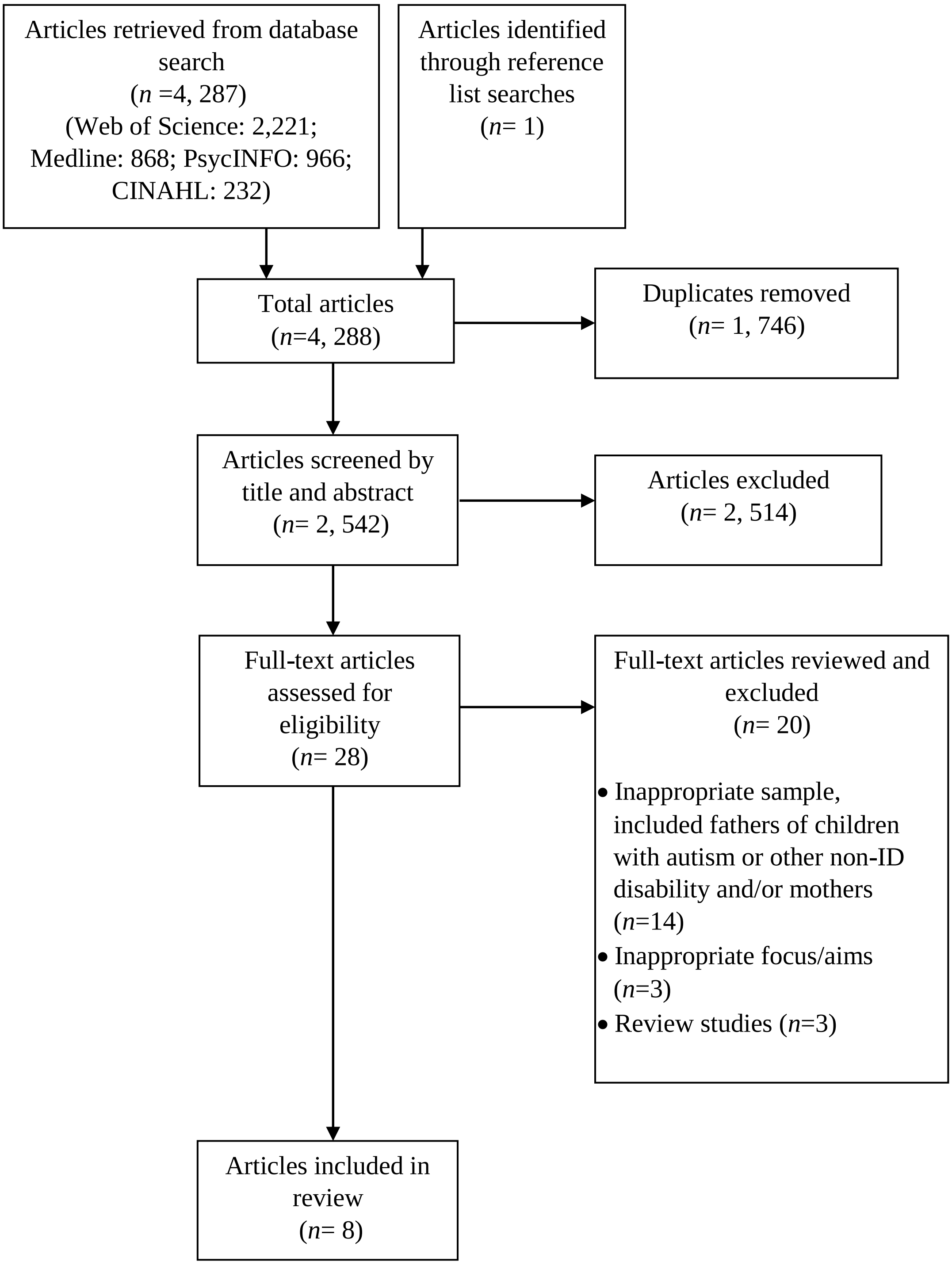

Table 2

*QATSDD Scoring Guidance Notes*

| Criteria | 0 = Not at all | 1 = Very slightly | 2 = Moderately | 3 = Complete |
|---|---|---|---|---|
| Explicit theoretical framework | No mention at all. | Reference to broad theoretical basis. | Reference to a specific theoretical basis. | Explicit statement of theoretical framework and/or constructs applied to the research. |
| Statement of aims/objectives in main body of report | No mention at all. | General reference to aim/objective at some point in the report including abstract. | Reference to broad aims/objectives in main body of report. | Explicit statement of aims/objectives in main body of report. |
| Clear description of research setting | No mention at all. | General description of research area and background, e.g. 'in primary care'. | General description of research problem in the target population, e.g. 'among GPs in primary care'. | Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands. |
| Evidence of sample size considered in terms of analysis | No mention at all. | Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design. | Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements. | Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements. |
| Representative sample of target group of a reasonable size | No statement of target group. | Sample is limited but represents some of the target group or representative but very small. | Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative. | Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace. |
| Descriptions of procedure for data collection | No mention at all. | Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'. | States each stage of data collection procedure but with limited detail, or states some stages in details but omits others. | Detailed description of each stage of the data collection procedure, including when, where and how data were gathered. |
| Rationale for choice of data collection tool | No mention at all. | Very limited explanation for choice of data collection tool. | Basic explanation of rationale for choice of data collection tool, e.g. based on use in a prior similar study. | Detailed explanation of rationale for choice of data collection tool, e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment. |
| Detailed recruitment data | No mention at all. | Minimal recruitment data, e.g. no. of questionnaire sent and no. returned. | Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used. | Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment. |

Table 2

*Continued*

| | | | | |
|---|---|---|---|---|
| Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only) | No mention at all. | Reliability and validity of measurement tool(s) discussed, but not statistically assessed. | Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken. | Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used. |
| Fit between stated research question and method of data collection (Quantitative) | No research question stated. | Method of data collection can only address some aspects of the research question. | Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition. | Method of data collection selected is the most suitable approach to attempt to answer the research question. |
| Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative) | No research question stated. | Structure and/or content only suitable to address the research question in some aspects of superficially. | Structure & content allows for data to be fathered broadly addressing the stated research question(s) but could benefit from greater detail. | Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research questions(s). |
| Fit between research question and method of analysis | No mention at all. | Method of analysis can only address the research question basically or broadly. | Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail. | Method of analysis selected is the most suitable approach to attempt answer the research question in detail. |
| Good justification for analytical method selected | No mention at all. | Basic explanation for choice of analytical method. | Fairly detailed explanation of choice of analytical method. | Detailed explanation for choice of analytical method based on nature of research question(s). |
| Assessment of reliability of analytical process (Qualitative only) | No mention at all. | More than one researcher involved in the analytical process but no further reliability assessment. | Limited attempt to assess reliability, e.g. reliance on one method. | Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds. |
| Evidence of user involvement in design | No mention at all. | Use of pilot study but no involvement in planning stages of study design. | Pilot study with feedback from users informing changes to the design. | Explicit consultation with steering group or statement or formal consultation with users in planning of study design. |
| Strengths and limitations critically discussed | No mention at all. | Very limited mention of strengths and limitations with omissions of many key issues. | Discussion of some of the key strengths and weaknesses of the study but not complete. | Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis. |

## 6.1 Characteristics of Included Studies

Table 3 contains the details of the included studies. The eight studies included a total of 311 participants, and the mean age of fathers, where reported within individual studies, ranged from 36.91 to 49 years. Although, it is notable that Bentley, Zvonkovic, McCarty & Springer (2015) and Hornby (1995) recruited fathers up to the age of 65 and 62 respectively. Two studies reported including fathers who were not living at home with their child and the child’s mother (Bentley et al., 2015; Cohen, Zeedyk, Tipton, Rodas & Blacher, 2016).

Most studies included fathers of children with DS (Bentley et al., 2015; Cohen et al., 2016; Gault, 2009; Herbert & Carpenter, 1994; Hornby, 1995; Rodrigue, Morgan & Geffken, 1992), although two studies did not specify the aetiology of the child’s ID  (Cummings, 1976; Houser & Seligman, 1991). The mean age of children, where reported in individual studies, was 7.2 to 27, although it is important to note that several studies did not report means and Bentley et al. (2015) included children of a large age range (from 2 months- 25 years old).

The studies focused on fathers’ experiences in general, with two studies focusing specifically on the time of birth (Gault, 2009; Herbert & Carpenter, 1994). Although each study focused on different aspects of experiences, most studies focused on psychological wellbeing with four studies using varying quantitative measures to assess fathers’ symptoms (Cohen et al., 2016; Cummings, 1976; Hornby, 1995; Houser & Seligman, 1991). Three studies used specific measures to assess fathers’ coping (Bentley et al., 2015; Houser & Seligman, 1991; Rodrigue et al., 1992) and a further three also assessed spousal support using specific measures (Cohen et al., 2016; Hornby, 1995; Rodrigue et al., 1992).

When considering methodology, four studies involved a case-controlled study design, comparing fathers of children with an ID with fathers of children without an ID, such as children with TD  (Cohen et al., 2016, Cummings, 1976, Houser & Seligman, 1991, Rodrigue et al., 1992). Two of these included an extra group of children with additional needs;

Rodrigue et al. (1992) included a group of fathers of children with ASC and Cummings (1976) included a group of ‘chronically ill’ and ‘neurotic’ children, although it is acknowledged these terms are now outdated. One study reported longitudinal data, following up fathers regularly when their children were different ages (ranging from 3-9 years) (Cohen et al. 2016). In terms of publication dates, only three papers were published in the last 10 years indicating the somewhat dated nature of research in this area.

Five of the eight studies were carried out in the USA and the remaining three studies were conducted in the UK.

Five studies included information regarding where the sample of fathers were recruited from. Most studies recruited fathers exclusively through service providers (Cohen et al., 2016; Cummings, 1976; Herbert & Carpenter, 1994) and support groups (Bentley et al., 2015) , although Rodrigue et al. (1991) recruited fathers from both.

Table 3

*Descriptions of the Eight Papers Included for Review*

| **Authors** | **Focus/Constructs explored (and measures used)** | ***N*** | **Country** | **Study design** | **Mean age of father (Range)** | **Mean age of child (Range)** | **Aetiology of ID (where reported)** | **Results** |
|---|---|---|---|---|---|---|---|---|
| Bentley et al. (2015) | Within the framework of 'Ambiguous Loss Theory':<br>('Herth Hope Index')<br>Satisfaction ('Couples Satisfaction Index'; 'Satisfaction With Life Scale')<br>Coping ('Family Crisis Orientated Personal Scales')<br>Attitudes & impacts of diagnosis (3 open ended questions) | 50 | USA | Mixed method: Quantitative and Qualitative: Content Analysis<br>Cross-sectional | 49 (30-65) | 7.2 (2mths-25 years) | DS | 3 "types of fathers" identified, separated into clusters which differed on hope and satisfaction: *F* (6, 90) = 24.44, *p*< .001, η2 = .62) and coping: *F* (2, 47) = 3.59, *p*< .05, *η2* = .133:<br>• *Mastering* (n=13): experiences related to daily struggles; fatigue; helplessness; positive outlook on life despite challenges; push children to greatest potential. Lowest scores on hope, coping and personal & couple satisfaction.<br>• *Connecting* (n=23): experiences related to fear; mourning & uncertainty but also benefits. Used emotion-focused coping, social support & group involvement. Recognised benefits and challenges to parenting a child with DS and focused on positive experiences they would not have had without this. Mean scores on measures in the middle of 'Mastering' and 'Thriving' clusters.<br>• *Thriving* (n=14): experiences related to hope, satisfaction; self development; personal growth; resilience with fathers describing themselves as 'being chosen' and how having a child with DS makes them a better person. Highest average scores on hope, coping and personal & couple satisfaction. |
| Cohen et al. (2016) | Fathers' perceptions of behaviour challenges ('The Child Behaviour Checklist'), psychological symptoms ('Symptom Checklist') and spousal support ('The Spousal Agreement and Support Scale') | 66 | USA | Quantitative: questionnaires at 7 time points<br>Longitudinal case control (ID & TD) | 36.91 | Mean not reported (3-9) | DS (27.8%)<br>Cerebral palsy (16.7%)<br>Undifferentiated DD (36.1%) | • Fathers of children with ID had significantly more child behaviour challenges than those of TD children across 7 time points: (*t* = -4.43, P<0.001); (*t* = -4.60, *p*<0.001); (*t* = -5.53, *p*<0.001); (*t* = -5.27, *p*<0.001); (*t* = -3.78, *p* <0.001); (*t* = -4.91, *p*<0.001); (*t* = -4.29, *p*<0.001).<br>• Fathers indicated significant initial distress levels, which did not change over the child's developmental trajectory.<br>• Having a child with ID did not predict initial paternal psychological symptoms $(g_{01} = -0.16, \text{r} P < 0.001)$ntribute to change in symptoms over time $(g_{11} = 0.03, \text{ns})$ child behaviour problems predicted initial paternal psychological symptoms $(g_{02} = 0.02,$<br>• Spousal support predicted initial paternal psychological |

Table 3

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|---|---|---|---|---|---|---|---|---|
| | | | | | | | | symptoms $(g_{03} = -0.01, P < 0.001)$, but did not explain change over time $(g_{13} = -0.00, \text{ns})$ nor decrease the effects of child behaviour. |
| Cummings (1976) | Psychological functioning and personality variables of fathers related to:<br>mood,<br>self-esteem,<br>interpersonal satisfactions and child rearing attitudes ('Sentence Completion Test'; 'Self- Acceptance Scale of the Berger Inventory'; 'Shoben Parental Attitudes Inventory'; 'Edwards Personal Preference Schedule') | 60 | USA | Quantitative: postal questionnaires<br>Case control: ID & TD | No mean reported. | No mean reported (4-13) | Not specified. | • Fathers of children with ID differ to those of TD children.<br>• Fathers of children with ID scored:<br>○ higher for depressive feeling (*t* =5.20, *p* =.01) and pre-occupation with child (*t* =2.88, *p* =.01).<br>○ lower on self esteem: expressed self-acceptance (*t* = -1.33, *p* =.10) & sense of paternal competence (*t* =-2.78, *p* =.01).<br>○ lower on enjoyment of child (*t* =-8.64, *p* =.01).<br>○ lower on evaluations of their wife (*t* =-1.68, *p* =.05).<br>○ Higher on evaluations of other children (*t* =-1.77, *p* =.05)<br>• Fathers of children with ID demonstrated more rejection (ignoring) (*t* =1.30, *p* =.10).<br>• Differences also in fathers' psychological needs: Fathers of children with ID indicated higher need for order e.g. neatness, routine (*t* =3.95, *p* =.10) and lower need for dominance e.g. assertiveness (*t* =-1.97, *p* =.05) and heterosexuality e.g. expressions of sexual interest in members of opposite sex (*t* =-2.10, *p* =.05).<br>• Fathers of older children (9-13) show lower levels of psychological stress (e.g. less depressive feeling & more enjoyment of child) than those of younger children (4-8). |
| Gault (2009) | Practical & emotional experiences at birth (grief/mourning), reactions from professionals & needs of fathers | 1 | England | Qualitative: Case-study | Not reported | 27 | DS | • A father recalls his grief (e.g. shock, paralysis, confusion & disbelief) at the birth of his child and the fantasies he had that his son did not have DS.<br>• Professional reactions reflected upon, particularly how the diagnosis was communicated negatively, with some professionals expressing their own emotion. Needs identified: a key person to communicate in a timely manner focusing on positive, factual information.<br>• Father reported on benefits to support groups.<br>• Father also reflected on the dominance of the medical model in society that ascribes worth to humans depending on their economically active contributions. |

Table 3

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|---|---|---|---|---|---|---|---|---|
| Herbert & Carpenter (1994) | Experiences at time of birth | 7 | UK | Qualitative: interviews<br>Cross-sectional | Not reported | Not reported | DS | Themes related to:<br>• Diagnosis communication: style of delivery ranged from ‘abrupt to sympathetic & understanding’.<br>• Fathers’ responses: helplessness, anger, shock, disbelief.<br>• How, when & what content was communicated: some professionals forecast negative effects on family life.<br>• Lack of father-orientated support.<br>• Strategies used by fathers to deal with diagnosis: information seeking, networking amongst other families, support from extended families, searching for normality and planning for the future. |
| Hornby (1995) | Adaptation (‘The Judson Self-Rating Scale’), stress (‘Malaise Inventory’), social support (‘Inventory of Parent Experiences’), personality (‘The Eysenck Personality Inventory’), marital functioning (‘Measure of Marital Satisfaction’) | 87 | UK | Quantitative: postal questionnaires<br>Cross-sectional | 41 (27-62) | 9.2 (6-14 years) | DS | • The gender (*Cohen’s* $d = 0.432$) or IQ level ($r\ (84) = 0.05$, $p > 0.05$) of the child did not affect fathers’ adaptation.<br>• The child’s age did not predict fathers’ stress ($r\ (84) = 0.06$, $p > 0.05$).<br>• Fathers’ stress affected by marital satisfaction ($r\ (81) = 0.34$, $p < 0.01$), unemployment ($d = 0.611$) & personality ($r\ (82) = 0.78$, $p < 0.001$).<br>• Fathers’ adaptation was not correlated with the *amount* of social support ($r\ (85) = 0.12$, $p > 0.05$) but their *satisfaction* with support ($r\ (80) = 0.42$, $p < 0.001$).<br>• 24% of sample met cut-offs for clinical depression.<br>• Fathers’ stress not significantly correlated with social class ($r\ (84) = 0.18$, $p > 0.05$) but negatively correlated with educational level ($r\ (82) = -0.31$, $p < 0.01$) and perceived level of financial adequacy ($r\ (84) = -0.24$, $p < 0.05$).<br>• Overall, fathers’ adaptation negatively correlated with neuroticism ($r\ (83) = -0.46$, $p < 0.001$) & marital satisfaction ($r\ (81) = -0.32$, $p < 0.01$) & positively correlated with lying ($r\ (83) = 0.32$, $p < 0.01$). |
| Houser & Seligman | Stress (‘Perceived Stress Scale’) & | 40 | USA | Quantitative: postal | Not reported | 15.43 males | Not specified | • Fathers of children with ID did not differ on levels of stress from those of children with TD (although fathers did report |

Table 3

*Continued.*

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| (1991) | coping ('The Ways of Coping Scale-Revised') | | | questionnaires<br>Case-control: ID and TD. | | 15.22 females (12-19) | | higher stress scores, this was non-significant).<br>• Socio-economic status significantly correlates with fathers' stress *r* = 0.33).<br>• No significant differences between fathers of ID & TD children, linked to gender.<br>• Fathers' coping strategies did not depend on the child's gender.<br>• Between group differences found for types of coping strategies (*F* =2.50, *p*=0.05): Fathers of children with ID used distancing (*d* = 0.911) and escape-avoidance more (*d* = 0.353) and positive re-appraisal less (*d* = 0.581).<br>• Similarities in the use of problem solving between groups- most frequently used coping strategy. |
| Rodrigue et al. (1992) | Paternal perceptions; Sense of competence ('The Parenting Sense of Competence Scale'); Coping ('The Ways of Coping Scale'); Marital satisfaction ('Marital Adjustment Scale'); Family adaptability & cohesion ('Family Adaptability and Cohesion Evaluation Scales-III'); Impact of raising child ('Revised Impact on Family Scale'); Support ('Social Support Questionnaire'); Interactions with child (observation) | 20 | USA | Quantitative: postal questionnaires & observation of father-child play<br>Case control: ID, ASC & TD. | 40.9 | 11.9 | DS | • Fathers of children with ID use coping strategies such as wish-fulfilling (*d* = 0.988), information seeking (*d* = 0.781) and cognitive-restructuring (*d* =1.346) more than fathers of children with TD.<br>• Gender affected fathers' perceived value of parenthood (*F* (1, 53) = 4.63, *p* < .05. ). Fathers of boys reported more satisfaction than those of girls.<br>• Children with ID have a greater impact on the family than children with TD (*d* = 1.796): financial impact (*d* = 1.290) ; disruption of planning (*d* = 1.389); more caretaker burden (*d* = 1.207).<br>• No significant differences between groups for marital satisfaction, perceived parenting competence, satisfaction with social support and ratings on father-child interactions. |

## 6.2 Quality Assessment Scores

The item scores for each individual domain of quality assessment are presented in Table 4. There was considerable variability with regard to overall quality, with no consistent bias between each of the studies. Summary scores for each study are therefore not reported. The Cochrane Collaboration does not support the use of summary scores, due to them being less transparent and carrying a greater risk of confusing and misleading the reader of reviews. This review followed their guidance and used a simple approach reporting the individual criterion scores of each study (Schünemann et al., 2011).

In terms of overall quality, it can be seen that the most recently published study by Cohen et al. (2016) achieved high scores across most of the domains on the QATSDD with a clear accurate method that provided a template for replication. A strength of Cohen et al.'s (2016) study was the amount of detail throughout, including their explicit statement of theoretical frameworks, clear aims and clear descriptions of their data collection procedures and rationale. The study, however, scored zero out of a possible three on two key aspects of the QATSDD. These included, providing no evidence of consideration of their sample size for analysis and not including service users in the study design.

It can also be seen that some of the lowest quality assessment scores were associated with qualitative studies (Gault, 2009; Herbert & Carpenter, 1994). Whereas Gault's (2009) QATSDD scores reflected the choice of methodology and the aims and focus of his study, a brief yet rich account of his own experiences was provided which allowed the reader to understand and empathise with his personal experience. Herbert and Carpenter's (1994) research provided limited information regarding data collection, interview schedules and provided no information on how qualitative data was analysed to produce themes. The study additionally only included brief excerpts of participant direct quotes and failed to discuss strengths and limitations.

The quantitative studies consisted of small sample sizes in nearly all cases. Out of the five quantative studies, not one discussed whether the sample size had adequate power to detect statistical significance and most omitted reasons for their chosen statistical analyses, with only two providing justification for the analytic method used (Bentley et al., 2015; Cohen et al., 2016). Moreover, two studies provided limited statistics to support their results (Hornby, 1995; Houser & Seligman, 1991).

Of the one mixed- method and two qualitative studies, only the mixed-method study (Bentley et al., 2015) reported on the analytic process which was considered suitable to address the research question. Evidently, Gault (2009) used a single case study design and thus the analytic process did not need to be considered, however Herbert & Carpenter (1994) fail to outline how they analysed their qualitative interviews. The studies' sample sizes were deemed appropriate.

A number of studies also lacked detailed information regarding how participants had been recruited, for example not stating how many participants they approached (Bentley et al., 2015; Cummings, 1976; Herbert & Carpenter, 1994). It is thus impossible to determine whether these fathers include a good representation of the target population, leading to difficulties determining how generalisable the quantitative study findings are.

Overall, the discussion of strengths and limitations was poor across all studies, with three studies only briefly referencing limitations and thus scoring one out of a possible three (Cummings, 1976; Herbert & Carpenter, 1994; Hornby, 1995) and only one study scoring the maximum three points (Cohen et al., 2016) for considering the weaknesses across the design, measures, procedure, sample and analysis.

The only study to evidence service user involvement was the study written by the father of a child with ID himself (Gault, 2009) which has previously been acknowledged as substantially different to the other studies. This study provided a personal, albeit brief, insight into paternal experiences.

In summary, the papers had a number of clear strengths. Most papers contained a clear statement of aims, a description of recruitment data and, for quantitative studies specifically, there was a clear fit between the studies' research questions and the data collection methodology. Although a general trend was expected whereby the quality of the study design and reporting would increase amongst the three more-recently published papers, this was not found.

Table 4

*Quality Assessment Ratings Using the QATSDD*

| **Item (Score 0-3)** | **Bentley et al., (2015)** | **Cohen et al., (2016)** | **Cummings (1976)** | **Gault (2009)** | **Herbert & Carpenter (1994)** | **Hornby (1995)** | **Houser & Seligman (1991)** | **Rodrigue et al., (1992)** |
|---|---|---|---|---|---|---|---|---|
| Explicit theoretical framework | 3 | 3 | 2 | 1 | 2 | 3 | 2 | 3 |
| Statement of aims/objectives in main body of report | 2 | 3 | 2 | 2 | 2 | 3 | 3 | 2 |
| Clear description of research setting | 2 | 2 | 2 | - | 2 | 2 | 2 | 3 |
| Evidence of sample size considered in terms of analysis | 0 | 0 | 0 | - | 2 | 0 | 0 | 0 |
| Representative sample of target group of a reasonable size | 0 | 2 | 0 | - | 1 | 2 | 2 | 2 |
| Description of procedure for data collection | 1 | 3 | 2 | - | 1 | 3 | 3 | 3 |
| Rationale for choice of data collection tool(s) | 0 | 3 | 3 | - | 0 | 3 | 3 | 3 |
| Detailed recruitment data | 2 | 2 | 2 | - | 1 | 3 | 3 | 3 |
| Statistical assessment of reliability and validity of measurement tool(s) (Quant. only) | 0 | 3 | 0 | - | - | 3 | 3 | 3 |
| Fit between stated research question and method of data collection (Quant. only) | 3 | 3 | 2 | - | - | 3 | 3 | 2 |
| Fit between stated research question and format and content of data collection tool. (Qual. only) | 3 | - | - | - | 0 | - | - | - |
| Fit between research question and method of analysis | 3 | 3 | 2 | - | 0 | 3 | 3 | 3 |
| Good justification for analytic method selected | 2 | 3 | 1 | - | 0 | 0 | 1 | 1 |
| Assessment of reliability of analytic process (Qual. only) | 0 | - | - | - | 0 | - | - | - |
| Evidence of user involvement in design | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 |
| Strengths and limitations critically discussed | 2 | 3 | 0 | - | 0 | 0 | 2 | 2 |

## 6.3 Overall Outcomes

All eight studies captured various elements of fathers' experiences, although a number of studies focused on the same aspect of experience but assessed these using different measures. The findings of these studies have been summarised under 'themes'.

For the purpose of this review, and due to the different methodologies of the studies involved, quantitative and qualitative results are separated below.

**6.3.1 Quantitative studies.** Six of the eight studies utilised quantitative methodologies (Cohen et al., 2016; Cummings, 1976; Hornby, 1995, Houser & Seligman, 1991; Rodrigue et al., 1992). Bentley et al. (2015), used mixed methodology and the quantitative data will be considered within this section.

***6.3.1.1 Psychological wellbeing/stress.*** All six studies considered the psychological wellbeing of fathers when parenting a child with an ID. Three of these studies used a specific measure of fathers' wellbeing/stress which differed across studies (Cohen et al., 2016; Hornby, 1995; Houser & Seligman, 1991). A further three studies referred to fathers' stress, without specifically using a measure to assess this but making inferences from other measures used (Bentley et al., 2015; Cummings, 1976; Rodrigue et al., 1991).

Of the studies measuring fathers' stress, four used a case-control design and compared the stress of fathers of children with ID to the stress experienced by fathers with TD (Cohen et al., 2016; Cummings, 1976; Houser & Seligman, 1991). In a further study a group of fathers of children with ASC were included as a comparator (Rodrigue et al., 1991). These studies provide inconsistent conclusions about the stress experienced by fathers of children with ID and whether this differs from fathers of TD children.

Cummings (1976) described the stress of fathers of children with ID, stating that fathers of children with an ID have an increased pre-occupation with their child, lower self-esteem and lower sense of paternal competence. Fathers in this study also scored higher for depressive feeling, when compared to fathers of children with TD. Additionally, Rodrigue et al. (1992) suggested that a child with an ID has a greater impact on fathers than a child with TD, particularly associated with finances and overall care-taker burden which could be hypothesised as causing increased stress for fathers. Interestingly, neither of these two studies used a specific measure to assess fathers' stress or psychological symptoms.

Conversely, two studies that did use specific measures highlighted that fathers of children with ID did not differ from fathers of children with TD when considering stress and psychological symptoms (Cohen et al. 2016; Houser & Seligman, 1991). Fathers in Houser and Seligman's (1991) study did report higher stress scores for parenting a child with an ID, however the results were not significant. Cohen et al. (2016) went further to suggest that the presence of a child's ID did not contribute to a change in psychological symptoms as their child developed. The results of both of these studies have to be interpreted with caution however, due to the limited information provided about the sample used. For example, Cohen et al. (2016) included fathers of children with "undifferentiated developmental disability", without explaining further what type of disability these children had and Houser and Seligman (1991) provided no information on the children's ID aetiologies. It is therefore possible that children with an ASC might have been represented within this sample, impacting upon the results.

Moreover, a further two studies which did not employ a case-control design and thus did not include fathers of children with TD within their sample, supported these findings (Bentley et al., 2015; Hornby, 1995). Hornby (1995) concluded that the IQ level of the child did not affect fathers' overall adaptation or stress, although limited statistics were provided to support this claim. It was evident, however, that only a small minority of their sample (24%) reached cut offs for clinical depression, comparable to occurrence within a typical population, on the 'Malaise Inventory' (MI; Rutter, Tizard & Whitmore, 1970). Additionally, despite

Bentley et al., (2015) describing a proportion of their sample as ‘struggling’, upon closer inspection these participants had higher scores than the norms on certain positive measures (i.e. higher scores than fathers of children with TD). This was particularly apparent on the ‘Family Crisis Orientated Personal Scales’ (F-COPES; McCubbin, Olson, & Larsen, 2000) and the Herth Hope Index (HHI, Herth, 1992) which demonstrated that fathers were relatively hopeful, despite parenting struggles. Furthermore, 74% (n=37) of fathers scored average to high average on the ‘Satisfaction with Life Scale’ (SWLS; Diener, Emmons, Larsen & Griffin, 1985) indicating they were highly satisfied with their parenting experiences. The remaining 26% (n=13) of fathers still indicated struggles which contributed to mean scores of slightly ‘below average’ on the scale but fathers did not fall into the ‘dissatisfied’ category.

It is worth highlighting that when fathers’ interactions were recorded in Rodrigue et al.’s (1992) study, there appeared to be no differences between father-child interactions of TD or ID children. These results, however, might have been a reflection of the observational task used. The researchers observed video interactions between fathers and their child during interactive play and scored fathers on dyads assessing their engagement, mood and responsiveness. The task might have been too emotionally low-key to reveal differences between the two groups and it is also possible fathers presented in socially desirable ways due to their awareness of being observed.

Of these studies which measure fathers’ experiences, Cohen et al. (2016) was the only study to measure the longer-term effects of parenting a child with an ID on fathers’ psychological wellbeing. The authors collected data at several time points for fathers of children ages 3 to 9 years old.  Although they found that fathers’ psychological symptoms fluctuated over time for fathers of ID and TD children, with some fathers indicating anxiety and depression, this was not attributable to the presence of an ID or related to stress from the child or child-rearing. The same study, however, also found that child behaviour challenges predicted initial paternal psychological symptoms, and that fathers of children with ID reported significantly more child behaviour problems than those of TD children. It can be concluded therefore, that although there is not a direct link between ID and paternal psychological symptoms, children with ID and the often associated behavioural problems will subsequently impact on fathers' wellbeing.

In addition to overall psychological wellbeing/stress, all six studies explored the variables that impacted on fathers' overall adaptation and wellbeing which will now be outlined below.

***6.3.1.2 Demographics.*** A number of studies indicated that fathers' overall experiences were impacted upon by their demographics (i.e. their employment status, educational level, finances and socio-economic status) and also their child's demographics (i.e. gender and age).

In terms of employment, stress was reported as much higher by fathers who were unemployed (Hornby, 1995). Hornby (1995) also identified that fathers' stress was negatively correlated with their educational level and perceived finances. Despite correlations between their socio-economic status (referred to in the study as 'social class') and financial adequacy and education, Hornby (1995) found that fathers' stress was not significantly correlated with socioeconomic status alone, in contrast to a previous study (Houser & Seligman, 1991). The associations were further explored by Rodrigue et al. (1992) who found that children with ID have a much greater financial impact upon the family than children with TD.

The child's age was suggested to have an impact on fathers' experiences by Cummings (1976). This study highlighted that fathers of older children (aged 9-13) showed lower levels of stress and depressive feelings, and higher evaluations of their child and spouse, compared to those fathers of younger children (aged 4-8). Conversely, Hornby (1995) and Houser and Seligman (1991), found that the age of the child did not impact on fathers' adaptation or stress. This could be due to the age of children within these samples with Hornby's (1995) sample including 6-14 year olds and Houser and Seligman (1991) including children with a mean age of 15.43 for males and 15.22 for females. It is therefore possible that fathers might find younger children, included in Cumming's (1976) sample, at the pre-school ages more challenging. Although, Cohen et al. (2016) used wider age ranges (3-9 years old) to measure fathers' psychological wellbeing over time, and observed no age effects, supporting Hornby (1995) and Houser and Seligman (1991).

In relation to the demographics of children, Hornby (1995) concluded that there are no gender effects related to fathers' adaptation (i.e. adaptation to daughters did not significantly differ to adaptation of sons). Houser and Seligman (1991) similarly found that fathers' coping strategies did not depend on their child's gender and fathers from both ID and TD samples, used 'problem solving' most frequently regardless of their child's gender. In contrast however, Rodrigue et al. (1992) suggested that fathers of boys reported more satisfaction than fathers of girls. This may be attributable to the differences in measures used, and therefore constructs assessed, between these three studies.

Interestingly, none of the included studies explored whether fathers' age and number of children impacted upon their overall experiences.

***6.3.1.3 Spousal Relationships.*** Five of the six studies referenced fathers' relationships with their spouses. Cohen et al. (2016) focused on spousal support and observed close links with initial paternal psychological symptoms. The more support fathers received from their partners, the fewer psychological symptoms they appeared to experience and report. These links however, were not found when fathers were assessed at further time points. Moreover spousal support did not decrease the effects of child behaviour problems which, as outlined above, impacts greatly on fathers' psychological symptoms.

Fathers of children with ID also reported marital satisfaction and thus increased levels of adaptation. Hornby (1995) further explored spousal relationships through measuring marital functioning using the ‘Measure of Marital Satisfaction’ (MMS; Kelso, Stewart, Bullers, & Eginton, 1984). Fathers’ stress and overall adaptation was found to be negatively correlated with scores on the MMS, highlighting the importance of the spousal relationship to fathers’ overall adaptation and subsequent experiences. The scores of the fathers of children with ID within this study however did not significantly differ to the norms of non ID samples (Kelso et al., 1984). This study was the only study to further explore marital relationships by including divorce rates (8.7%), which were close to the national average at the time the study was carried out. Bentley et al.’s (2015) sample did include 2% of fathers who were separated from their partners but this was not explored further.

Bentley et al. (2015) further supported the above findings, by measuring participants’ relationships with ‘The Couples Satisfaction Index’ (CSI; Funk & Rogge, 2007) with 74% of fathers scoring above the measures norms for the broader population. The suggestion that fathers of children with ID are equally as satisfied with their marital relationships as fathers of TD children is also supported by Rodrigue et al. (1992). The researchers found no significant differences between the ID and TD groups with regards to marital satisfaction.

Conversely, Cummings (1976) found that fathers of children with ID evaluated their wives lower than their TD counterparts, suggesting fathers might be less satisfied than the research above suggests. A specific measure however, was not administered to participants to assess marital relationships and satisfaction. It is also possible that these results reflect the age of the study in that fathers are now taking much more active roles in family life which might impact on their relationships with their children and spouses.

***6.3.1.4 Coping.*** Four studies referred to fathers’ coping when describing their overall experiences (Bentley et al., 2015; Cummings, 1976; Houser & Seligman, 1991; Rodrigue et al., 1992) .

Bentley et al. (2015) suggested that fathers have higher levels of coping and problem solving ability than the general population, evidenced by fathers exceeding the norms on the F-COPES, which assesses how individuals cope with stress. Furthermore, Bentley et al. (2015) and Houser and Seligman (1991) reported few differences between fathers of ID and TD children.

In contrast, Rodrigue et al. (1992) suggested there were larger differences between the groups despite using a similar coping scale. Both studies measured fathers’ coping strategies using the ‘Ways of Coping Scale’ (WCS; Felton, Revenson, & Hinrichsen, 1984). Houser & Seligman (1991) used a revised version of the measure (WCS-R; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986) and this might explain the contrasting results as both measures examined different constructs. Differences might also be attributable to the sample sizes between the two studies, with Rodrigue et al. (1992) using a smaller group of fathers.

When examining fathers’ coping strategies, Houser and Seligman (1991) found that ‘distancing’ and ‘escape-avoidance’ were used much more by fathers of ID than TD children. ‘Positive re-appraisal’ was also reportedly used less by fathers of children with an ID. On closer inspection of the statistics within this study, there was however not a great deal of difference between the groups’ scores. Fathers of both ID and TD children used coping strategies such as ‘self-control’, ‘social support’ and ‘problem solving’ (Houser & Seligman, 1991). Rodrigue et al. (1992) further reported that fathers of children with ID used ‘wish-fulfilling’, ‘information seeking’ and ‘cognitive restructuring’ much more than fathers of children with TD. ‘Emotional expression’, ‘self blame’ and ‘threat minimization’ appeared to be used similarly regardless of the child’s additional needs.

Associated with coping, Cummings (1976) explored fathers' psychological needs and indicated that fathers of children with ID differed from fathers of children with TD. For example, they expressed a higher need for order (e.g. neatness, routine) and a lower need for dominance (e.g. assertiveness) and heterosexuality (e.g. expressions of sexual interest in members of the opposite sex). These needs will subsequently affect their coping strategies used and might also be associated with fathers' personality characteristics outlined below.

***6.3.1.5 Support.*** When considering fathers' coping strategies, an important element seemed to be fathers' attitudes towards support and their experiences, which three studies examined.

Rodrigue et al. (1992) explored the support systems of fathers of children with and without an ID, concluding there were no significant differences between fathers in regards to their satisfaction with support.

Hornby (1995) further explored father's satisfaction with support gained from intimate relationships, friendships and the community and used the Inventory of Parent Experiences (IPE; Crnic, Greenberg, Ragozin & Robinson, 1982). The authors found that fathers' adaptation was not associated with the *quantity* of support received but the *quality* of support they received (i.e. support satisfaction).

Cohen et al. (2016) only explored whether spousal support predicted fathers' psychological symptoms and found that although support mediated fathers' initial symptoms, it did not account for changes in fathers' symptoms over time nor reduce the effects of their child's behaviour.

***6.3.1.6 Personality.*** Fathers' experiences and stress also appeared to be linked to their personality characteristics. Cummings (1976) suggested that fathers of children with an ID undergo long-term personality changes when adjusting to their role. They reported that fathers of children with an ID scored much lower than fathers of children with TD on several constructs. These included lower scores on self-esteem, sense of competence and interpersonal satisfaction referring to lack of relationship gratification and low satisfaction related to their enjoyment of their child. They further concluded that fathers evaluated others much lower (i.e. their child with an ID, their other children and their wife, as indicated earlier) and overall demonstrated more rejection (e.g. ignoring). As mentioned earlier, these results might be a reflection of the age of this research. Over the last 30 years, research has indicated fathers have moved from the traditional ‘breadwinner’ roles whereby they provided limited input into home life, towards the much more involved ‘nurturer’ with a focus on relationships with their child and partners (Chanfreau et al., 2011).

Hornby (1995) similarly found that fathers’ general adaptation was negatively correlated with scores on neuroticism on the Eysenck Personality Inventory (EPI; Eyesenck & Eyesenck, 1964), with 31% of fathers scoring within 1 S.D of the ‘abnormal’ population (Hornby, 1995). Hornby (1995) also suggested that social desirability (i.e. lying or, as the authors referred to as “faking good”) was positively correlated with adaptation, although only 25% of fathers’ scores indicated this.

It is unclear whether fathers’ personalities change as a result of having a child with an ID, or whether certain pre-existing personality characteristics influence the types of experiences they have.

**6.3.2 Qualitative studies.** Two studies (Gault, 2009; Herbert & Carpenter, 1994) qualitatively explored fathers’ experiences, and as outlined earlier, a further mixed-method study (Bentley et al., 2015) contained a qualitative component. Both Gault (2009) and Herbert and Carpenter (1994) explored fathers’ experiences at the time of their child’s birth and Gault (2009) reflected on his own experiences as a mental health professional and also a father of a child with an ID. Bentley et al. (2015) also explored the attitudes and impacts of the diagnosis and birth. Due to their sample including participants with children of a large age range, some of these participants will have referred only to experiences at birth (i.e. participants with children in the lower ages, two months and above).

Overall, the studies highlighted themes related to fathers' emotional experiences (e.g. fear, shock, mourning and uncertainty), the communication of the diagnosis, and the strategies fathers used to adapt to having a child with an ID. The main findings of each study are presented in Table 3.

Bentley et al. (2015) separated fathers into three distinct clusters dependent on their scores on quantitative measures, outlined earlier, and the qualitative data obtained through the use of open-ended questions. The three clusters were 'mastering', 'connecting' and 'thriving'. Fathers representing the 'thriving' cluster spoke about their hope, satisfaction and personal growth and development as a result of having a child with an ID. A pervasive positive attitude was described by fathers who considered themselves as 'being chosen' for their role and how having a child with additional needs makes them a better person. Although the remaining two clusters ('mastering' and 'connecting') described the continual challenges they faced as a result of parenting a child with additional needs, they still maintained hope and a positive outlook on life. Fathers within the 'connecting' cluster also recognised the benefits to their circumstances (e.g. opportunities to connect with other families, social network ties and a sense of focus).

Herbert and Carpenter (1994) further explored fathers' experiences at the time of their child's birth. Themes were described relating to the communication of the diagnosis, fathers' initial responses and the strategies fathers used to adapt to the challenges the diagnosis brought.

One theme (i.e. 'breaking the news') focussed on the initial feelings fathers experienced when the paediatrician gave the news of their child's diagnosis. Fathers reported experiencing a variety of communication styles from ‘abrupt’ to ‘sympathetic and understanding’.

The theme of ‘too much too soon’ captured how much information fathers feel they should receive and when this information should be given.

‘The responses’ captured the shock, anger and disbelief fathers felt. Other themes represented the strategies fathers used to facilitate their adaptation towards their child (i.e. ‘Information seeking’, ‘Networking’, ‘Source of support’, ‘Searching for normality’). For example, participants described how making contact with other families experiencing similar circumstances was beneficial.

Participants also reported how limited the help that was offered to them was and how all support was mother-orientated. The theme ‘Professional access’ encapsulated how the majority of support services take place during the day which means fathers often receive second-hand information from mothers regarding their child.

In his brief personal account of being a father to a child with additional needs, Gault (2009) encapsulated his experiences at his child’s birth. Similar to the participants studied by Herbert and Carpenter (1994) and Bentley et al. (2015), he recalled his grief and the fantasies he had about his son not having an ID. Gault (2009) also considered the communication of the diagnosis and went further in an attempt to explain professional reactions and how these can be improved upon for future fathers. Both Gault (2009) and Herbert and Carpenter (1994) suggested that networking with others, in particular at support groups, is beneficial.

## 7. Discussion

Previous reviews and individual studies have demonstrated that fathers can positively adjust to having a child with an ID, despite the challenges they encounter (Hastings & Taunt, 2002; Hornby, 1992; Lillie, 1993; Seltzer et al., 2009). These reviews however, are now outdated and lack evidence of systematic searches. This review aimed to identify, summarise and appraise studies, including those published in the last 13 years since the previous review, which reported the paternal effects of parenting a child with an ID.

The search strategy and application of inclusion/exclusion criteria identified eight papers to be reviewed, none of which were excluded on the basis of quality. The search strategy used was quite broad in that it did not include the specific names of the many different types of IDs, in order to discover a large pool of research and to capture all available evidence. Despite this and the hand searching of references however, the pool of research relating to the research question appears small and thus the main findings of this review are limited. The limited number of studies supports previous suggestions that fathers are overlooked and that much less is known about their psychological wellbeing (Machin, 2015; Ricci & Hodapp, 2003).

This review found that there were a number of factors which influence fathers' parenting experiences. Quantative and qualitative research recognised the challenging nature of parenting a child with an ID and the subsequent stress father’s experience. Due to the qualitative nature of the research question (i.e. exploring fathers’ experiences), it is however surprising that most of the papers included in the review are quantitative. Qualitative methodologies are arguably much better matched to the aims of these studies (Cuskelly, Hauser-Cram & Riper, 2008).

Across all of the eight studies, the experience of stress was referenced, and although four studies attempted to explore the differences in stress between fathers of ID and TD children, results remained inconclusive (Cohen et al., 2016; Cummings, 1976; Houser & Seligman, 1991; Rodrigue et al., 1991). This could be due to the differences in measures used particularly because two studies (Cummings, 1976; Cohen et al., 2016), which highlighted differences, did not use specific measures to assess fathers’ stress. Cummings’ (1976) study also appeared to have poor methodological quality. Many of the themes generated in the qualitative studies encapsulated the stress, difficult emotions and challenges fathers encountered, similar to previous research which included both parents (Bartlett, 2004).

Fathers' overall experiences, and in particular stress, appeared to be influenced by a number of factors. These included their own demographics (i.e. their employment, socio-economic and financial status) and also the demographics of their children (i.e. gender and age), although findings again remained inconsistent (Cummings, 1976; Cohen et al., 2016; Hornby, 2009; Houser & Seligman, 2001; Rodrigue et al., 1992). There was evidence to suggest that fathers' experiences are influenced by their spousal relationships (i.e. satisfaction and support) (Bentley et al., 2015; Cohen et al., 2016; Cummings, 1976; Hornby, 1995; Rodrigue et al., 1992). In order to cope with their experiences, it is understandable that fathers utilised various coping mechanisms and sought out support, similar to previous research findings (Hastings & Taunt, 2002).

Much of the focus of previous research has been on the stressors experienced by fathers; it was therefore refreshing to explore more hopeful accounts as in Bentley et al. (2015). The authors demonstrated the hope and satisfaction of fathers parenting a child with an ID, whilst also recognising challenges. Most of the other studies included in this review failed to examine how positive factors influence fathers' adjustment and psychological symptoms (e.g. optimism).

Furthermore, these studies provide evidence to support existing research regarding the stressors faced by parents of children with ID and the factors which influence these stressors, such as the parent's age, support, finances and relationship with spouse (Baker et al., 2002; Houser-Cram et al., 2002; Lanfranchi & Vianello, 2012). The impact of the child's age and gender remains unclear (Frey et al., 1989).

In line with existing research, a number of studies described fathers experiencing difficulties adapting to their child's initial diagnosis, which can be experienced as a loss to some (Graungaard & Skov, 2007). Although coping strategies were explored within this review, it was unclear whether previous suggestions that fathers contain emotions to protect mothers could be an example of 'escape avoidance', as suggested by Houser and Seligman (1991) (Barak-Levy & Atzaba-Poria, 2013; Locock & Alexander, 2000).

Despite previous evidence suggesting that attachment styles and the impact of caring for multiple children with disabilities influence fathers' experiences (Hartley et al., 2012; Keller & Honig, 2004), the studies presented in this review did not explore these factors.

The quality of each study is discussed in detail in the 'Quality Assessment' section above. Overall, the papers included in this review had a number of strengths. It is important to recognise these, alongside their limitations, when considering their findings.

The QATSDD (Sirreyeh et al., 2012) was used to quality assess studies and was selected based upon the diverse methods used between the eight studies. A strength of this tool was that it allowed all eight studies to be assessed using one tool, rather than separate tools for each methodological design. The QATSDD provides guidance notes for each item which facilitated the author's decision making whilst also allowing space for critical thinking and personal judgment. The omission of summary scores, as previously outlined, enabled potential flaws to be identified without misleading readers with potentially high quality assessment summary scores.

Alongside the quality assessment, further additional characteristics/ factors have the potential to influence overall findings. Of the eight studies, five were carried out in the USA, with only three studies conducted in the UK, which may have implications when trying to generalise the findings to British fathers. One potential difference between fathers within the UK and USA, is the cost of healthcare in the USA. Although not acknowledged in any of the studies, this might be a contributor to fathers' stress, particularly because the financial impacts of raising a child with an ID were recognised (Hornby, 1995; Rodrigue et al., 1992).

Moreover, of the five studies that mentioned where fathers were recruited from, three studies recruited fathers exclusively through service providers (Cohen et al., 2016; Cummings, 1976; Herbert & Carpenter, 1994), one exclusively through support groups (Bentley et al., 2015) and another through both (Rodrigue et al., 1991). It is therefore important to note that the studies included self-selecting samples and those fathers who chose to participate, or who were actively seeking support, might have different experiences to fathers who refuse to take part or are not known to services or support groups. There are potential difficulties, therefore, when attempting to generalise the findings to this other group of fathers. Interestingly, none of the studies addressed whether fathers who were struggling were in receipt of any professional support (past or present) as this may impact on their views of their experiences and possibly the coping strategies used.

Cummings (1976) was the oldest study included in this review and as such the results might be outdated, particularly considering changes in fathers' roles (Machin, 2015). Cummings (1976) and Houser and Seligman (1991) used outdated language to describe children with ID. Further, Houser and Seligman (1991) appear to disregard fathers' needs (Machin, 2015) by concluding that fathers need to change for the benefit of mothers.

The studies included were heterogeneous in that they all answered the research question but in varying ways. The few similarities included four studies featuring case-control design (Cohen et al., 2016, Cummings, 1976, Houser & Seligman, 1991, Rodrigue et al., 1992), with most studies having been published within the last 20 years.

Furthermore, the aims of the papers were varied leading to differences in methodological approaches used and sample sizes. The reasons for contradictory findings might be due to the varying degree of questionnaires that were measuring different aspects of fathers’ experiences. Additionally, the different ages of children included have the potential to impact on participants’ experiences. For example, fathers of older children may have had a longer time to come to terms with the child’s diagnosis and make adjustments which impact on their overall experiences. Although Cohen et al. (2016) carried out a longitudinal study, their findings did not support this. The study however used a limited age range which might have been too small to detect effects on fathers’ psychological symptoms. Also, the oldest child in their sample was nine and differences in experiences may not be recognised by fathers until their children are older. Bentley et al. (2015) was the only study to include a large age range, however age effects were not explored.

Similarly, the time of diagnosis was not considered by any of the studies which could be hypothesised to affect fathers’ experiences (i.e. fathers of children who are diagnosed with an ID at birth have longer to adapt than fathers whose children receive a diagnosis at a later stage).

When considering all eight studies, a limitation includes the lack of longitudinal findings, with only one study exploring how fathers’ experiences change over time (Cohen et al., 2016).

Some of the quantitative studies explored similar factors related to fathers’ experiences; however no study used the same measure which made it difficult to explore consistencies between results. As mentioned earlier, Houser and Seligman (1991) and Rodrigue et al. (1992) both used the WCS, but different versions that included very different constructs (Felton et al., 1984; Folkman et al., 1986).

Further limitations include the general lack of reporting of the ethnicity of participants and the limited age ranges of children in some studies. Of the three studies that reported participants’ ethnicity, one provided unclear information about the sample characteristics (Cummings, 1976), one reported that 90% of the sample were white (Rodrigue et al., 1991) and similarly Bentley et al.'s (2015) sample consisted of 86% white fathers. Although Rodrigue et al. (1992) recognised this limitation, many studies did not acknowledge this.

It is also important to be cautious of making inferences from Cohen et al.'s (2016) findings due to significant differences between fathers of ID and TD children, particularly on fathers' education and income which might impact on overall experiences.

Regarding the age range of children included in the studies, Bentley et al. (2015) was the only study to include a large range encompassing children from aged two months to 25 years. Of the remaining studies that reported ages, much more limited ranges were included (Cohen et al., 2016; Cummings, 1976; Hornby, 1995; Houser & Seligman, 1992).

Additionally, two studies did not state the aetiology of the child's ID (Cummings, 1976; Houser & Seligman, 1991). The most common ID included in samples was DS (Bentley et al., 2015; Cohen et al., 2016; Gault, 2009; Herbert & Carpenter; 1994; Hornby, 1995; Rodrigue et al., 1992). No studies, however, outlined whether children with DS also had additional co-morbidities, for example, some children might also present with ASC. This is important as different diagnostic groups might present with unique challenges for fathers, especially DS which is believed to contribute to more positive views of care giving (Cuskelly, 1999; Hartley et al., 2012; Lanfranchi & Vianello, 2012). Also, a child with an ASC and DS might present differently to a child with DS alone, contributing to an overall divergent parenting experience (Bostrom et al., 2009; Hartley et al., 2011).

## 7.1 Strengths and Limitations

To the best of the author's knowledge, this review is the first to attempt to systematically examine fathers' experiences of parenting a child with an ID.

The review process has both strengths and limitations, which are outlined below.

Strengths of this review include the use of a quality assessment tool and the screening of papers against clear inclusion and exclusion criteria, carried out by two independent reviewers to reduce the potential for interpretation bias. Good inter-rater reliability was found as both reviewers shared agreement over the quality assessment. Additionally, no studies were excluded on the basis of their quality and as such greater precedence was given to higher quality studies. Although it is recommended to reduce bias, the reviewers were not blinded to the title, authors or publication journal of the study (Antman, Lau, Kupelnick, Mosteller & Chalmers, 1992)

Despite a further strength being the inclusion of single and mixed-methodology papers, a limitation is the exclusion of non-English language papers and work not published in peer-reviewed journals (i.e. theses). The inclusion of paternal accounts published in books may have provided further detail regarding fathers' experiences of parenting children with IDs.

Further, due to the vast aetiology of different IDs, search terms were broad to ensure coverage of the limited amount of papers. Individual diagnostic categories were not used in the search terms which led to a large diversity in the type of papers included and as outlined above, most participants of the studies were fathers of children with DS (Bentley et al., 2015; Cohen et al., 2016; Gault, 2009; Herbert & Carpenter; 1994; Hornby, 1995; Rodrigue et al., 1992).

### 7.2 Clinical Implications and Future Research

Due to the paucity of the literature outlined above it is very difficult to draw firm conclusions concerning clinical implications, thus some tentative implications will be stated below.

The findings of this review have implications for healthcare professionals and services that offer support to parents and families who have a child with an ID. In order to benefit the child, fathers and families, the couple should be approached as an equal partnership (Chanfreau et al., 2011; Ramchandani et al., 2013). Gault (2009) and Herbert and

Carpenter (1994) both highlighted how healthcare professionals can improve the ways in which they communicate the children's diagnoses and provide adequate information. Gault (2009) further suggested that parents of a child with an ID should be allocated a key person who can answer questions to whom parents can direct their queries to.

Furthermore, the findings of these studies suggest that a number of fathers experience pleasures and can overcome challenges associated with parenting a child with an ID. It is important thus, for professionals to not project negative expectations onto fathers and expect all fathers to be experiencing stress as potentially only a minority require intervention (Hornby, 1995; Houser & Seligman, 1991). For those fathers that might need support, the studies can help clinicians identify areas in which they can offer support, particularly Bentley et al. (2015) which took a non-deficit approach to exploring fathers' experiences and clinicians can help support fathers to experience growth and self-development. It is possible that the most appropriate intervention which could be offered to fathers' experiencing challenges might differ depending on individual characteristics. For example, some research suggests that personality might play a key role in how fathersexperience parenting (Cummings, 1976; Hornby, 1995).

Additionally, Cohen et al. (2016) indicated that paternal psychological symptoms were influenced by child behaviour problems. Thus, when clinicians work with children with behaviour that challenges, fathers' wellbeing should also be considered and individual support offered where necessary.

Several studies also identified the benefits of non-professional support and thus services should consider how best to signpost fathers to support groups and empower them to access support, particularly within their own family (Cohen et al., 2016; Gault, 2009; Herbert & Carpenter, 1994; Hornby, 1995). Spousal support and satisfaction were identified by a number of studies as impacting on fathers' experiences and thus services should seek to help both parents to facilitate supportive relationships (Cohen et al., 2016; Hornby, 1995; Rodrigue et al., 1992).

One area for further research to explore is why some individual's struggle and experience chronic stress when parenting a child with an ID and others do not. Further exploration of fathers' personal accounts is needed to add to the sparse literature base. Cohen et al. (2016) and Hornby (1995) attempted to expand the literature base by including fathers separated from their spouse, and non-biological fathers (i.e. step fathers and foster carers) respectively. Further study of these groups would allow for differences between these groups to be explored.

Finally, there was an apparent lack of evidence for service user involvement in the study designs. Service user involvement adds value to research (Carter, Beech, Coxon, Thomas & Jinks, 2013) and future researchers should attempt to utilise the expertise of fathers with lived-experiences of parenting a child with an ID.

### 7.3 Conclusion

This review aggregates all of the currently available qualitative, quantitative and mixed-method literature within the area of fathers' experiences to parenting a child with an ID. The available literature suggests a range of consequences for fathers parenting a child with an ID, influenced by a number of factors. The review identifies the limitations of the current evidence-base, providing directions for future research to address methodological issues and involve service-users. Although there is some evidence to suggest that fathers of children with ID experience more stress and parenting challenges than fathers of children with TD, other studies contradict these findings.

Whilst the body of research in this area is expanding, a clear understanding of fathers' experiences is still lacking. Further high quality research is also needed to explore individual diagnostic groups. Rather than group fathers of children under the umbrella of 'ID', where unique experiences are lost, researchers need to focus on how fathers adjust and adapt to individual diagnoses and their subsequent parenting experiences (Cuskelly, 1999). There is also a need for more longitudinal research conducted with more diverse populations to fully explore fathers’ experiences over time and across cultures.

The overall findings of this review have implications for clinical practice, in that findings can facilitate clinicians’ strategies to identify struggling fathers and identify areas in which they can offer support. Due to the limitations, however, within the individual studies and this review process, findings should be interpreted with caution.

Despite changing roles and the above research highlighting fathers’ increased involvement with their children, there is still a gap in service provision and professionals need to recognise fathers’ needs.

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[1] It is important to note there is variation in the terms used between studies i.e. some use the term "Down syndrome" and others use "Down's syndrome".

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# *9. Chapter Two*

# A Grounded Theory Approach to Understand Paternal Adjustment to Parenting a Child with Down’s Syndrome: Fathers’ Roles, Satisfaction and Contributions to Family Functioning

## 10. Abstract

**Purpose:** Historically research exploring the impact of having a child with an Intellectual Disability (ID), has focussed exclusively on mothers. The present study aimed to investigate fathers' experiences of parenting a child with Down's syndrome (DS), their contributions, influences on family functioning, and inclusion in their child's support provision.

**Method:** Semi-structured interviews were conducted with 15 fathers. Interviews were analysed using Grounded Theory (GT).

**Results:** Fathers' adjustment appeared to be on a fluid trajectory with three key categories influencing this trajectory: 'Accommodating the Child', 'Adapting the Parental/Spousal Role' and 'Adapting Society'.

**Conclusion:** The accounts uncovered fathers' adjustment trajectory to parenting a child with DS, concluding that despite practical and emotional challenges, fathers employed strategies to achieve positive adjustment. Fathers identified the need for services to recognise their role and involve them in their child's support provision. Implications for clinical practice and future research are discussed.

**10.1 Keywords:** fathers, adjustment, Down's syndrome, intellectual disability

This article will be submitted to the Journal of Applied Research in Intellectual Disabilities (maximum word count 7,000 words, for author guidelines see Appendix A).

## 11. Background

For years society has failed to facilitate men's parenting roles, despite changes in social circumstances and cultural values which have seen an increase in the active involvement of fathers in their children's care (Lillie, 1993; Machin, 2015; Schoppe-Sullivan et al., 2004). There remains a dearth of research focussing exclusively on fathers as carers, with studies often relying on indirect reports from mothers (e.g. Redshaw & Henderson, 2011). Despite studies showing the importance of paternal involvement from birth for childrens’ and fathers’ development and satisfaction (Brown et al., 2012; Palm & Fagan, 2008; Pleck & Masciadrelli, 2004), it is suggested that many researchers view fathers as not worthy of researching in their own right (e.g. May & Fletcher, 2013).

### 11.1The Impact of Parenting a Child with an Intellectual Disability

Historically, research exploring the impact of an ID on the family regarded mothers’ experiences as representing the whole family (Hastings, 2003). This research highlighted increased maternal distress often closely linked with uncertainty related to the child’s diagnosis and transition points (e.g. starting school) (Baker et al., 2002; Baxter et al., 1995; Gallimore et al., 1993). Spousal well-being and the age of the child further affect parent experiences (Baker et al., 2005; Lanfranchi & Vianello, 2012).

Furthermore, it is suggested that parental adjustment is achieved over time, and is affected by flexible employment and the parent’s ability to implement routine through making adaptations to roles (Carpenter & Towers, 2008; Foundation for People with Learning Disabilities [FPLD], 2007; West, 2000).

Much less is known specifically about the wellbeing of fathers, attributed to fathers being ‘hard to reach’ (e.g. Carpenter & Towers, 2008; Ricci & Hodapp, 2003).

### 11.2 Fathers of Children with Intellectual Disabilities

A number of studies suggest that fathers’ and mothers’ experiences differ, particularly in regards to stress (Bailey & Blasco, 1992; Lanfranchi & Vianello, 2012). This could be attributable to the variables predicting stress, for example fathers have been shown to be more affected by their child’s delay in social skills and acceptability and status (Lanfranchi & Vianello, 2012). Alternatively, maternal-paternal differences might be attributable to differences in coping strategies, such as fathers concealing their emotions to protect their family (Barak-Levy & Atzaba-Poria, 2013; Houser & Seligman, 1991) and dealing with their difficulties alone due to less accessible support (Parette et al., 2010; Pelchat et al., 2003).

Rodrigue et al. (1992) suggest that the child's gender affects fathers' parenting experiences; however this has not been supported elsewhere (Houser & Seligman, 1991).

Fathers' stressors and coping strategies appear to change as their child develops; with fathers initially seeking out information to cope with difficult feelings at birth, subsequently provided by support groups to ameliorate concerns for the future (Cummings, 1976; Harrison et al., 2007; Rendall, 1997; West, 2000). In contrast, however, a recent longitudinal study exploring fathers' experiences over several years observed no changes in fathers' distress as the child develops (Cohen et al., 2016). Moreover, initial distress was associated with the child's behaviour problems rather than disability status (Cohen et al., 2016).

It should be noted however that, similar to mothers, fathers of children with ID also recognise their personal growth and the positive aspects of parenting, for example the joy and pride they experienced from their relationship with their child (Carpenter & Towers, 2008; Hornby, 1992).

### 11.3 Fathers of Children with Down's syndrome

Down's syndrome (DS) is a genetic condition, resulting from an extra chromosome 21 in each of the body's cells. The speech and language of children with DS often develops slowly and most will have mild to moderate levels of ID (Dykens et al., 2000).

Research exploring the specific impact of parenting a child with DS is limited, due to samples focusing mainly on mothers and frequent inclusion of fathers in broader studies covering other IDs and autistic spectrum conditions (ASCs). Parenting a child with DS may evoke different responses to other IDs; studies combining different diagnostic groups fail to fully explore the impacts specific to a particular group (Cuskelly, 1999; Hodapp & Dykens, 2012). For example, Hartley et al. (2012) refer to a 'DS advantage' whereby parents report lower stress levels, more positive views and more support-seeking strategies compared to parents of children with other IDs. Researchers attribute this to the child's personality, frequent hospitalisations which provide opportunities to strengthen the parental bond and the availability of support groups (Derrington et al., 2013; Sullivan, 2002).

There is a dearth of literature exploring the specific factors involved in the adjustment of fathers of children with DS. Most of the studies which solely recruit fathers of children with DS highlight that, despite challenges particularly at the time of birth, fathers adapt positively (Bentley et al., 2015; Gault, 2009; Henn & Piccinini, 2010; Herbert & Carpenter, 1994; Hornby, 1995). Moreover, fathers' overall adjustment appears to be associated with spousal support and satisfaction; the child's behavioural difficulties; the fathers' employment status and his subsequent finances (Cohen et al., 2016; Hornby, 1995; Rodrigue et al., 1992).

To cope with challenges, fathers employ a range of strategies including seeking out information and planning for the future. For some fathers, family support groups are found to be beneficial, although it is recognised that father-orientated support is limited (Gault, 2009; Herbert & Carpenter, 1994; Rodrigue et al., 1992)

A number of these studies utilise quantitative measures which do not provide an in-depth understanding of fathers' experiences to the same extent as qualitative methods (Cuskelly et al., 2008). The current study is therefore designed to gain a qualitative understanding of the processes of fathers' adjustment to parenting a child with DS.

### 11.4 Aims and Research Questions

The aim of this study is to develop a model to account for fathers' experiences of parenting a child with DS, their contributions, influences on family functioning, and inclusion in their children's support provision. The following research questions will be addressed:

1) How do fathers adjust to living with a child with DS and what parenting roles do they play?

2) What specific factors contribute to their adjustment and how?

## 12. Methods

This study aimed to explore paternal adjustment to parenting a child with DS. Qualitative methodology, particularly Grounded Theory (GT), was considered most congruent with the study aims. GT allowed the researcher to examine experiences in-depth, and contributed to a theoretical understanding and development of a model (Kennedy & Lingard, 2006). Due to the researcher being new to GT, there was a preference to follow the framework of Strauss and Corbin (1998) whilst identifying with the ‘social constructivist’ element of GT (Charmaz, 2000). A reflexive statement is provided in Appendix B.

### 12.1 Sample

The sample consisted of fifteen fathers of children with DS, recruited from support groups within the North-West of England. The study was advertised in group meetings via a poster or brief research presentation (by the author). Participants were aged from 26 to 52 years old (*M*= 40.6 years old) and were able to communicate verbally in English. Additionally, fathers were only recruited if they had a birth child under ten years old, to allow for some variation in a recent and well-defined cohort. It was felt that fathers with older children might be at a different stage of adjustment (Cummings, 1976). Children’s ages ranged from 8 months to 8 years old (*M*= 4.3 years old).

Participant demographics were obtained prior to interviews (see Table 1), and used to guide recruitment following identification of the first participant in line with theoretical sampling used in GT. After the first interview and throughout recruitment, participants with different demographics (e.g. age, number of children, employment status) were selected with the hope of adding variance to the data and exploring emerging themes. This is highlighted through a flowchart (Appendix C). Two participants who initially expressed interest in the study were purposefully not recruited due to their similar characteristics to previously recruited participants.

Table 1

*Participant Demographics*

| No. | Age | Age of child | Number of Children | Birth order of child with DS | Type of Employment |
|---|---|---|---|---|---|
| 1 | 32 | <1 | 1 | First | Unemployed |
| 2 | 46 | 4 | 3 | Second | Full-time |
| 3 | 36 | 5 | 2 | First | Full-time |
| 4 | 52 | 6 | 2 | Last | Full-time |
| 5 | 47 | 4 | 3 | First | Full-time |
| 6 | 41 | 5 | 3 | Second | Full-time |
| 7 | 43 | 2 | 2 | Second | Unemployed |
| 8 | 40 | 5 | 2 | First | Full-time |
| 9 | 46 | 3 | 3 | Third | Unemployed |
| 10 | 40 | 8 | 2 | First | Part-time |
| 11 | 38 | 2 | 2 | Second | Full-time |
| 12 | 26 | 2 | 1 | First | Full-time |
| 13 | 45 | 7 | 2 | Second | Full-time |
| 14 | 42 | 5 | 4 | Third | Full-time |
| 15 | 35 | 6 | 2 | First | Unemployed |

**12.1.1 Recruitment.** Prior to ethics permission being granted, the researcher liaised with group leaders from DS support groups to assess the feasibility of the study within the imposed doctoral time constraints. Post ethical approval, fathers attending support groups were given copies of the participant information sheet (PIS; Appendix D) and those that expressed interest in participating provided their contact details. The researcher contacted potential participants and provided the PIS and a consent form at least twenty four hours prior to each interview. Participants' demographics were taken, to guide recruitment, and any queries about the study were addressed by the researcher. A consent form was reviewed and signed by the participant and researcher at the time of interview (Appendix E).

## 12.2 Procedure

**12.2.1 Ethical considerations.** Ethical approval was granted by the University of Liverpool's Doctorate in Clinical Psychology Research Committee (Appendix F).

Throughout the study, participants' confidentiality was maintained. All interviews were digitally recorded by the researcher and transcribed verbatim by a University administrator. Participant names were omitted during recording to preserve anonymity, and participants were allocated a unique identifier. Other names that were potentially identifiable were replaced with synonyms post-transcription. Digital recordings and transcriptions, and consent forms containing identifiable information, were stored separately.

It was agreed that, should participants become distressed during the interview, they would be signposted to appropriate support services. Participants were aware of their right to withdraw at any time and no participant highlighted distress during interviews.

**12.2.2 Research interviews.** Each participant chose the location of the interview, usually at their home, which lasted on average one hour. Interview duration gradually reduced throughout data collection, as expected with the methodology, and the shortest interview lasted 40 minutes (Polit & Beck, 2003). Semi-structured interviews were guided by an initial schedule which provided a broad, flexible approach to exploring fathers' experiences (Appendix G). The initial interview schedule was discussed in supervision and piloted with a father of a child with DS who did not fulfil the geographical inclusion criterion for the main study. After each interview the researcher noted hypotheses, reflections, a general summary and critique, and learning points for future interviews (Appendix H). Participants' narratives were transcribed and coded prior to the next interview to allow exploration of concepts in subsequent interviews.

The initial interview schedule broadly explored paternal parenting experiences (e.g. "What are the good things about being a Dad to [child's name]?" and "Tell me a little bit about your caring responsibilities at home. How much time, do you and [child's name] spend together?"). The schedule was refined after the fifth interview and a second schedule developed (Appendix J) to allow a sharper focus to be taken with subsequent interviews and to explore the emerging theory (Glaser & Strauss, 1999)

It was agreed through supervision that theoretical saturation (Glaser & Strauss, 1999; Strauss & Corbin, 1998) of the major categories was reached by interview 10 within this study. The analysis of recent interview uncovered no new data and categories appeared to be well-developed. The further five interviews were therefore used to refine the emerging theory (selective coding).

### 12.3 Analysis

The analysis of interviews was supported by use of the data software package, NVivo 10 (QSR International, 2012), to aid identification and collation of codes and themes.

In accordance with the GT approach, data collection and analysis occurred simultaneously (Glaser, 1992; Strauss, 1987) following Strauss and Corbin's (1998) three stages of analysis: open coding; followed by axial coding; and finally, selective coding. Constant comparison, comparing new data with data already collected and coded, to identify emerging patterns, themes and concepts (Glaser, 1992), is an integral part of GT and occurred throughout.

During open coding the first five interviews were subjected to micro-analysis, or line-by-line coding, which allowed the curiosity of the researcher to develop and provided the initial analytic direction. The majority of the codes constructed from the data used active language to capture processes (e.g. 'preparing for the future'). Additionally, *in vivo* codes used participants' own language from the data to capture meaning, for example 'recognising the good times'. The process of open coding is highlighted in Appendix J and a selection of the codes created is provided in Appendix K. Supervision and reflection on interview memos enabled the clustering of codes into larger categories and sub-categories. A storyline (Appendix L) was created to capture the first five narratives and contribute to a composite narrative and initial model (Appendix M).

Axial coding followed open coding, whereby relationships between each of the categories and sub-categories were explored, allowing for the construction and testing of relational hypotheses over the next five interviews (see Appendix N). Due to the minimal changes that occurred within the initial model, the final five interviews continued with the focus on relational hypotheses, exploring the existence of a category hierarchy, and identifying which categories appeared most important for adjustment (see Appendix O).

Selective coding enabled the testing of relationships between the major categories and the overall model, however, no new information was uncovered with respect to understanding fathers' experiences. The final coding structure is provided in Appendix P.

Model development occurred in parallel with developments in the coding structure. The initial theoretical model of participants' experiences, which was produced after the first five interviews, informed the modification of the interview schedule for the following five interviews. A second model was then produced which provided the focus for the final five interviews. Salient emerging data was incorporated into the second model, and a theoretical account of all participants' experience was developed (see Fig. 1).

## 13. Results

In this section a narrative summary of the theoretical storyline will be provided, describing how fathers adjust to having a child with DS. The second section provides a diagrammatic representation of the theoretical storyline, the 'model'. The third section describes the major conceptual categories, and sub-categories, which are conceptualised as properties and dimensions (D) in line with Strauss & Corbin's (1998) approach. Quotations (presented in italic font) provide support for the author's interpretations and words within '*[ ]*' have been added to provide clarity, while '…' indicates the omission of text to provide a quotation appropriate in length.

## 13.1 Narrative Summary of the Model

Participants all reported they had made a positive adjustment to parenting their child with DS. Analysis of participants' narratives led to the identification that parenting a child with DS is on a fluid trajectory, highlighting that adjustment has a course that changes over time for each father. Being a father to a child with DS presents challenges that can hinder the adjustment process, and fathers have employed deliberate strategies to shape their adjustment course and ultimately achieve positive adjustment.

There are three categories which feed into this trajectory: 'Accommodating the child'; 'Adapting the parental/spousal role'; and 'Adapting society'.

The first category that all fathers felt was fundamental to their overall adjustment was 'Accommodating the child', which is influenced by their child's age. Fathers began to make accommodations at birth which continued throughout their children's lives.

Fathers identified several challenges which dictated how demanding this process could be, and how successfully accommodation is achieved. 'Negative emotions and stress' conceptualised the 'emotional rollercoaster' of parenting a child with DS, with especially difficult emotions being present at birth which faded as their child grew older. Fathers also described the challenges related to their child having DS ('Challenge of DS') and in particular how the 'Presence of co-morbidities' impacted on their ability to accommodate. Other challenges included the 'Challenge of comparing' their child to others, either siblings or other children outside the family, and the 'Challenges to accessing support'.

In light of the above challenges, fathers spoke about strategies which enabled them to accommodate, such as 'Involvement at birth' which facilitated the development of a bond between themselves and their child. The 'Family set-up' was also considered important in terms of the presence of siblings and birth order of the child with DS. All fathers also referenced how 'Employment' had impacted on their ability to accommodate to their child, highlighting the importance of seeking out support and flexible working arrangements from employers. Additional strategies described by fathers as beneficial included ‘Adaptation’ (i.e. practical and emotional changes), ‘Information searching’ and finally ‘Accessing support’ all of which captured the positive steps fathers make to overcome the challenges encountered.

A second category feeding into adjustment was ‘Adapting the parental/spousal role’ which included processes relating to the adaptations fathers make as a parent and how they actively negotiate and re-negotiate their relationship with their spouse.

In a similar way to ‘Accommodating the child’, this category was influenced by the ‘Age of the child’ and the challenge of ‘Negative emotions and stress’. Additional challenges included ‘Challenges to relationships’ and ‘Challenges of gender role’, whereby fathers described the impact of having a child with DS on their relationships with their other children and their spouse, and how being male impacted upon the adaptations made.

To facilitate their adaptations, fathers employed a number of strategies including recognising the positives (‘Positivity’) and the ‘Renegotiation of relationships’, which covered the active changes fathers reported, mostly related to their spousal relationship. Further strategies were related to their ‘Gender role’ and their ‘Employment’.

When exploring the temporal relationship between these two categories, most fathers identified that ‘Accommodating the child’ and ‘Adapting the parental/spousal role’ were equally as important, with no consensus as to the timing of each.

A third category, ‘Adapting society’ was included in the model for completeness, although the majority of fathers did not find this significant in terms of their adjustment process. A small number of fathers, however, did feel that the negative experiences they encountered in relation to parenting their child with DS, and their perceived level of social acceptance of their child, influenced their adjustment.

Fathers’ experiences of adjusting to parenting a child with DS are depicted in Figure 1.

### 13.2 Diagrammatic Representation of the Theoretical Storyline

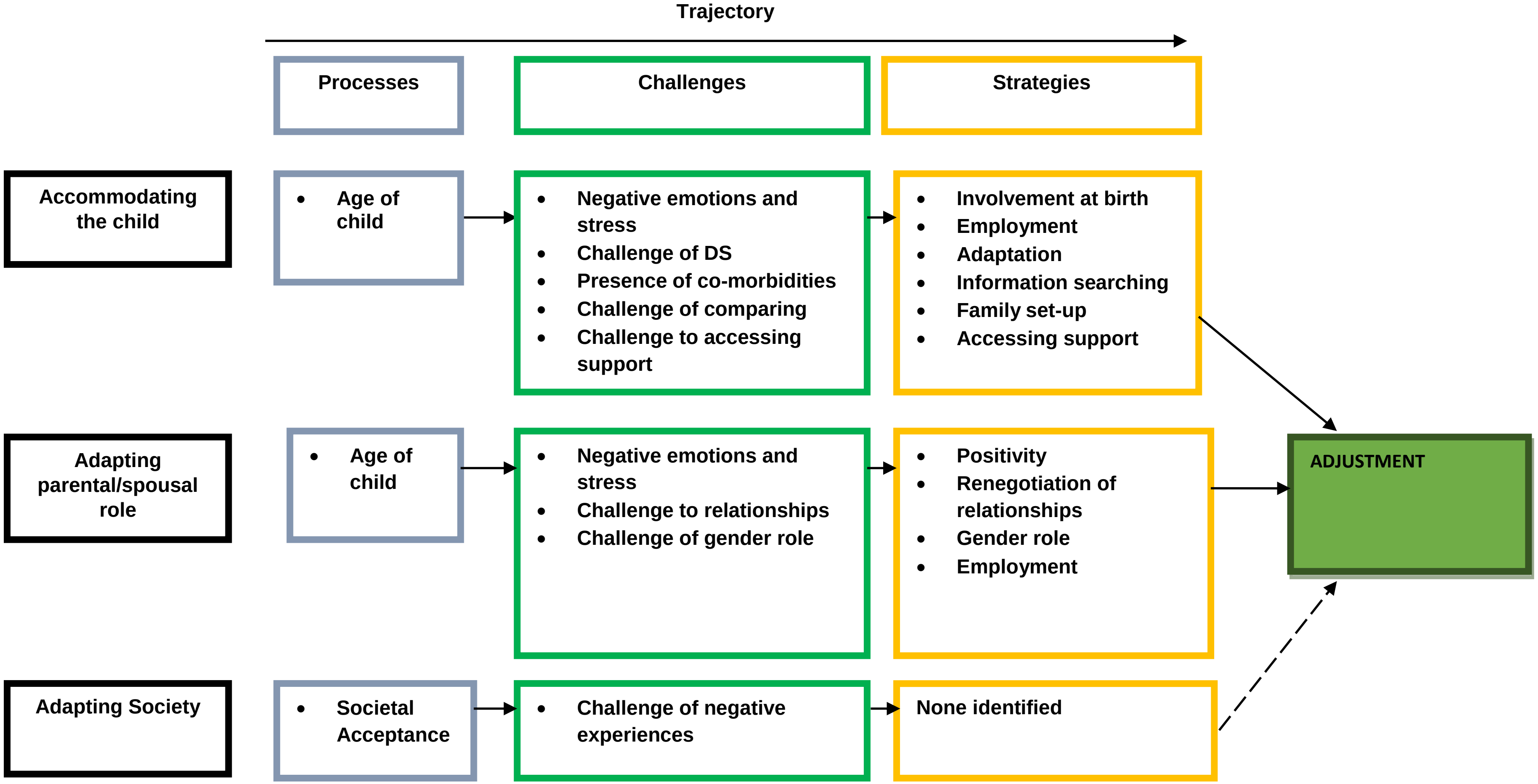

*Figure 1*. Diagrammatic representation of the theoretical storyline of fathers' adjustment to parenting a child with Down's syndrome

### 13.3 Accommodating the Child

The process of ‘Accommodating the child’ was influenced by the ‘Age of the child’ (D). Participants described a number of challenges that impacted on their ability to accommodate to their child. These included: experiencing ‘Negative emotions and stress’ (predominantly when their child was born); ‘Challenge of DS’; ‘Presence of co-morbidities’ (D); ‘Challenge of comparing’ and; ‘Challenges to accessing support’. To overcome these challenges fathers utilised strategies such as: ‘Involvement at birth’; ‘Employment’ (D); ‘Adaptation’; ‘Information searching’; ‘Family set-up’ and ‘Accessing support’.

**13.3.1 Age of child.** The child’s age seems to dictate fathers’ position on the trajectory and the accommodations made:

> *Originally when he was younger…the behaviour side wasn’t as much of an issue as the medical side. As they get older the medical side for some things has decreased and …you’re more focussed on behaviour and how well they’re doing, how they’re interacting that side of things. So it’s kind of changed over time.* (Participant [P] 6, 83-8)

**13.3.2 Negative emotions and stress.** The challenge of negative emotions and stress that come with having a child with DS were emphasised with one participant describing their experiences as an “*emotional rollercoaster*” (P5, 412).

Fathers reflected on their feelings in the early days when learning of the DS diagnosis, with one participant describing it as a “*grieving process…you feel it’s like the end of the world*” (P7, 267-71) and another describing difficulties accepting the loss of “*a perfect child*” (P14, 199-200).

Feelings of helplessness and uncertainty contributed to fathers’ stress: “*I would’ve thought having [DS] it does has an influence no matter what you say… you do think all the time…what’ll happen when you’re older and like I’m not here*”. (P2, 201-4)

**13.3.3 The challenge of Down's syndrome.** One aspect contributing to fathers' stress was the challenges related with their child's developmental delay associated with DS (e.g. communication, toilet training). One participant mentioned the more child-related challenges, the "*more interventions*" (P8, 63) are needed.

**13.3.4 Presence of co-morbidities.** Another challenge for fathers is the presence of the child's co-morbidities which seem to slow down the process of 'Accommodating the child', (i.e. the more physical health complaints the child has, the harder it is to accommodate).

Within this property, an inherent strategy described by fathers was the use of downwards comparison whereby they described feeling "*lucky*" (P8, 72; P10, 198; P13, 44) when their child did not present with additional health problems. One participant explicitly noted the lack of co-morbidities for his child "*helped…[him] come to terms with things much quicker*" (P11, 14).

**13.3.5 Challenge of comparing.** Although downwards comparison is highlighted as a positive strategy above, most fathers described the upward comparisons they made between their child and other children without DS.

> *It doesn't help in that your comparing [him] all the time to what they can do…You try and not draw comparisons to others but you do which can be upsetting…then you're more upset with the fact that you've let yourself get upset* (P4, 381-6).

**13.3.6 Challenges to accessing support.** Participants identified that accessing professional, and in some cases family, support can be challenging; contributing to stress and impacting on their ability to accommodate their child.

A number of participants expressed feeling let down by professional support and described a constant battle for services in light of budget cuts and an apparent 'postcode lottery'.

> *A team of specialists should be helping her. So we're talking to the GP at the moment and he said he going to try and see what's going on and if that doesn't come up with anything I'll have to go and see the MP.* (P7, 235-8)

Most participants felt that they could challenge services if they were struggling, although one recognised that "*not everyone is capable of being a strong advocate for their child*" (P9, 310-11).

Further, the limited services available were perceived to disregard fathers in terms of their location, focus or the timing of support, which were all more mother-orientated.

> *Sometimes especially as a dad…going to some of…the…groups…the response I'd get from parents… was always that you know you're a bloke there was a bit of wariness…parents sort of keeping their child away.* (P10, 332-7)

Some participants expressed reluctance about attending male-only support, unless it was fact-focused, with one participant describing emotion-focused support as "*pulling teeth*" (P6, 752).

As can be seen in the model, fathers adopted a number of strategies related to these challenges which will now be presented.

**13.3.7 Involvement at birth**. Although most participants recalled their initial shock upon discovering their child had DS, they still mentioned they *"couldn't imagine not being there, I think that was extremely important to my adjustment if I'm honest"* (P2, 192-3).

**13.3.8 Employment.** The challenges in accommodating their child appeared to be exacerbated by increased working hours: *"It was all getting the irregular hours were a bit, you know a bit more challenging even though she was younger then"* (P8, 121-2).

Employers who were flexible and supportive were credited as facilitating positive adjustment.

**13.3.9 Adaptation.** Another strategy that participants felt important was making practical (e.g. home adjustments and giving up hobbies) and emotional adaptations (e.g. embracing the role of becoming a father).

Most fathers recognised the close paternal bond they have with their child and the view that regardless of what disability their child has, they are still <u>their</u> child.

Another emotional adaptation is accepting that their child has DS which involves an adjustment of their expectations, a re-focus on the positives and utilisation of downwards comparison.

> *It probably sounds horrible but…I bet we all do it, we get in the car and we kind of go phew glad I'm not X's mum oh my goodness did you hear what he did at X and suddenly you kind of think actually we got off lightly there.* (P6, 325-8)

A number of participants also believed their attitude and perspective on life was an important predictor of their adjustment, describing changes in attitude since having a child with DS. Being mindful and taking "*each day as it comes*" (P1, 243-4) enabled accommodation to their child. One participant highlighted "*…you just cope, 'cos the alternative is to just sort of put your hands in the air and cry*" (P5, 420-1).

**13.3.10 Information searching.** This strategy begins at the child's birth when fathers search the internet for information about DS: *"I'm at home and of course what you do, the first thing you do is go on Google and understand what's going on…so I'm going through all the signs oh and [I'm] thinking oh no she's not got that"* (P3, 445-8).

This strategy seems to be relied upon less as the child grows older, replaced by seeking interpersonal support.

**13.3.11 Family set-up.** For participants who had more than one child, the family set-up and subsequent birth order of children was considered important. *"His brother's… five years older than him but they're quite competitive…and I think…that competition is not a* *bad thing…that helps Bertie, he knows then, right oh Billy can do that I want to be able to do that"* (P9, 84-92).

**13.3.12 Accessing support.** To overcome the challenges regarding accessing professional support outlined earlier, support was sought from elsewhere (i.e. from family and the "*DS community*") (P4, 450). One participant described: "*Going off meeting other parents of children with [DS] and actually it's quite an interesting disability because there's a lot of us about*" (P5, 190-2).

Most, but not all, participants referenced the benefits of attending groups to learn from "*parents sharing their experiences*" (P2, 608-9), with one participant referring to his group as "*family*" (P12, 91-92).

### 13.4 Adapting Parental/Spousal Role

An important finding of this study was that in order for fathers to adjust, there are additional factors external to the father-child relationship considered important, such as relationship changes with their spouse and other children. As outlined in the previous domain, the 'Age of child' impacts upon the timing of fathers' need and ability to adapt his role. Challenges that exist in relation to fathers adapting their roles include: 'Negative emotion and stress'; 'Challenges to relationships'; and the 'Challenge of gender role'. Fathers appear to employ strategies to overcome these challenges such as: 'Positivity' and the 'Renegotiation of relationships'. Further, strategies are related to fathers' 'Gender role' and fathers' 'Employment' (D).

**13.4.1 Age of child.** Most participants recognised that their spousal relationship changes as their child develops. For example, appointments may decrease as the child grows older and as routines are developed: *"we've ironed out a lot of the things we do as a couple and as parents*" (P9, 223-5).

One participant stated:

> *It also helps that…we've had a lot of time to adapt as a couple now and actually the creases from the early days have been ironed out and we've changed as a couple because we've overcome challenges together and sat down in those early days and talked through how we can make it work.* (P14, 153-6)

**13.4.2 Challenge of negative emotions and stress.** Also present in the previous category, 'Negative emotions and stress' impacted upon a participant's ability to adapt their roles. A few participants experienced guilt for not being as involved as their partner: *"you can't always be there…and therefore you do feel guilty"* (P2, 470-1).

Some participants referred to the difficulties in talking to their partners, one participant summarised: *"we do bottle things up and we maybe don't communicate to each other as well as we could do…I guess longer term it's probably a bad thing"* (P3, 210-12).

**13.4.3 Challenges to relationships.** Participants outlined the challenges to personal relationships that come with having a child with DS.

> *Just getting away for a night, if it was not Jay you could rock up but you can't leave Jay alone. In 6.5 years we've spent two nights away from Jay and that wasn't very far away, we were probably 5 miles away. Your personal relationships struggle, erm you don't have much time for each other.* (P4 289-292)

**13.4.4 Challenges of gender role.** The challenges that arise from being male were discussed. Almost all participants had a "*relatively traditional*" (P2, 52) parental arrangement whereby the mother was the main carer and they were the "*breadwinner*" (P2, 56), despite participants emphasising the importance of equal roles. One participant explained that "*the stereotype of the female [as] the giver and carer [still exists]…quite often a lot of the dads step back"* (P10, 390-3). Another requested that professionals recognised fathers:

> *Professionals what they need to learn is a dad's got just as much responsibility as the mum so they need to be able to talk to the dads the way they talk to the mums and not*

> *turn round and hold stuff back from the dad… [We're] fighting like hell to be accepted by the professionals but they're just turning, turning away because you're not the mother.* (P12, 241-6)

**13.4.5 Positivity.** It is important to note that despite the challenges participants identified in adjusting to parenting a child with DS, many positives were credited as facilitating their adaptation: *"I can think of all the things that help…If I couldn't notice all those positives about her as a mum and what we bring as parents then I wouldn't be in the position I am today"* (P7, 401-3)

**13.4.6 Renegotiation of relationships.** A further overall strategy employed is the 'Renegotiation of relationships', which concerns fathers' relationship changes, especially their spousal relationship, with a few fathers highlighting how their child with DS had brought them "*closer together*" (P1, 688).

A key change to relationships involved 'Sharing caring responsibility' facilitated by the setting of routines and agreement on roles soon after their child's birth.

One participant explained that "*maintaining a separate relationship so you're not defined by your parental role*" (P7, 397-8) is important.

**13.4.7 Gender role.** In regards to fathers' relationships with their spouses, and linked to the 'Challenges of gender role', participants spoke about staying strong to protect their partner*: "it was away from 'er, probably at night time when she went asleep…I'd come down an' like go outside for a fag and then [cry] outside so then she couldn't see me or hear"* (P1, 323-5).

This could be seen as a, potentially maladaptive, strategy to help fathers' adjustment by not burdening their spouse.

**13.4.8 Employment.** Fathers in full-time employment explained how tiredness impacts on their ability to share caring responsibility, and how annual leave is often used for their child's appointments: "*I should and possibly could do more which makes me feel bad but I struggle with how busy my job is"* (P4, 56-57).

Therefore participants found it helpful to have a "*reasonable, sensible employer*" (P6, 549) who provides time off for appointments and allows participants to be increasingly involved with their family. A number of participants had changed jobs or reduced their hours, with three becoming full-time primary carers for their children.

### 13.5 Adapting Society

As mentioned previously, only a minority of participants felt that 'Adapting society' was fundamental to their overall adjustment.

**13.5.1 The challenge of negative experiences.** Negative experiences were mainly linked to the circumstances around their child's birth, and participants' disappointment with the communication of the DS diagnosis: *"the docs just didn't communicate it right, we was just left to wait and we had no clue what DS was"* (P12, 15-18).

**13.5.2 Societal acceptance.** Conversely, participants described how societal views had changed for the better and how this helped counteract negative experiences: *"I feel fortunate that we've had her now and not…20 years ago 'cos it just seems a lot's happened in the last 20 years"* (P3, 488-9).

## 14. Discussion

The study aims were met through developing a model to account for fathers' adjustment to parenting a child with DS and the key findings will be discussed below. This is the first study to produce a theoretical framework outlining the processes of adjustment specifically for fathers of children with DS. Given the limited evidence base specifically for DS, the findings of the study will be situated within, and compared to, the broader existing evidence base of ID that characterises adjustment as a global concept (Baker et al., 2005).

The overall analysis of participants' narratives supported previous research that suggests adjustment to parenting a child with a disability is achieved over time and experiences are determined by the child's age (Carpenter & Towers, 2008; Lanfranchi & Vianello, 2012). This study has further added to the evidence base by highlighting that for positive adjustment to occur, fathers have to adjust not only to their child ('Accommodating the child'), as suggested by Gallimore et al. (1993), but also adjust their parental/spousal role ('Adapting the parental/spousal role'). The links between fathers' adjustment and their relationship with their spouse are supported by previous research conducted with fathers of children with DS (Cohen et al., 2016; Hornby, 1995).

Similar to findings from a study exploring fathers of children with ID (Lanfranchi & Vianello, 2012), 'Adapting society' was identified as important, although most fathers of children with DS felt their child's acceptability and status was not pertinent to their overall adjustment. This was potentially as a consequence of the 'DS advantage', and the public's understanding of DS (Hartley et al., 2012; Derrington et al., 2013).

Across all three categories in the model, several challenges and strategies were captured. From the challenges described by fathers throughout the interviews, it was apparent, fathers *are* playing an active role in family life through providing care for their children and also supporting their spouse, in contrast to previous suggestions (Bailey & Blasco, 1992). Despite their active involvement, however, fathers still feel like secondary parents to mothers, suggesting very little has changed in 20-30 years (Lillie, 1993; Parette et al., 2010).

This study highlights fathers, similar to mothers, *do* experience stress, particularly in the early days, but this is generally hidden through using coping strategies such as concealing their emotions to stay strong for the family, and dealing with difficulties alone (Barak-Levy

& Atzaba-Poria, 2013; Cummings, 1976;  Houser & Seligman, 1991; Pelchat et al., 2003; Rodrigue et al., 1992).

The early days, in particular their child's birth and diagnosis were a particular challenge for participants who experienced uncertainty and grief, which has been highlighted in previous reports (Baxter et al., 1995; Gault, 2009; Herbert & Carpenter, 1994). The limited information provided at birth exacerbated feelings of helplessness, and fathers consequently relied on the internet for support. As their children develop, fathers' challenges become more associated with campaigning for support due to the apparent 'postcode lottery' of services, and balancing the demands of childcare with paid employment, matching previous findings (Baxter et al., 1995; Hastings, 2003).

Similar to the findings of Houser and Seligman (1991), but in contrast to Rodrigue et al., (1992), fathers did not reference the gender of their child as a challenge to their adjustment.

Despite experiencing challenges, fathers were able to actively manage and overcome these by using a range of strategies which enabled them to positively adjust with love and commitment towards their child. In line with previous studies, fathers spoke of personal growth, attributing this to their strong paternal bond and the positive changes they had made (Bentley et al., 2015; Carpenter & Towers, 2008; Hornby, 1992).

In contrast to Cohen et al.'s (2016) study which suggested that fathers' stress did not change as their child developed, fathers in the current study indicated otherwise, despite similar ages ranges of children in both studies. The differences in findings could be attributable to the different methodology used as Cohen et al.'s (2016) methodology was limited to fathers' responses on questionnaires.  Fathers' coping strategies also appeared to change over time, in support of Rendall's (1997) and West's (2000) conclusions. For example, most fathers found that the need to search online for information was replaced by attendance at DS support groups. In support of previous research, fathers in this study focused pragmatically on challenges by just ‘getting on with it’ and planning for the future, highlighting their resilience (Bentley et al., 2015; Herbert & Carpenter, 1994). As mentioned earlier, they mostly dealt with challenges alone, which links closely with research highlighting that when males experience distress, beliefs such as ‘I must not be weak’ govern their behaviour and emotions (Endler & Parker, 1994; Kingerlee, 2012).

Although involvement at birth was not an active strategy fathers might have undertaken to facilitate adjustment, the successful outcomes fathers experience as a result of being present at their child’s birth, found in current and previous studies, should be communicated to fathers (Palm & Fagan, 2008; Brown et al., 2012; Pleck & Masciadrelli, 2004). Similarly, ‘Employment’ might not have been seen as an active strategy to facilitate adjustment, but participants highlighted how flexible and supportive employers impacted upon their adjustment trajectory. The association between employment status, finances and fathers’ stress is supported by Hornby (1995).

Another strategy fathers used to overcome challenges, promoted by previous research, was the renegotiating of roles and relationships, involving sharing the caring responsibility (FLPD, 2007; West, 2000) which allowed opportunities for respite, considered important for some fathers.

In summary, this study supported previous findings that, despite the emotional and practical challenges that come with parenting a child with DS, fathers can positively adjust (Bentley et al., 2005; Henn & Piccinini, 2010).

### 14.1 Clinical Implications

Based on the experiences of current participants, there remains a gap in service provision which suggests more could be done to involve and support fathers. If fathers of children with DS do access support concerning their adjustment, services could acknowledge the two, potentially three, key domains fathers might need support with.

A recommendation specifically for medical professionals, particularly at the child's birth, is to involve fathers and communicate the implications of a DS diagnosis by stating facts and focusing on the *positive* attributes, which in the past have been neglected by research, that having a child with DS can bring to the family. For example, fathers referenced personal growth, their strong bonds with their children and how having a child with DS had strengthened their relationships with their spouse. Participants felt this would have reduced their anxiety and limited their risk of finding inaccurate information online which potentially could have had detrimental effects on their adjustment (Gault, 2009).

Additionally, participants talked about the importance of being present at their child's birth to strengthen future bonds and help with accelerate the adjustment trajectory. It is therefore important that professionals, specifically midwives, are trained to communicate this to fathers who have become aware their child has DS through pre-natal testing.

### 14.2 Strengths and Limitations

This is the first study within the United Kingdom which offers an understanding of fathers' adjustment to parenting a child with DS, highlighting the interest and motivation of fathers to participate in research. Importantly this study has addressed a major criticism identified with many studies in this area (e.g. the use of mothers to represent 'parent views').

The study benefited from GT methodology with a strength including the use of theoretical sampling which allowed the in-depth exploration of fathers with different backgrounds. Conversely, the use of qualitative research methods, and in particular theoretical sampling, may limit the generalising of findings to other populations. The use of qualitative methodology, however, allowed a variety of experiences to be captured highlighting how individual level factors, such as psychological resources (e.g. downwards comparison) and community resources (e.g. flexible employment) work to influence fathers' experiences.

Another limitation which should be recognised is the self-selecting sample consisting of mainly White British fathers in financially stable jobs. It could be hypothesised that fathers attending support groups and volunteering to participate in research may be more likely to feel able to communicate their experiences, or hold particular views. Their employment status may also enable them to better support their family financially. It could also be hypothesised that fathers who refused to take part may have had different experiences, or not achieved positive adjustment. In common with all research, it is also important to consider the possibility of 'social desirability' in the fathers' responses to questions about their family life, coping and challenges.

### 14.3 Future Research

Future researchers need to utilise the strong desire of fathers to participate in research, evident in this study. There is a need to explore fathers' experiences across varying diagnostic categories, rather than grouping fathers under one umbrella of ID, where specific implications might be lost (Cuskelly, 1999).

Additionally, there needs to be consideration about how researchers can reach fathers not obtaining support to capture their adjustment experience, especially those who might be struggling. Fathers who are not currently residing with their partners and child are of particular interest, potentially providing insight into adjustment challenges and what may have led them to leave the family home. Recruiting from other geographical areas and cultures may provide further variation in the findings.

Although there are numerous studies exploring mothers' experiences of parenting a child with an ID, it would be interesting to explore mothers' adjustment specifically to a child with DS, to see if similarities exist with the adjustment domains, and to explore the complexities of parental relationships from their perspective.

Further replication studies would add strength to the findings of this study, and are warranted to explore why adapting society is important for some fathers but not all.

### 14.4 Conclusion

In conclusion this study contributes to a neglected literature base, through providing the only GT study to explore the adjustment trajectory for a previously hidden group of fathers who, despite experiencing challenges, have positively adjusted, demonstrating strength, resilience and commitment to their children and families.

It is hoped this study will help to raise awareness of the importance of the fathers' roles when parenting children with DS, whilst highlighting the need for further father-focused research.

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[2] It is important to note that there is variation in terms used between studies i.e. some studies use the term "Down syndrome", whilst others use "Down's syndrome".

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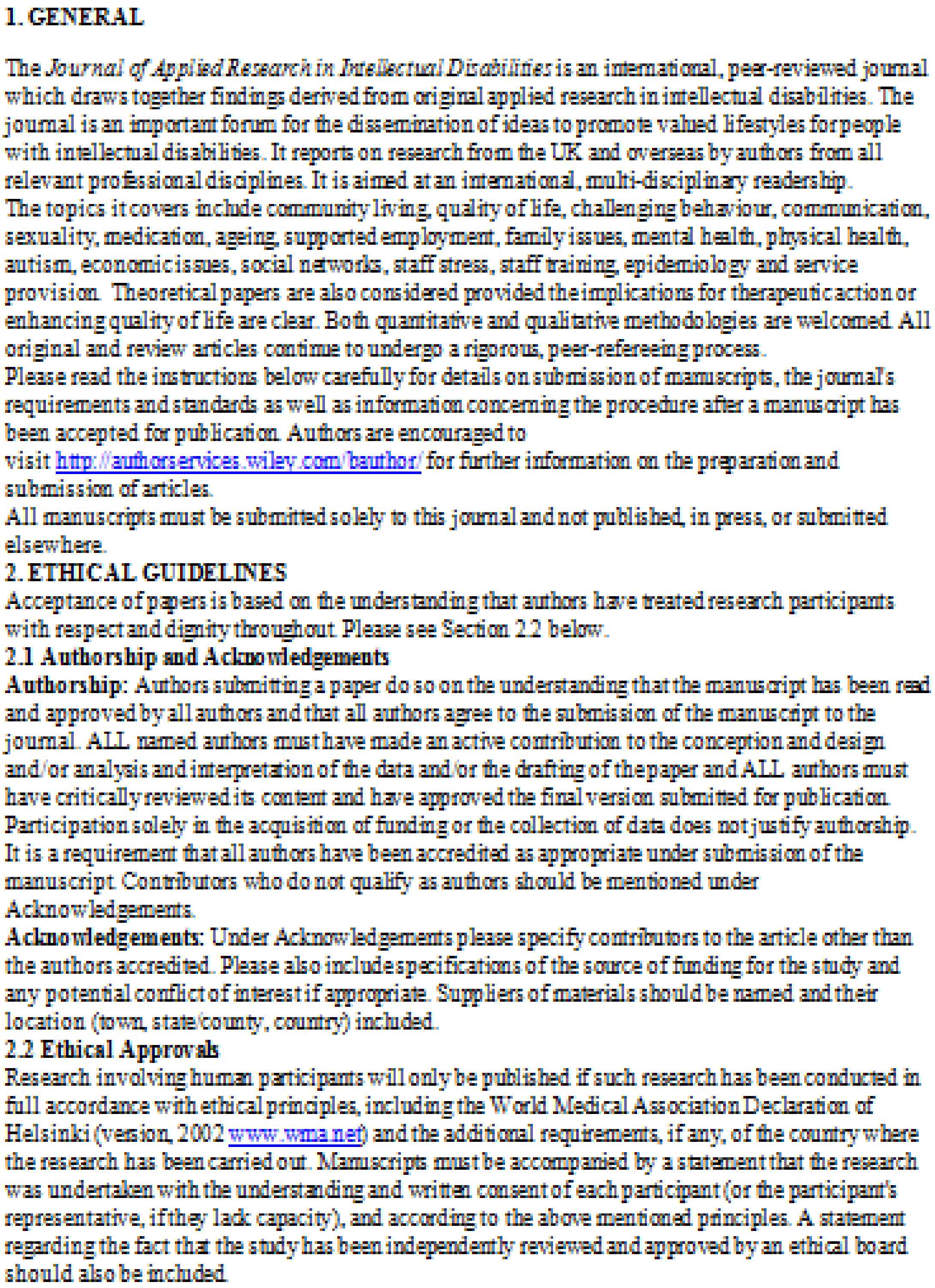
# Appendix A

## Author Guidelines: Journal of Applied Research in Intellectual Disabilities



### 1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

### 2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

#### 2.1 Authorship and Acknowledgements

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

**Acknowledgements:** Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

#### 2.2 Ethical Approvals

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If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

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-In the cover email, specify any special characters used to represent non-keyboard characters.
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-Use a tab, not spaces, to separate data points in tables.
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Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

### 6.3 References

The reference list should be in alphabetic order thus:
-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145
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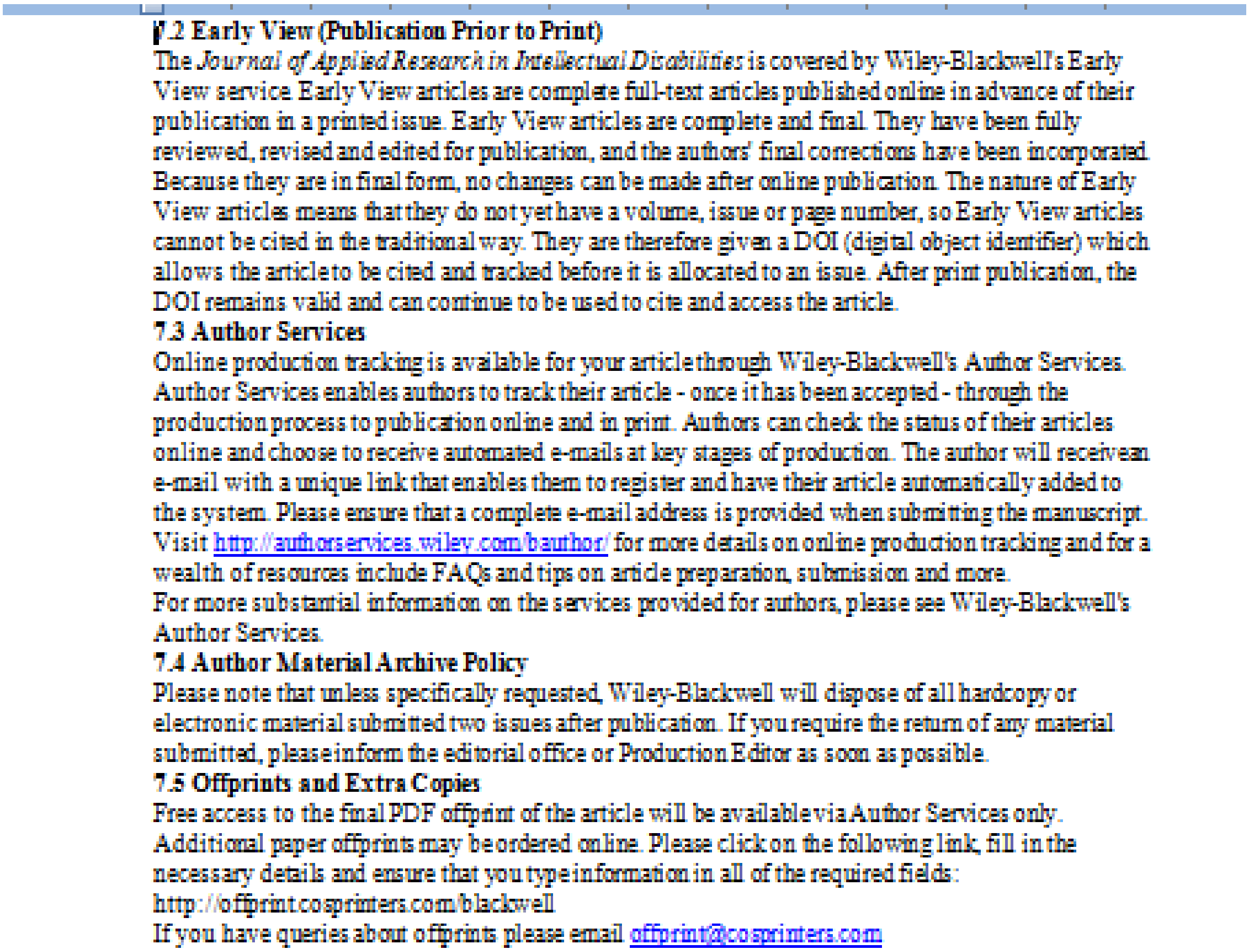

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# Appendix B

## Reflexive Statement

The following statement is reflexive in that it highlights the influence the researcher imposes on the process of research; her background, experience, prior assumptions and the epistemological stance taken, in line with Charmaz's (2000) recommendations.

I am a 28 year old female Trainee Clinical Psychologist with voluntary and paid experience of working with people with intellectual disabilities and their parents. Through this work and academic teaching on the D.Clin.Psychol programme, I have come to understand some of the challenges that people with intellectual disabilities and their families can experience.

Since the birth of my niece, Annie May, I have since come to understand more about how having a child with Down's syndrome (DS) can impact upon the family. Each member of the family has been impacted in one way or another and although as an Aunty I had to make minimal adjustments, I am aware this was not the case for her mum and dad. I heard stories in the local media of dads who had walked out on their families and felt they could not cope with a child with a disability. My sister (Annie May's mum), who attended support groups and followed blogs online, frequently told me about the challenges parents faced in adjusting to having a child with DS.

I did not have an in-depth understanding of how families adjusted as I had not really reviewed any of the literature in this area. At first, I was not even sure whether this area needed inquiry as I assumed a vast evidence base already existed. After briefly reviewing the literature it became apparent that dad's voices were neglected. I knew from working in children's services that some professionals (myself included) usually ask to speak to the mothers of children and aimed support at them. There appeared to be no models to explore how dad's adjusted and so I felt a GT approach to build a model would hopefully pull together their experiences when adjusting to having a child with DS. I was fortunate in that I had a very clear idea of what I wanted to study as part of my D.Clin.Psychol. thesis.

The aim of using GT is to remove myself as much as possible from my pre-conceived ideas which will enable me to think about how my participants are creating meaning of the world.

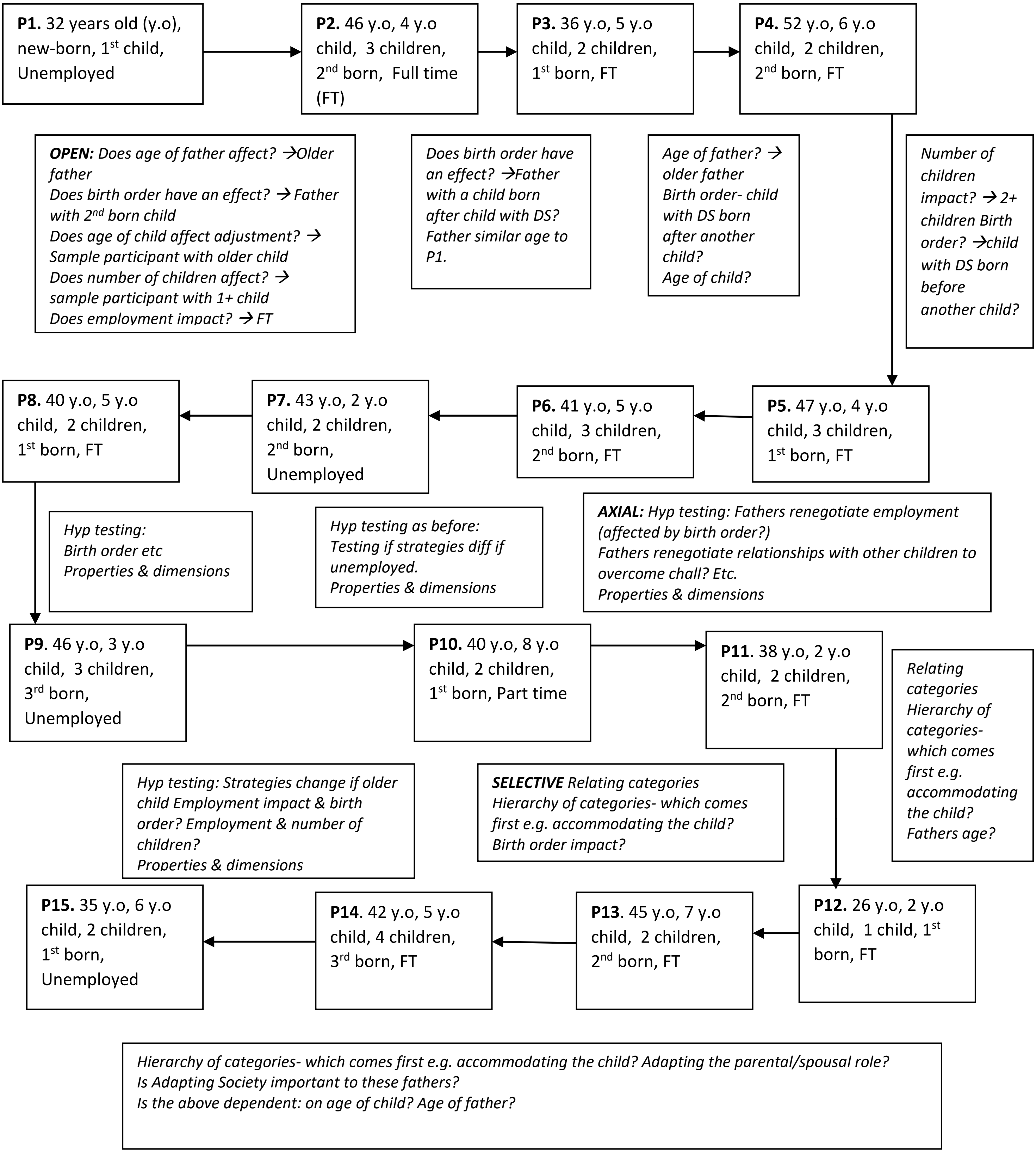
Charmaz's (2000) approach to Grounded Theory (GT) aligns with the researcher's epistemological stance by viewing knowledge as not induced, but constructed. Knowledge (in this case the data from interviews) about the phenomenon of interest is a subjective co-construction between the participant and the researcher. Therefore, through recognising the 'constructivist' element of GT, the researcher will assume a position of mutuality between themselves and the participant.

My initial assumptions are that fathers will find adjusting to having a child with DS as a challenging experience. As a family, I feel we have adjusted relatively well, although I know that for those stories I've read, this has not been the case. Dads talk about receiving very little support and almost no information from professionals. Although stories are coming out through the media lately, I'd assume that most people would still be unaware of what DS is and shocked and fearful about what it means for their child to have it. I expect dads to protect their partners and live up to the "alpha male" by hiding a lot of their feelings. It may be the case the many dads find it hard to talk to others or reach out for support, even if it is available.

I will need to revisit this page of preconceptions to ensure that participants' narratives that match these have not been led by my interview questions. It might be that I expect certain responses or over interpret responses to align with my assumptions about what I might find. Field notes, personal reflective memos, revisiting this statement and seeking supervision will help minimise subjectivity and bias. I will continue to keep a journal to reflect on the 'new' information that appears from interviews and consider how dads are making sense of their experiences.

# Appendix C

## Flowchart of the process of Theoretical Sampling



**P1.** 32 years old (y.o), new-born, 1st child, Unemployed

**P2.** 46 y.o, 4 y.o child, 3 children, 2nd born, Full time (FT)

**P3.** 36 y.o, 5 y.o child, 2 children, 1st born, FT

**P4.** 52 y.o, 6 y.o child, 2 children, 2nd born, FT

***OPEN:*** *Does age of father affect? →Older father*
*Does birth order have an effect? → Father with 2nd born child*
*Does age of child affect adjustment? → Sample participant with older child*
*Does number of children affect? → sample participant with 1+ child*
*Does employment impact? → FT*

*Does birth order have an effect? →Father with a child born after child with DS?*
*Father similar age to P1.*

*Age of father? → older father*
*Birth order- child with DS born after another child?*
*Age of child?*

*Number of children impact? → 2+ children Birth order? →child with DS born before another child?*

**P5.** 47 y.o, 4 y.o child, 3 children, 1st born, FT

**P6.** 41 y.o, 5 y.o child, 3 children, 2nd born, FT

**P7.** 43 y.o, 2 y.o child, 2 children, 2nd born, Unemployed

**P8.** 40 y.o, 5 y.o child, 2 children, 1st born, FT

*Hyp testing:*
*Birth order etc*
*Properties & dimensions*

*Hyp testing as before:*
*Testing if strategies diff if unemployed.*
*Properties & dimensions*

***AXIAL:*** *Hyp testing: Fathers renegotiate employment (affected by birth order?)*
*Fathers renegotiate relationships with other children to overcome chall? Etc.*
*Properties & dimensions*

**P9.** 46 y.o, 3 y.o child, 3 children, 3rd born, Unemployed

**P10.** 40 y.o, 8 y.o child, 2 children, 1st born, Part time

**P11.** 38 y.o, 2 y.o child, 2 children, 2nd born, FT

*Relating categories*
*Hierarchy of categories- which comes first e.g. accommodating the child?*
*Fathers age?*

*Hyp testing: Strategies change if older child Employment impact & birth order? Employment & number of children?*
*Properties & dimensions*

***SELECTIVE*** *Relating categories*
*Hierarchy of categories- which comes first e.g. accommodating the child?*
*Birth order impact?*

**P12.** 26 y.o, 2 y.o child, 1 child, 1st born, FT

**P13.** 45 y.o, 7 y.o child, 2 children, 2nd born, FT

**P14.** 42 y.o, 5 y.o child, 4 children, 3rd born, FT

**P15.** 35 y.o, 6 y.o child, 2 children, 1st born, Unemployed

*Hierarchy of categories- which comes first e.g. accommodating the child? Adapting the parental/spousal role?*
*Is Adapting Society important to these fathers?*
*Is the above dependent: on age of child? Age of father?*

# Appendix D

## Participant Information Sheet

Version No. 2: 23/03/2015

## PARTICIPANT INFORMATION SHEET

### A Grounded Theory approach to understand paternal adjustment to parenting a child with Down's syndrome: his role, satisfaction and contribution to family functioning

I would like to invite you to take part in my research study. My name is Anna Ridding and I am conducting this research as a Trainee Clinical Psychologist, as part of my Doctorate in Clinical Psychology at the University of Liverpool. Before you decide if you would like to take part, I would like to give you some information about what the study involves and why the research is being carried out.

Please give yourself time to read the information sheet. If something remains unclear or you have further questions, contact details are provided at the end. You may also wish to talk to others about this study.

**What is the purpose of the study?**

The purpose of the study is to explore father's experiences of parenting a child with Down's syndrome (DS). The study will aim to explore father's experiences and discover how fathers adjust to parenting a child with DS, their satisfaction, and support provision, impact on roles within the family, and views and expectations for the future. Fathers are an under-researched group, compared to mothers of children with DS, and therefore it is important that father's experiences are explored further.

**Why have I been invited?**

Fifteen fathers will be invited to take part in the study. You have been invited because you live within the North West, and are a father of a child with DS. You are eligible to take part in this study if your child with DS is under the age of 10.

**Do I have to take part?**

Taking part in this research is entirely voluntary. I will review the participant information sheet with you prior to the interview, giving you plenty of time to ask any questions. If you agree to take part, you will be required to sign a consent form. You are free to withdraw from the study at any point without giving a reason.

**What will happen to me if I take part?**

If you agree to take part in the study, you will be contacted to arrange a date for interview. This will be conducted at a mutually convenient time and the researcher will visit you at home if this is convenient.

The interview will last approximately 1 hour and will be 1:1. Before the interview begins, the participant information sheet will be reviewed and opportunity to ask questions will be provided. A digital recorder will be used to audio record the interview. All information will remain confidential and anonymous. The research will be completed by September 2016.

You have the right to withdraw after the interview has taken place. You can contact me by email or telephone (details at the end of this document) if you no longer wish to take part.
It will not be possible to withdraw once the data has been anonymised as the data will no longer be identifiable and will not be able to be linked back to your details. All personal information will be destroyed at the end of the study. Audio recordings will be stored securely for 5 years after the research has ended and destroyed thereafter.

**What are the possible disadvantages and risks of taking part?**

There are no physical risks involved in this study and it is not anticipated that you will experience any danger or discomfort by taking part. In the event that you do feel uncomfortable or experience distress from discussing your personal experience, a debriefing sheet will be given at the end of the interview containing the numbers of a variety of services (e.g. Samaritans, SANE, and local Psychological Services) who can offer further support and advice.

**What are the benefits to taking part?**

Although there are no direct benefits to taking part, you may find it interesting and useful to talk about your experiences. You will be provided with an opportunity to ask questions and the researcher can point you in the direction of support services in the local area, if you feel they would be useful. The research aims to explore father's experiences of parenting a child with DS. Therefore the research will help our understanding of how fathers adjust, which may potentially benefit NHS and other services; supporting and enhancing the provision of services to fathers and families in the future.

**Will my data be confidential?**

All information that is collected about you will remain confidential, unless you disclose that you or others may be at significant risk of harm. If this were to occur, I would aim to discuss our concerns with you first and have a duty of care to report this to my supervisor. Confidentiality will be discussed in detail at the beginning of the interview.
All data collected will be stored securely in a password protected computer file, which will be stored on a University of Liverpool computer server. My supervisor will have access to collected data, via secure login. All paper copies of participant information will be stored securely and destroyed immediately after the study ends. Audio recordings will remain anonymous and stored securely in a password protected computer file. Each participant will be given a unique participant number (known only to the researcher) which will be used for transcription and analysis. Direct quotations will be used in the dissertation write up and any publications arising from this; yet quotations will not be identifiable and your name will not be used in the write up of the research report.

The University will keep all electronic data for a period of 5 years following completion of the research (approximately September 2016), after which time it will be destroyed.

**What will happen to the results of the research study?**

The results will be reported in the form of a major research dissertation as partial fulfilment of the researcher's Clinical Psychology Doctorate. The research will be completed by the end of September 2016. It is hope the findings will be submitted for publication in an academic journal. All participants will receive a study summary, including its main findings, unless participants explicitly state they do not wish to receive this.

**Who is funding the research?**

The University of Liverpool is sponsoring this research.

### Who has reviewed the study?

The study has been reviewed by the Doctorate in Clinical Psychology Research Review Committee and the Research Ethics Subcommittee for Physical Interventions who have given favourable opinion.

### Further information and contact details.

If you have any questions about the study or require further details, please contact the researcher:
Email. aridding@liverpool.ac.uk Tel. 07555 328782/ 0151 795 5446

Alternatively you can contact the supervisors;

University Research Supervisor

**Dr. James Williams**

Email. j.r.williams@liv.ac.uk

Tel. 0151 794 5484

NHS External Research Supervisor

**Dr Lesley Taylor**

Email. Lesley.taylor@stockport.gov.uk

Tel. 0161 218 1220 (Ext. 1389)

### What if there is a problem?

If you have a concern about the study and do not wish to speak to the researcher or supervisors above, you can contact:

Joanne Dickson PhD
Research Director
Doctorate of Clinical Psychology Programme
Division of Clinical Psychology
University of Liverpool
Email: j.dickson@liv.ac.uk
Tel: 0151 7945530

Thank you for taking the time to read the participant information sheet

---

**If you agree to take part in the research, please contact Anna Ridding either by phone (0151 7945530) or email (aridding@liverpool.ac.uk) to arrange an interview time and date.**

---

This is your copy to keep. If you agree to take part in the study, you will also be given a signed consent form to keep.

# Appendix E

## Consent Form

Participant Identification Number: Version No. 2:
23/03/2015

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## CONSENT FORM

---

### A Grounded Theory approach to understand paternal adjustment to parenting a child with Down's syndrome: his role, satisfaction and contribution to family functioning

Name of Researcher: **Anna Ridding** Name of Supervisors: **Dr James Williams, Dr Lesley Taylor**

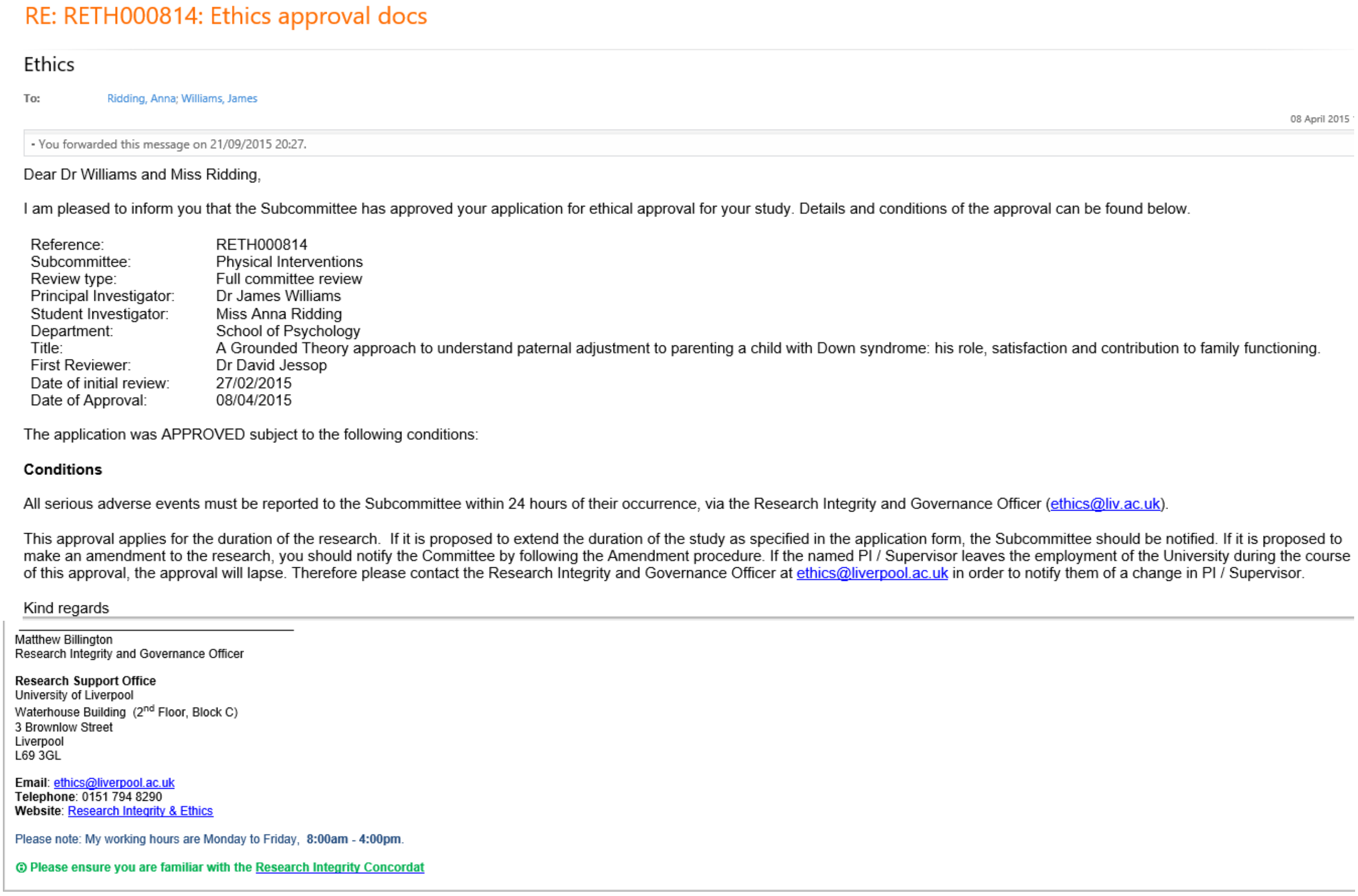
Please initial boxes

1. I confirm that I have read and understand the information sheet dated 23.03.2015 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that all information I provide will be dealt with in a confidential manner. ☐
4. I agree to the interview being audio recorded and deleted once transcribed. ☐
5. I agree to the use of anonymised quotes in publications. ☐
6. I agree to the researcher contacting me to discuss initial results (either face:face or by telephone). ☐
7. I understand that relevant data collected during the study, may be looked at by individuals from The University of Liverpool or from regulatory authorities. I give permission for these individuals to have access to this data.' ☐
8. I agree to take part in the above study. ☐

| | | |
|---|---|---|
| Name of Participant | Signature | Date |
| Name of Person taking consent | Signature | Date |

# Appendix F

# Ethics Approval



RE: RETH000814: Ethics approval docs

Ethics

**To:** Ridding, Anna; Williams, James

08 April 2015

• You forwarded this message on 21/09/2015 20:27.

Dear Dr Williams and Miss Ridding,

I am pleased to inform you that the Subcommittee has approved your application for ethical approval for your study. Details and conditions of the approval can be found below.

| | |
|---|---|
| Reference: | RETH000814 |
| Subcommittee: | Physical Interventions |
| Review type: | Full committee review |
| Principal Investigator: | Dr James Williams |
| Student Investigator: | Miss Anna Ridding |
| Department: | School of Psychology |
| Title: | A Grounded Theory approach to understand paternal adjustment to parenting a child with Down syndrome: his role, satisfaction and contribution to family functioning. |
| First Reviewer: | Dr David Jessop |
| Date of initial review: | 27/02/2015 |
| Date of Approval: | 08/04/2015 |

The application was APPROVED subject to the following conditions:

**Conditions**

All serious adverse events must be reported to the Subcommittee within 24 hours of their occurrence, via the Research Integrity and Governance Officer (ethics@liv.ac.uk).

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Subcommittee should be notified. If it is proposed to make an amendment to the research, you should notify the Committee by following the Amendment procedure. If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the Research Integrity and Governance Officer at ethics@liverpool.ac.uk in order to notify them of a change in PI / Supervisor.

Kind regards

Matthew Billington
Research Integrity and Governance Officer

**Research Support Office**
University of Liverpool
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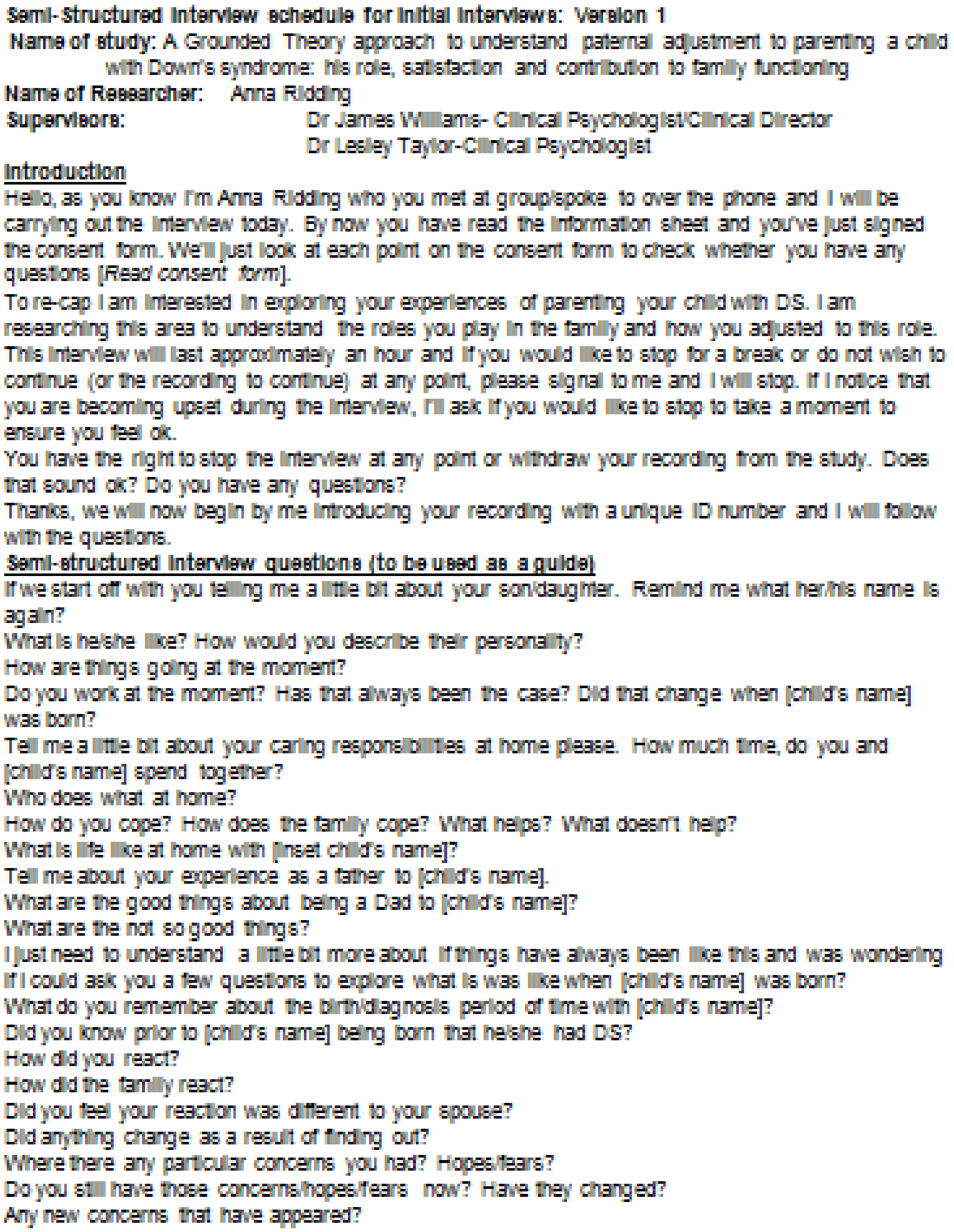
Please note: My working hours are Monday to Friday, **8:00am - 4:00pm**.

**Please ensure you are familiar with the Research Integrity Concordat**

# Appendix G

## Initial Interview Schedule



**Semi-Structured Interview schedule for Initial Interviews: Version 1**

**Name of study:** A Grounded Theory approach to understand paternal adjustment to parenting a child with Down's syndrome: his role, satisfaction and contribution to family functioning

**Name of Researcher:** Anna Ridding

**Supervisors:** Dr James Williams- Clinical Psychologist/Clinical Director
Dr Lesley Taylor-Clinical Psychologist

**Introduction**

Hello, as you know I'm Anna Ridding who you met at group/spoke to over the phone and I will be carrying out the interview today. By now you have read the information sheet and you've just signed the consent form. We'll just look at each point on the consent form to check whether you have any questions [*Read consent form*].

To re-cap I am interested in exploring your experiences of parenting your child with DS. I am researching this area to understand the roles you play in the family and how you adjusted to this role. This interview will last approximately an hour and if you would like to stop for a break or do not wish to continue (or the recording to continue) at any point, please signal to me and I will stop. If I notice that you are becoming upset during the interview, I'll ask if you would like to stop to take a moment to ensure you feel ok.

You have the right to stop the interview at any point or withdraw your recording from the study. Does that sound ok? Do you have any questions?

Thanks, we will now begin by me introducing your recording with a unique ID number and I will follow with the questions.

**Semi-structured Interview questions (to be used as a guide)**

If we start off with you telling me a little bit about your son/daughter. Remind me what her/his name is again?
What is he/she like? How would you describe their personality?
How are things going at the moment?
Do you work at the moment? Has that always been the case? Did that change when [child's name] was born?
Tell me a little bit about your caring responsibilities at home please. How much time, do you and [child's name] spend together?
Who does what at home?
How do you cope? How does the family cope? What helps? What doesn't help?
What is life like at home with [inset child's name]?
Tell me about your experience as a father to [child's name].
What are the good things about being a Dad to [child's name]?
What are the not so good things?
I just need to understand a little bit more about if things have always been like this and was wondering if I could ask you a few questions to explore what is was like when [child's name] was born?
What do you remember about the birth/diagnosis period of time with [child's name]?
Did you know prior to [child's name] being born that he/she had DS?
How did you react?
How did the family react?
Did you feel your reaction was different to your spouse?
Did anything change as a result of finding out?
Where there any particular concerns you had? Hopes/fears?
Do you still have those concerns/hopes/fears now? Have they changed?
Any new concerns that have appeared?

What support have you received in relation to parenting [child's name]?
Do you think you need more support? If so, what would make a difference?
Is there anything that we have not touched on today that you would think is useful for me to know in relation to exploring your experiences of parenting [child's name]?
Any questions?
Thank you for taking part. Would you like a copy of the findings of the study at the end?

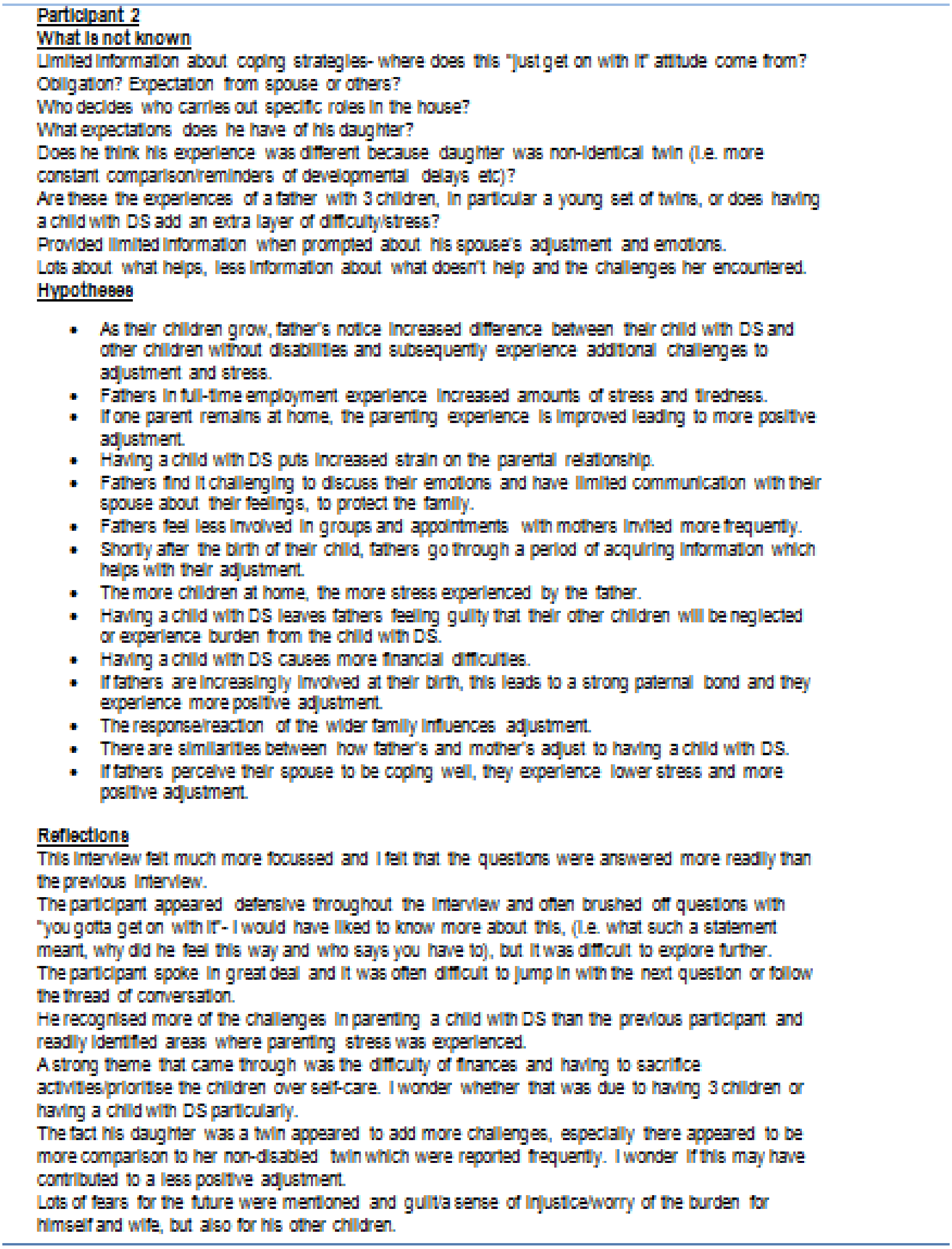
**Prompts to be used when necessary**

- Can you tell me a bit more about that/ Can you expand upon that?
- Could you describe that further?

# Appendix H

## Example of Brief Operational Memo

(completed after each interview)



**Participant 2**

**What is not known**

Limited information about coping strategies- where does this "just get on with it" attitude come from? Obligation? Expectation from spouse or others?

Who decides who carries out specific roles in the house?

What expectations does he have of his daughter?

Does he think his experience was different because daughter was non-identical twin (i.e. more constant comparison/reminders of developmental delays etc)?

Are these the experiences of a father with 3 children, in particular a young set of twins, or does having a child with DS add an extra layer of difficulty/stress?

Provided limited information when prompted about his spouse's adjustment and emotions.

Lots about what helps, less information about what doesn't help and the challenges her encountered.

**Hypotheses**

- As their children grow, father's notice increased difference between their child with DS and other children without disabilities and subsequently experience additional challenges to adjustment and stress.
- Fathers in full-time employment experience increased amounts of stress and tiredness.
- If one parent remains at home, the parenting experience is improved leading to more positive adjustment.
- Having a child with DS puts increased strain on the parental relationship.
- Fathers find it challenging to discuss their emotions and have limited communication with their spouse about their feelings, to protect the family.
- Fathers feel less involved in groups and appointments with mothers invited more frequently.
- Shortly after the birth of their child, fathers go through a period of acquiring information which helps with their adjustment.
- The more children at home, the more stress experienced by the father.
- Having a child with DS leaves fathers feeling guilty that their other children will be neglected or experience burden from the child with DS.
- Having a child with DS causes more financial difficulties.
- If fathers are increasingly involved at their birth, this leads to a strong paternal bond and they experience more positive adjustment.
- The response/reaction of the wider family influences adjustment.
- There are similarities between how father's and mother's adjust to having a child with DS.
- If fathers perceive their spouse to be coping well, they experience lower stress and more positive adjustment.

**Reflections**

This interview felt much more focussed and I felt that the questions were answered more readily than the previous interview.

The participant appeared defensive throughout the interview and often brushed off questions with "you gotta get on with it"- I would have liked to know more about this, (i.e. what such a statement meant, why did he feel this way and who says you have to), but it was difficult to explore further.

The participant spoke in great deal and it was often difficult to jump in with the next question or follow the thread of conversation.

He recognised more of the challenges in parenting a child with DS than the previous participant and readily identified areas where parenting stress was experienced.

A strong theme that came through was the difficulty of finances and having to sacrifice activities/prioritise the children over self-care. I wonder whether that was due to having 3 children or having a child with DS particularly.

The fact his daughter was a twin appeared to add more challenges, especially there appeared to be more comparison to her non-disabled twin which were reported frequently. I wonder if this may have contributed to a less positive adjustment.

Lots of fears for the future were mentioned and guilt/a sense of injustice/worry of the burden for himself and wife, but also for his other children.

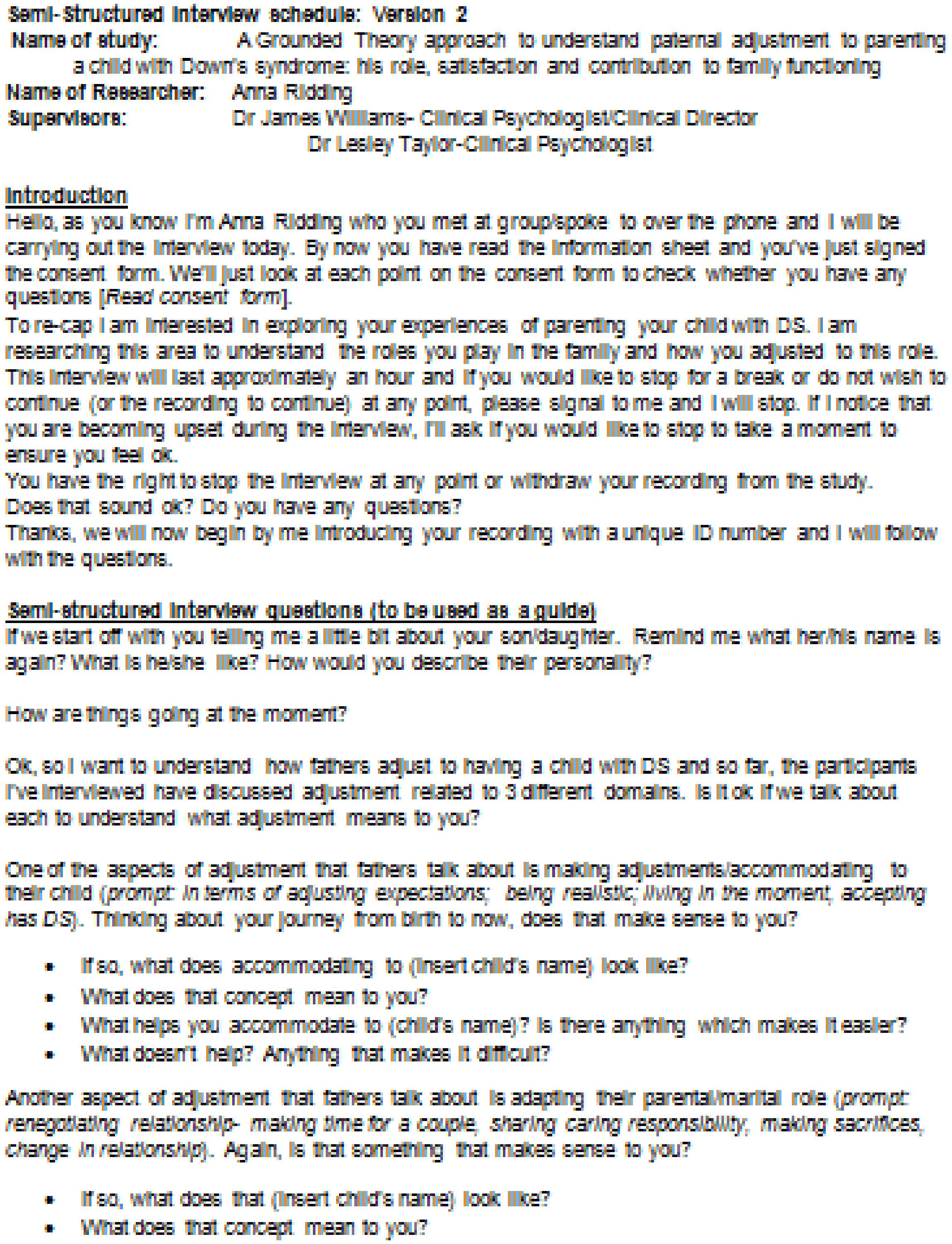
It appeared that this participant did not benefit greatly from attending the group and it was more professional support contributing to his adjustment.
It seemed important to his adjustment that he was realistic and continually prepared for the future.
Despite this participant giving a lot more information than participant 1, I perceived his adjustment to not be as positive and struggled with the idea of partial/positive adjustment.
It would have been useful as noted above, to have more information about the stress experienced, specific coping styles and how his coping differed from his spouse.

**Narrative**

Participant 2 was a father of a 4 year old daughter who had a non-identical (non-DS) twin. He also had a 9 year old daughter.
He seemed to generally be experiencing ok adjustment although this appeared to have changed from their birth. His adjustment appeared to have been more positive at birth, attributed to his long-stay in hospital alone with his daughter whilst his wife stayed at home with the other twin. However, he seemed to compare his daughters more frequently and notice more developmental delays as she had grown older.
He spoke of the shock at birth of discovering she had DS, financial constraints, fears for the future, stages of uncertainty, the challenges of full-time employment (e.g. tiredness, stress, availability and the strain on his and his spouse's relationship). He overcame challenges by adopting positive thinking styles, being proactive, seeking out information, having a sense of humour and support from family and friends. Positive adjustment was represented by a strong bond between him and his daughter.

# Appendix I

## Second Interview Schedule



**Semi-Structured Interview schedule: Version 2**

**Name of study:** A Grounded Theory approach to understand paternal adjustment to parenting a child with Down's syndrome: his role, satisfaction and contribution to family functioning

**Name of Researcher:** Anna Ridding

**Supervisors:** Dr James Williams- Clinical Psychologist/Clinical Director

Dr Lesley Taylor-Clinical Psychologist

**Introduction**

Hello, as you know I'm Anna Ridding who you met at group/spoke to over the phone and I will be carrying out the interview today. By now you have read the information sheet and you've just signed the consent form. We'll just look at each point on the consent form to check whether you have any questions [*Read consent form*].

To re-cap I am interested in exploring your experiences of parenting your child with DS. I am researching this area to understand the roles you play in the family and how you adjusted to this role. This interview will last approximately an hour and if you would like to stop for a break or do not wish to continue (or the recording to continue) at any point, please signal to me and I will stop. If I notice that you are becoming upset during the interview, I'll ask if you would like to stop to take a moment to ensure you feel ok.

You have the right to stop the interview at any point or withdraw your recording from the study.

Does that sound ok? Do you have any questions?

Thanks, we will now begin by me introducing your recording with a unique ID number and I will follow with the questions.

**Semi-structured interview questions (to be used as a guide)**

If we start off with you telling me a little bit about your son/daughter. Remind me what her/his name is again? What is he/she like? How would you describe their personality?

How are things going at the moment?

Ok, so I want to understand how fathers adjust to having a child with DS and so far, the participants I've interviewed have discussed adjustment related to 3 different domains. Is it ok if we talk about each to understand what adjustment means to you?

One of the aspects of adjustment that fathers talk about is making adjustments/accommodating to their child (*prompt: in terms of adjusting expectations; being realistic; living in the moment, accepting has DS*). Thinking about your journey from birth to now, does that make sense to you?

- If so, what does accommodating to (insert child's name) look like?
- What does that concept mean to you?
- What helps you accommodate to (child's name)? Is there anything which makes it easier?
- What doesn't help? Anything that makes it difficult?

Another aspect of adjustment that fathers talk about is adapting their parental/marital role (*prompt: renegotiating relationship- making time for a couple, sharing caring responsibility, making sacrifices, change in relationship*). Again, is that something that makes sense to you?

- If so, what does that (insert child's name) look like?
- What does that concept mean to you?

- What helps you adapt your role? Is there anything which makes it easier?
- What doesn't help? Anything that makes it difficult?

The final aspect of adjustment that fathers talk about is adapting society (*Prompt: acceptance, inclusion, acceptance from others*). Is this something that makes sense to you?

- If so, what does adapting society (insert child's name) look like?
- What does that concept mean to you?
- What helps (child's name)? Is there anything which makes it easier?
- What doesn't help? Anything that makes it difficult?

Are there any other aspects we haven't covered that you consider an important domain of adjustment? Which domain do you think employment fits into?

Out of the three we've gone through, thinking about a type of hierarchy, which is the most important? Which do you consider essential?

Are there any domains that if you hadn't have had, you wouldn't have felt as adjusted as you do now?

Are there any that are just beneficial but not essential, (i.e. if you have them, they are the icing on the cake?)

Any questions?

Thank you for taking part. Would you like a copy of the findings of the study at the end?

**Prompts to be used when necessary**

- Can you tell me a bit more about that/ Can you expand upon that?
- Could you describe that further?

# Appendix J

## Phase 1: Open Coding Example

*The transcript below was coded in NVivo. From this interview, 'Adapting Parental/Spousal Role' started to emerge and it was evident that this was becoming an important part of fathers' adjustment. Below is an excerpt from the interview of Participant 4 with examples of the initial codes (e.g. some of the subcategories and sub-sub categories) of 'Adapting Parental/Spousal Role'.*

***INTERVIEWER:*** Ok if we start off with you telling me a little bit more about J please?

*Positivity ('recognising strengths')*

*Positivity ('recognising strengths')*

***PARTICIPANT:*** Well he's cheeky little 6.5 year old boy really, amazing sense of humour, very cheeky ***(aww).*** He just happens to have down syndrome and that's a bi-product of what J is about and I wouldn't change him for the world ***(yeah).*** He tries to be independent, he is quite stubborn but then any child can be. He never ceases to amaze me with what he can achieve ***(yeah)*** he's very loving. He's good company for his older brother who is a couple of years older. He's had his health problems. He's had a series of strokes and its set him back. He's missed a year of school so has to start again in September. He never really caught up but he has now. His speech and language was quite hard hit by the penultimate stroke.So that's something else as well as the DS that I have to adjust to and we do everything we can to support him and get him up to speed ***(yeah)***

***INTERVIEWER:*** I can imagine that was a difficult time

***PARTICIPANT:*** Yeah a difficult time for us all ***(course)*** It was more than 2 weeks really; it was the lead up then the premeds then the cancelled operation. When you look back on it it was horrendous. All the other things ***(yeah)*** It was a stressful 3 months but we rallied around as family

***INTERVIEWER:*** I'll probably ask you a few more questions about this later. So how would you say things are at the moment?

*Positivity ('recognising strengths')*

***PARTICIPANT:*** Well he's back at school, doing really well. In fact we've been working on his homework earlier. He knows far more than people would expect ***(yeah)***. He's got really good teachers and he's with excellent children. He has consistency and continuity from two TAs. He adores his teacher. He forms connections and associations quickly. Like most children he is very visual.

***INTERVIEWER:*** And is that a mainstream school?

*Chall of gender role ('Mother main carer')*

*Employment ('chall. Of FT wor'k;' ltd support from employer')*

***PARTICIPANT:*** Yes it is, he's loving it there. K does a lot with him in and out of school. It's not easy, my wife does most things. I worked farther away originally and now I work closer ***(yeah, yeah)***. It wasn't the easiest and my last employer wasn't very supportive which didn't really help my overall experience of becoming a father to him ***(sure).*** I'm fully aware that I'd like to do more. Unfortunately I can't take a lot of leave or holiday in my new job but I'm hoping going forward things will get easier. That should give me more chance to pull my weight really.

***INTERVIEWER:*** Ok and with that was that a choice to get a different job?

*Employment ('chall. Of FT work')*

***PARTICIPANT:*** Yeah I'm hoping to get a better work life balance. I'm home in the evenings a lot better ***(yeah)***

***INTERVIEWER:*** Has that changed specifically to do with J having DS?

*Chall of gender role (Mother main carer)*

*Employment (chall. Of FT work)*

***PARTICIPANT:*** I'm not sure really. I suppose the difficulty is because his older brother was young when J was born. School takes up a lot of time and K normally has the option to and I unfortunately don't. So I'd like to think DS doesn't impact it and if I didn't have J things would still be as difficult ***(yeah)***. It does weigh on my mind thought that I should and possibly could do more which makes me feel bad but I struggle with how busy my job is ***(sure).***

***INTERVIEWER:*** Do you think your last employer not being supportive have influenced your adjustment to parenting?

*Positivity ('recognising strengths')*

***PARTICIPANT:*** We have a childminder who helps in the morning and afternoon most days which is helpful. We rely on her. It's a juggling act really. As the boys get older we are trying to give them equal opportunities. J just joined beavers last night where T has scouts. I never really thought J would do that which is amazing. K is very positive ***(yeah)*** and thought he would do that when he got old enough. I probably thought that was a bridge too far mainly because of his physical problems. I couldn't really imagine it them both in the setting. T was very boisterous and handled it but J I didn't think would, we'll see.

***INTERVIEWER:*** And are there other concerns that you've had regarding J?

*Neg. emo & stress ('Guilt')*

*Negative emo & stress ('Depression')*

*Chall of gender role*

***PARTICIPANT:*** Yeah definitely, I mean when J was born I still wince looking back at the email I put out to everybody. I announced to everyone he was born bla blah ***(sure)*** unfortunately he has down syndrome and I know now I would never write that. I wanted to cushion the shock for everybody else. That this little boy has been brought into the world with problems that will impact his life for the rest of time. I tell you what is was…I didn't really want people later on asking me? ***(yeah)*** What's he doing it? Why is he doing that now? Why is it taking him so long? The worst thing I did when I came home…and I always tell that people now when they ask about the birth that it's horrible. I looked when I got home from the hospital when I'd left J and his mum. I googled and got the wiki page for down syndrome, it was all the negatives you know, he'll never drive, he'll never have children…it was all the negative thing erm. It was he'll never live independently, all those kinda things. And I must admit then this dark cloud descended and I got very very depressed. It wasn't the fact we had never talked about it. K picked up something, she was clued in when she had the scan and knew what they were talking about when they measured the folds or whatever they do ***(yeah)***. But that passed me by, cos I'm a man, not a mother. Then there were other sort of erm concerns. The consultants looked concerned and told us the percent which was like half a percent and I thought I'll take that chance you know. Then even up to the point of birth we kinda pushed that out of her heads and thought we'll take whatever's given to us (yeah). It was a shock, a very big shock.

***INTERVIEWER:*** Could you tell me a little bit more about that please?

***PARTICIPANT:*** Oh I could tell as soon as he came out and I took him in my arms and you could just see. We were left to our own devices when we met him and we both knew straight away that there was something very untoward you know about him.

*Neg. emo & stress ('Robbed of exp')*

***INTERVIEWER:*** What was that feeling like?

***PARTICIPANT:*** That feeling? ***(yeah)*** What was that feeling like, erm (pause). It wasn't the joyous occasion I shared with my first son. We were leaping into the unknown and you don't know what you're preparing yourself or what that experience would like. When he was born, it was a sense of disappointment and a feeling like erm this is gonna be different. That disappointment sounds like the wrong word. It was because perhaps we hadn't considered it properly. I've spoken to parents who knew behind or that odds were stacked against them they thought about it ***(yeah)***

***INTERVIEWER:*** Do you think that influenced your reaction erm not knowing?

*Neg. emo & stress ('Robbed of exp')*

*Neg. emo & stress (Feeling responsible)*

***PARTICIPANT:*** Oh certainly, I would've reacted differently, if I'd have had time to process that he had DS. I mean I feel that I was robbed of what should have been a joyous occasion. I lost the birth of my second son I suppose. I think it's because it's such a big unknown and we had no concept of what having two kids was like. We didn't even know he was a boy and now we have a child with DS ***(yeah).*** The strange thing erm about it really is that it's always been at the back of my mind. Even before we had a child. It's completely rational .I mean I have a cousin with DS and a nephew with autism erm and I thought it would just be my luck really. My family have sorta always been around children with disabilities ***(yeah)*** erm and I know there's no link but I think probably that might have been. My thoughts before my first born came to fruition with J I reckon. But I think I've learnt a lot more about myself now we've had J.

***INTERVIEWER:*** Have you? In what way?

*Positivity ('recognising fortune')*

*Negative emo & stress ('Depression' 'Guilt')*

*Negative emo & stress ('Fear of future')*

*Positivity ('recognising strengths')*

***PARTICIPANT:*** Well K might disagree but I reckon I'm a lot less selfish than I used to be ***(yeah)***. I see things from his way and I admire his strength even if he doesn't know he's doing it. I mean I'll come home and I'll have had a shitty day but the first thing I do is look at his face and he'll smile cos y'know. He'll give me a kiss or whatever else and it's nice. I'm not sure that makes a lot of sense ***(it does).*** I mean it was a really dark period of my life. Erm and I've said this on many occasions to other people, I'm not proud of that person I was or what I thought or said. I even thought yes I can get him adopted , let's look into this. I was not a sensible human being at that point. I wasn't sleeping very well. Erm I had his older brother who was tiny and I was looking after him whilst K was in hospital. He was in childminding or nursery. I read all the negatives and thought this is reality, my future, I'm gonna have to spoon feed this boy for the rest of his life. I thought my life has ended in terms of all the things I wanted to do and could have done with children ***(yeah)*** Erm but that was just the negatives and some of things we have done or got passed have been astounding. We just happen to have a child who is a bit slower on the uptake than other children.

***INTERVIEWER:*** How long do you think that dark period you talk about lasted?

*Negative emo & stress ('Depression')*

*Negative emo & stress ('Depression')*

*Negative emo & stress ('Depression')*

***PARTICIPANT:*** Oh erm, am I out of it? Good question. I must admit that K was in hospital for 3 nights and his whole arrival was just one erm you couldn't have made it up. I mean erm the previous week I'd been admitted to hospital with meningitis ***(oh gosh)*** so I'd been there for 4 days with drip and our birth hospital was elsewhere. It's a very good hospital. So it was like I'm here on a drip and you're about to give birth to my child…So it was a case of I'm gonna have to discharge myself here. I got back home, got in the car, took her into hospital and he was born. It was quite tight really getting there. So that was that really, I wasn't well myself ***(yeah)*** At the time I spoke to K best friend who is a doctor well she's a GP now and she pretty much picked up on my negative vibes and called me and said I'm not putting this phone down until I know you're ok. I think she thought I'd do something silly like I dunno self harm or something. I'm not sure what I was doing at that point. I don't think it was ever that dark but I had a 2 year old, you know other people were relying on me. I mean I never say never ***(sure)***.

***INTERVIEWER:*** Do you think if you didn't have T relying on you things might have been different?

*Negative emo & stress ('Depression')*

***PARTICIPANT:*** Who knows who knows? As I say it's a period of my life I revisit occasionally ***(yeah)***. I'm not proud of any of the things I did. I guess I just wasn't prepared for this wave of negativity. I mean I do feel sorry for younger parents in their early 20s. I mean it must be hard when they are not prepared. Since J was born we've talked to a mixture and know they are not just born to older parents. Probably I revisit occasional when things aren't going so well. At the moment we are toilet training him which is awful cos we're having to benchmark him against not only children his age but erm typical children and other children with DS who might be a year or so younger in age but ahead in development. Then that's kind of frustrating cos we are aiming high with J, no negativity around what he can't do or anything. He started football training on Sunday ***(wow)*** and we try to push his buttons and find things to help his development.

***INTERVIEWER:*** And would you say you that kinda comes from you and K?

*Challenge of Gender role (Mother main carer;*
*Female flexibility)*
*Employment (chall. Of FT work)*
*Renegotiating rel. (Making sacrifices)*

***PARTICIPANT:*** Oh god yeah. But you know I'll hold my hand up that she knows a lot more about what we should do with J. You look around here and there are so many resources for him, that's all K. You know flashcards, folders, she's taken lots of time to go on courses ***(yeah)***. I wish I'd had that opportunity but she has a more empathic employer and she works hard in the week for hours spread over less days ***(sure)***. She's on conference calls and she's tenacious and she won't accept…how she's dealt with it, she's fought for stuff. We've spent our own money on training and going places. I started signing when I was off work for a while and that was useful. We still sign now as a family to each other in non verbal situations and other families they look at us ***(yeah)***.

***INTERVIEWER:*** You mentioned then about not having the opportunity, erm I mean what got in the way of that?

*Employment (chall. Of FT work)*

*Challenge of Gender role (Female flexibility; Mother main carer)*

*Chall. Of gender role (Mother oriented)*

***PARTICIPANT:*** Biggest problem for working parents and they'll all tell you is getting to attend stuff ***(yeah)***. It means one parent ultimately missing a days' pay and I guess in my experience it's mostly the women who go. Then I guess rightly or wrongly that's losing a day's pay for women is not as much as the man maybe something to do with unequal pay or something ***(right)***. Women have flexibility a lot don't return to work at all or stay at home. We do know a lot of mums who stay at home. Those families also cut the cloth accordingly, they don't have extravagant lifestyles. We don't, it's about you know we're not, we try to find out as much as we can rather than be told. We're always quite surprised when people say oh we didn't know about that benefit or that thing, we think well really you should do cos nobody is erm giving you anything or pushing you into stuff ***(yeah)***, you've got to push yourselves. There's nobody out there saying those parents with DS need to be shown this. I also think being a Dad you do tend to take a backseat and be aware it's joint, the phraseology is that a word, is mum oriented, there's a mum.

***INTERVIEWER:*** Would you like that to change?

*Employment (chall. Of FT work; Financial implications; ltd support from employer)*

***PARTICIPANT:*** Oh yeah but not sure it will. I mean I've never taken any of that…what you call it…the unpaid leave you're entitled to as a Dad ***(yeah)***. I think I'm allowed 18 days until J is 18 but I've never taken one because I'd lose money. Some employers are good with that others not. I mean I have 18 days and I know I will be calling on those over the next few years ***(sure)***. I know it's about having an employer who is perhaps you know willing to have a few hours here and a few there. My last two jobs that hasn't been an option ***(yeah).*** My current employer is far more family oriented so I've already been given the opportunity to take J to hospital appointments then go back to work ***(that's great).*** I do enjoy that opportunity of

*Employment*

taking J to appointments and all that blood samples and I think they happen to be K usually. She can drop things and go, but I can't working 35 miles away, yeah.

***INTERVIEWER:*** And what's that like?

*Chall. To rel. (Friction)*

*Chall. To rel. (Friction)*

***PARTICIPANT:*** It causes friction…yeah it causes friction. I don't think resentment is too strong a word ***(yeah)***. I mean it's that erm I'm trying to put myself in her shoes I mean we don't erm I don't do anything. I know that's not true. I could do more, I wish I could. I feel she thinks I could do more but I do. That leads to friction. I don't know you just get on with it ***(sure)***.

***INTERVIEWER:*** Do you think that's you or other dads experience that?

*Employment (chall. Of FT work)*

***PARTICIPANT:*** I'm trying to think of Dad's I know best, he does very little during the week, I don't suppose he sees his child from when he gets up in the morning until he gets home at night. I don't suppose he's ever attended appointments or anything ***(yeah)***. Some of the younger Dad's perhaps feel different but self employed. I think us older Dad's in professional services, without sounding snobby, do find it hard to create the time and space ***(yeah)***.

***INTERVIEWER:*** So the friction you speak of, do you think that's attributable to J having DS? Or do you think you'd have experienced that if you had two children without disabilities?

*Neg. emo & stress (Feeling responsible)*

*Chall. To rel. (Family upheaval)*

*Flexible employment*

Erm, good question. Hmmm. (pause). I think, I think I probably wouldn't feel quite so guilty not being available if it wasn't a child with a disability like J, you know if he had a dodgy ear or something not as serious. But having been for eye appointments in Cardiff as that's the best person for doing work with children with DS ***(yeah)***. It's a torturous process at other hospitals, they don't know how to deal with children with DS, you end up driving miles to see a lady who knows quite a lot about how to deal with J. Would I do that if he didn't have DS? ***(yeah)*** Well I'd like to think I'd do the same for any of my flesh and blood but there probably wouldn't be the same upheaval and uprooting of the whole family for a weekend to attend things and the guilt that comes with that wouldn't be there I don't reckon. It's not that I don't do any it's just I don't do as much as K or as much as I'd like to do ***(sure)***. Who knows you know I have a different job now with 5 more days leave, maybe that'll make a huge difference.

***INTERVIEWER:*** Yeah that might change. So in terms of who does what at home? Does K do the majority of home based tasks?

*Renegotiation of rel. ('Sharing the caring')*

*Chall to rel.*

*Chall. Of gender role*

***PARTICIPANT:*** No, not really, we have a cleaner. I mean K is at home a lot more, she does the cooking erm normally I don't get in much before 6 ***(right)*** so the childminder has fed the boys so we feed ourselves. K cooks as she's good, I'm not good at cooking and survived for many years but I'm not a natural and get frustrated when I cook using every pan in the kitchen. Quite often she produces large batches of food. We try to divide things as equally as possible. I mean one thing about K is that she is very organised. She likes to be in control with a lot of things and if she feels her control is slipping she gets very frustrated. You know there are times I think this I just can't be arsed as this won't be done to your standard that's just general ***(sure)***. But you know, I know I do a lot more than other Dad's with what I do. I do a lot more than my dad ever did as he was always away. Some Dad's are stay at home because wife is busy with a high flying job.

***INTERVIEWER:*** And do you think that was a conscious effort to try and split the things you do equally at home?

*Challenge of Gender role (Female flexibility)*

*Employment (change in employment; employment chall.)*

***PARTICIPANT:*** Yeah I mean that has nothing to do with J having DS. It's just the way things have developed, for the last 9 years I've pretty much been at least 40 mins away by car at work and don't have the ability to work from home or drop work ***(sure)***. K is flexible, she's not managed locally, and she can drop everything. I'm hoping with my new job going into work later gives me more time to be involved. It's a bit of conscious effort cos we couldn't have carried on the way we were…. I was getting home when it was dark and that cut down the time I had with my lads. They were getting out of the bath and I missed that and sneaking it out of the house before they got up.

***INTERVIEWER:*** How was that for you?

***PARTICIPANT:*** Erm I probably didn't realise that at the time and I'd try to drive bit faster home so I could spend a bit more time with them, yeah it was difficult erm yeah.

***INTERVIEWER:*** How would you say you cope and manage at the moment?

*Neg. emo & stress ('Sleep diff')*

*Positivity ('recognising fortune')*

***PARTICIPANT:*** Erm, how do I cope…erm…it's kind of…I think the frustrating thing is well it's the same with any parents really in that you try to create that bubble, a bubble for yourself and to be honest that time doesn't tend to get created very early in the day. So if I want to unwind I'm up at 1am in the morning, I survive on not many hours sleep which leads to friction and frustration ***(sure)***. But yeah there are fantastic times, we just went to London and J loved all the visual things. There are times when that's more difficult, K's Mum was ill last year and died ***(oh sorry to hear that)*** so there was backdrop of dealing with her and seeing her wither away. I tried to do more and K hasn't really probably dealt with that which there is probably guilt for not spending time with her mum because she has a child with special needs. I think she has dark moments at the moment. As a family we live on our nerves a lot of the time and it's not a relaxed place to be at the moment. You're trying to deal with your older child at the same time***(sure)***.

***INTERVIEWER:*** What do you think helps you cope?

*Neg emo & stress (distress)*

*Negative emo & stress ('Depression')*

*Chall to rel. (family upheaval)*

*Chall to rel. (Limited time as a couple; Lack of intimacy) Neg. emo & stress (Feeling inadequate; Feeling respons.)*

***PARTICIPANT:*** Well really a sense of having to, a sense of having to be for J. You know I mean erm I can see and I'm not saying this in anywhere in my mind but I can quite easily why people walk away or stay. I think they stay out of guilt because they never can imagine leaving one parent looking after those children. But I can also see the flipside where you say you know what I can't deal with this and I can totally see that ***(yeah)***. There are days that happen but that view gets modified cos you know you love your family and that's just the emotion you have at that particular time. The problem talking about this is you tend to pull out the negatives cos there at the back of your mind and never normally get talked about. But it's probably no more difficult or less difficult than having an autistic kid. J is a cute little boy and you can see he has DS which means people's expectations are tempered about his abilities. An autistic child looks typical from the outside but doesn't act within social norms and I've probably thought that's a naughty child and a bad parent. But from J we get so much love ***(sure)*** and attention, he's always coming up and hugging me and kissing me. He's funny like that, has his little moments of affection. He loves his granddad whereas his older brother has gone and stayed with grandparents alone, we've handed him over for the week. That's not gonna happen with J. Just getting away for a night, if it was not J you could rock up but you can't leave J alone. In 6.5 years we've spent two nights away from J and that wasn't very far away, we were probably 5 miles away and it was nice for us time. Your personal relationships struggle, erm you don't have much time for each other ***(sure)***. You're constantly worrying or beating yourself up about something like your child can't read, you wouldn't get that with a typical child. But with a child like J you can't think about yourselves as much. You feel you owe it to your child to give him more than just the school hours.

***INTERVIEWER:*** How would you say yours and K's relationship has changed since J was born?

*Chall. To rel. (Friction)*

*Neg. emo & stress (Feeling inadequate)*

*Chall to rel.*

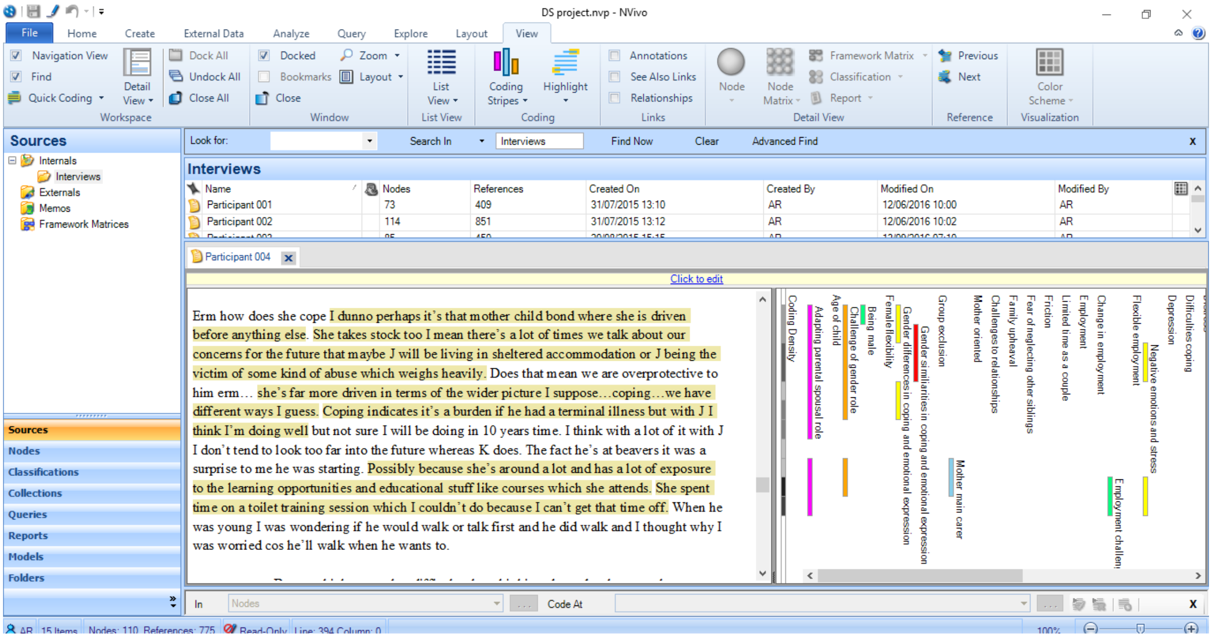
*Positivity ('you just have to cope')*

***PARTICIPANT:*** Erm… it's quite weird cos we're closer mentally definitely ***(yeah)***. But there's always a bit more friction, definitely, we weren't really sure what we were doing and we were more tired and everything was new. I was 45 before I had his older brother and I don't think I'd have coped at 25, well I definitely wouldn't have coped with a child with learning disabilities then…I dunno maybe I would, I'm thinking what the 25 year old me was like but I was a single man about town then. I wouldn't have had the necessary life skills back then. I find it hard now sometimes, major parent fail, nobody prepares you for being a parent and you try and build on your own experiences of your parents but mine weren't a particularly rich vein to draw on ***(sure)***. I never had a good relationship with them and spend big periods of my life not talking to them. I'm close to my brother as an adult. But yeah it puts strain on your relationship and I see others and think we can't all be happy families all the time. But I guess to other people from the outside we just look like a normal family. People will say to us we don't know how you cope I mean my boss he's a…he's new like me so we've got close in terms of getting to grips with things and he sees the strain from his own brother being an older parent and says to me how do you cope…but you just have to cos not coping is not an option.

***INTERVIEWER:*** Where do you think that comes from that idea that not coping isn't an option?

***PARTICIPANT:*** Pride I s'pose, trying to keep it altogether ***(sure)***. As much as my parents split up when I was younger my Dad was a role model for some time, he would've adored my children, especially J but he's gone. He was very caring to members of our family with special needs. I try to look at it through rose tinted glasses and be like he was but its 40 years since he had any caring responsibilities when I lived with my mum and step father which wasn't a particularly happy period. But I do what I can, there's no manual, people have written plenty of books please ***(sure)***. It was the same with my first born, nobody tells you what to do and all of a sudden you're responsible for another's wellbeing and have to feed them and I would do anything for J. You don't have favourites but he means a great deal.

The screenshot below illustrates the emerging category and sub-categories within NVivo (indicated by coding stripes) for Participant 4:



| Name | Nodes | References | Created On | Created By | Modified On | Modified By |
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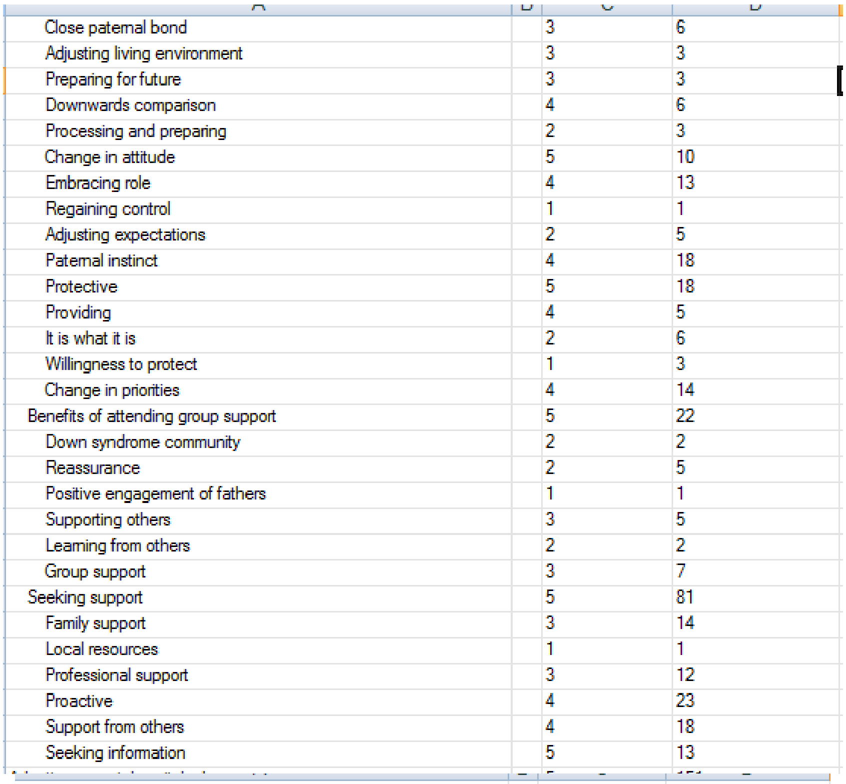
| Participant 001 | 73 | 409 | 31/07/2015 13:10 | AR | 12/06/2016 10:00 | AR |
| Participant 002 | 114 | 851 | 31/07/2015 13:12 | AR | 12/06/2016 10:02 | AR |

Erm how does she cope I dunno perhaps it's that mother child bond where she is driven before anything else. She takes stock too I mean there's a lot of times we talk about our concerns for the future that maybe J will be living in sheltered accommodation or J being the victim of some kind of abuse which weighs heavily. Does that mean we are overprotective to him erm… she's far more driven in terms of the wider picture I suppose…coping…we have different ways I guess. Coping indicates it's a burden if he had a terminal illness but with J I think I'm doing well but not sure I will be doing in 10 years time. I think with a lot of it with J I don't tend to look too far into the future whereas K does. The fact he's at beavers it was a surprise to me he was starting. Possibly because she's around a lot and has a lot of exposure to the learning opportunities and educational stuff like courses which she attends. She spent time on a toilet training session which I couldn't do because I can't get that time off. When he was young I was wondering if he would walk or talk first and he did walk and I thought why I was worried cos he'll walk when he wants to.

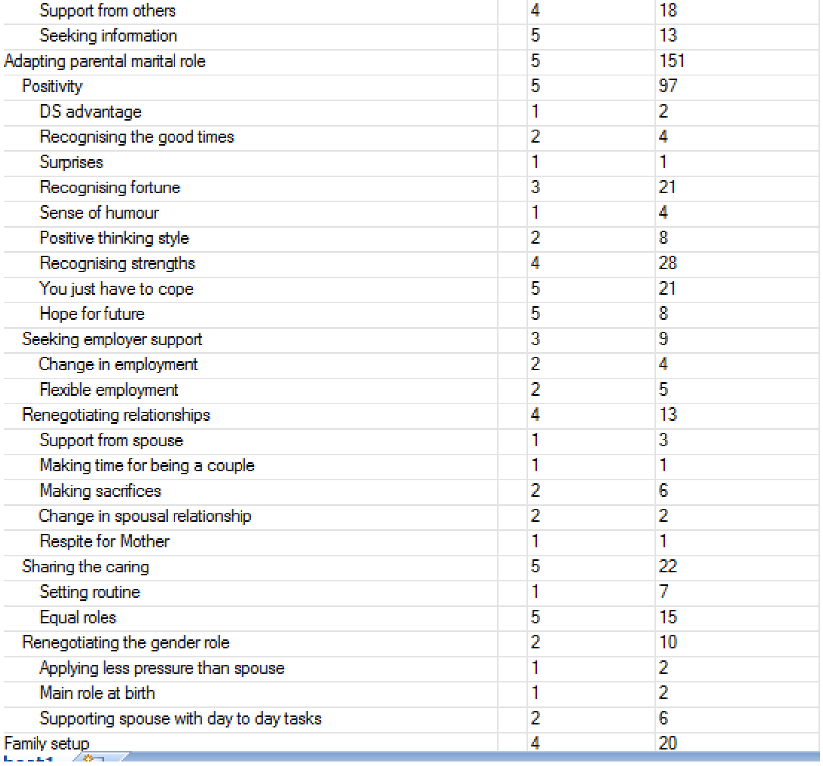
# Appendix K

## ‘Open coding’ Nodes Screenshot

Selection of nodes exported from NVivo to MS Excel during ‘Open coding’



| | | |
|---|---|---|
| Close paternal bond | 3 | 6 |
| Adjusting living environment | 3 | 3 |
| Preparing for future | 3 | 3 |
| Downwards comparison | 4 | 6 |
| Processing and preparing | 2 | 3 |
| Change in attitude | 5 | 10 |
| Embracing role | 4 | 13 |
| Regaining control | 1 | 1 |
| Adjusting expectations | 2 | 5 |
| Paternal instinct | 4 | 18 |
| Protective | 5 | 18 |
| Providing | 4 | 5 |
| It is what it is | 2 | 6 |
| Willingness to protect | 1 | 3 |
| Change in priorities | 4 | 14 |
| Benefits of attending group support | 5 | 22 |
| Down syndrome community | 2 | 2 |
| Reassurance | 2 | 5 |
| Positive engagement of fathers | 1 | 1 |
| Supporting others | 3 | 5 |
| Learning from others | 2 | 2 |
| Group support | 3 | 7 |
| Seeking support | 5 | 81 |
| Family support | 3 | 14 |
| Local resources | 1 | 1 |
| Professional support | 3 | 12 |
| Proactive | 4 | 23 |
| Support from others | 4 | 18 |
| Seeking information | 5 | 13 |



| | | |
|---|---|---|
| Support from others | 4 | 18 |
| Seeking information | 5 | 13 |
| Adapting parental marital role | 5 | 151 |
| Positivity | 5 | 97 |
| DS advantage | 1 | 2 |
| Recognising the good times | 2 | 4 |
| Surprises | 1 | 1 |
| Recognising fortune | 3 | 21 |
| Sense of humour | 1 | 4 |
| Positive thinking style | 2 | 8 |
| Recognising strengths | 4 | 28 |
| You just have to cope | 5 | 21 |
| Hope for future | 5 | 8 |
| Seeking employer support | 3 | 9 |
| Change in employment | 2 | 4 |
| Flexible employment | 2 | 5 |
| Renegotiating relationships | 4 | 13 |
| Support from spouse | 1 | 3 |
| Making time for being a couple | 1 | 1 |
| Making sacrifices | 2 | 6 |
| Change in spousal relationship | 2 | 2 |
| Respite for Mother | 1 | 1 |
| Sharing the caring | 5 | 22 |
| Setting routine | 1 | 7 |
| Equal roles | 5 | 15 |
| Renegotiating the gender role | 2 | 10 |
| Applying less pressure than spouse | 1 | 2 |
| Main role at birth | 1 | 2 |
| Supporting spouse with day to day tasks | 2 | 6 |
| Family setup | 4 | 20 |

# Appendix L

## Storyline of First Five Interviews

Fathers described the emotional rollercoaster, negative experiences and stress they encounter initially when their child is born with Down Syndrome, highlighting feelings of helplessness, frustration and fear of the future that lessen as the years pass by. Parenting a child with DS though is not all negative; fathers talk about hope and the positive aspects of parenting which they experience as their child grows and develops. Additionally, fathers that were heavily involved at birth seem to have a more positive parenting experience.

A period of acquiring information appears to take place shortly after their child is born, to help prepare them for the journey ahead. The impact of discovering negative information online appears to be mediated by positivity and seeking support.

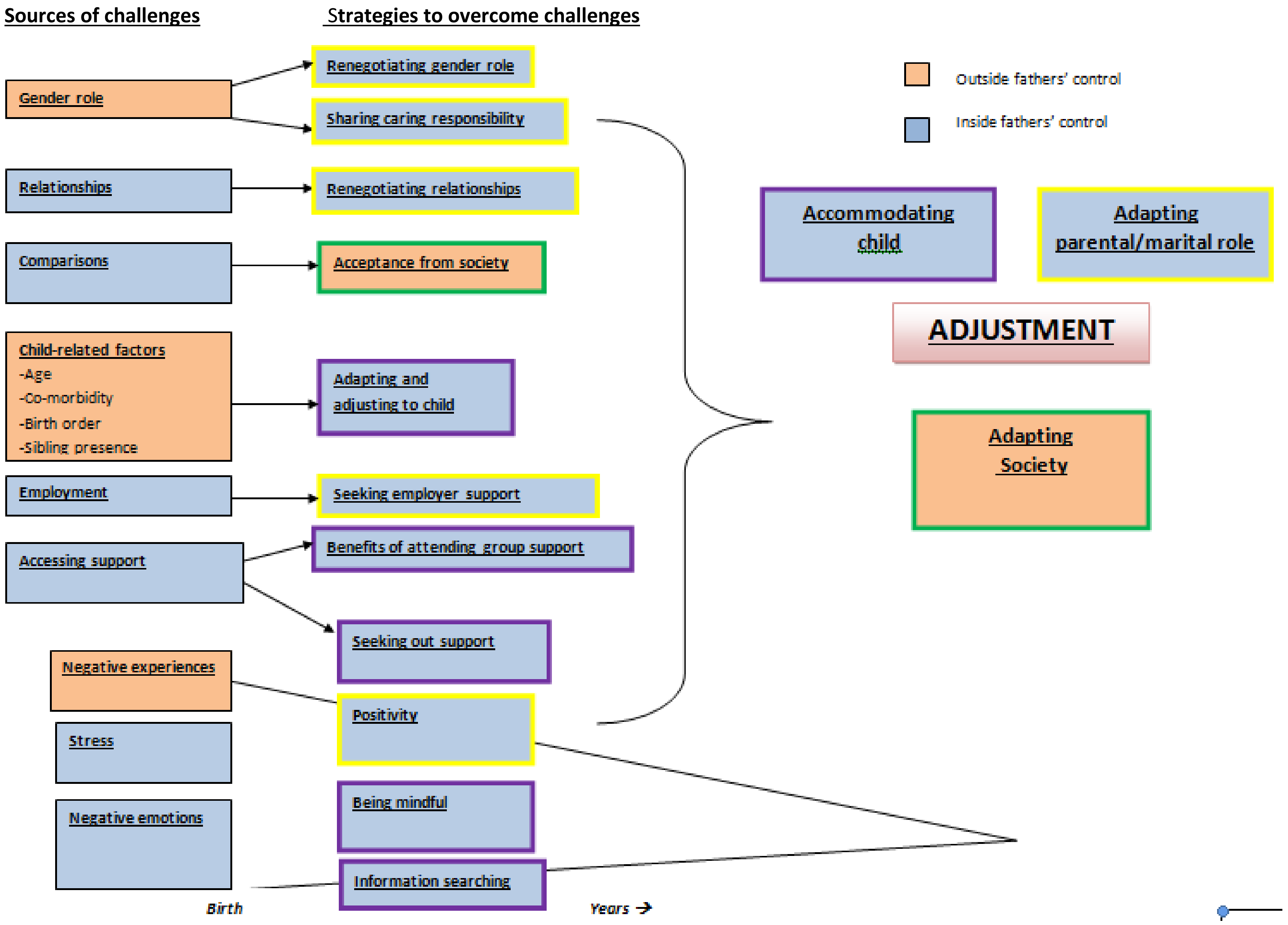
All fathers talked about hiding their emotions, partly due to the difficulties sharing feelings attributed to them being a male and partly having the desire to protect their partners.

Linked to gender role all fathers reported that their spouse still takes on the main caring role meaning services/support groups are mother-oriented and can leave fathers experiencing challenges accessing group support. There appears to be a process whereby parents renegotiate the gender role by fathers becoming increasingly involved in parenting and sharing caring responsibility, helped by setting routines shortly after birth. Similarly, challenges in relationships appear to be overcome by fathers renegotiating their relationships (i.e. making more time for being a couple). These challenges and strategies are impacted hugely by the type and flexibility of employment and fathers' ability to seek out support from their employer.

The makeup of the family and child-related factors appear to have an important influence on fathers' adjustment in a number of ways. Fathers of first born children with DS or with only one child seem to have an increasingly positive experience. I suspect that birth order might affect adjustment in that fathers with only one child with DS have no opportunity to make comparisons to previous parenting experiences; making comparisons was something all fathers referenced in regards to comparing their children to others within and outside the family. However, this appears to occur less or have limited impact when fathers' perceive their child to be accepted by society. There is also something about the presence of siblings that can have a positive and negative impact on adjustment in that siblings provide reassurance about future caring responsibilities but fathers also worry about their needs being neglected.

Professional support appears to be sporadic in that there is a postcode lottery as to which fathers can access specific services. Those who do not have increased amount of specialist professional support (through the council) however, still report adjusting well by seeking support from family, the school and overcoming barriers to attend support groups and other local resources.

# Appendix M Initial model



# Appendix N

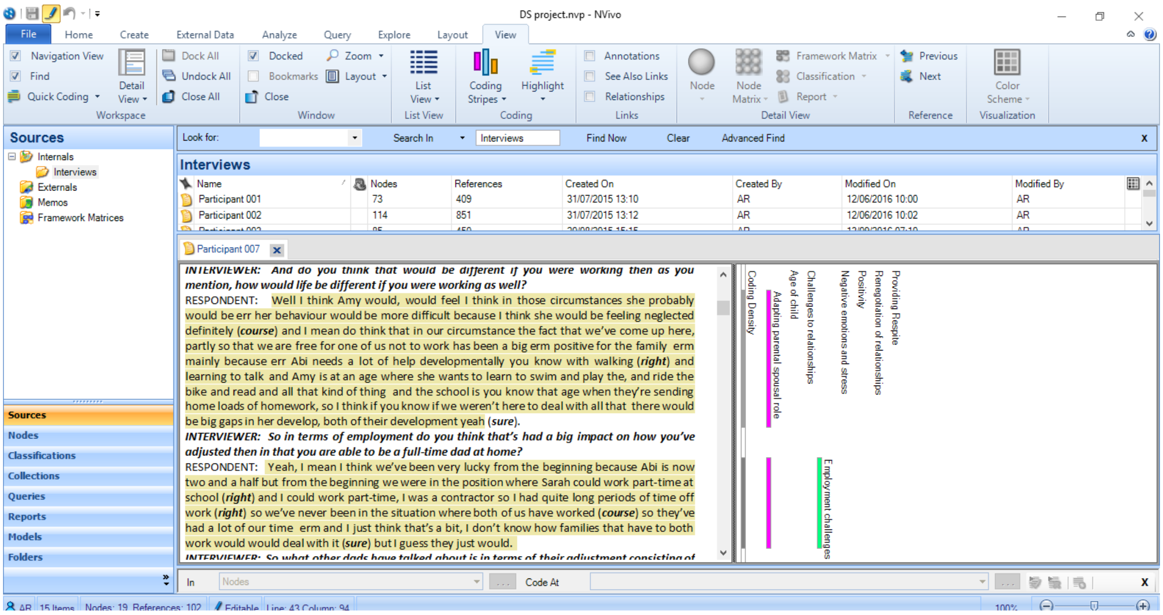
## Phase 2: Axial Coding

Within axial coding, hypotheses were formed about the emerging categories, in this case ‘Adapting Parental/Spousal Role’.

These hypotheses were tested with 5 participants throughout axial coding. A selection of the hypotheses are highlighted below, accompanied by screenshots of participant transcripts to highlight where links between the sub-categories were being made (e.g. links between specific challenges and strategies) and properties and dimensions of each category formed.

*Hypothesis 1: Full-time employment results impacts on how fathers adjust*

Participant 7 was chosen through the process of ‘theoretical sampling’ because his status was unemployed



Interviews

| Name | Nodes | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| Participant 001 | 73 | 409 | 31/07/2015 13:10 | AR | 12/06/2016 10:00 | AR |
| Participant 002 | 114 | 851 | 31/07/2015 13:12 | AR | 12/06/2016 10:02 | AR |

***INTERVIEWER: And do you think that would be different if you were working then as you mention, how would life be different if you were working as well?***

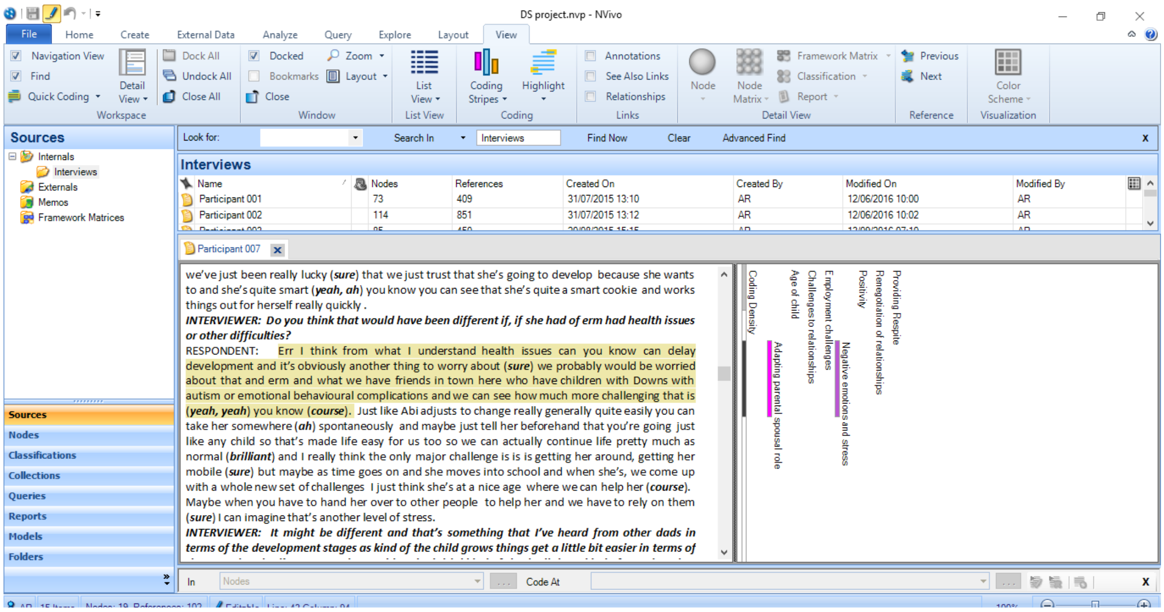
RESPONDENT: Well I think Amy would, would feel I think in those circumstances she probably would be err her behaviour would be more difficult because I think she would be feeling neglected definitely (***course***) and I mean do think that in our circumstance the fact that we’ve come up here, partly so that we are free for one of us not to work has been a big erm positive for the family erm mainly because err Abi needs a lot of help developmentally you know with walking (***right***) and learning to talk and Amy is at an age where she wants to learn to swim and play the, and ride the bike and read and all that kind of thing and the school is you know that age when they’re sending home loads of homework, so I think if you know if we weren’t here to deal with all that there would be big gaps in her develop, both of their development yeah (***sure***).

***INTERVIEWER: So in terms of employment do you think that’s had a big impact on how you’ve adjusted then in that you are able to be a full-time dad at home?***

RESPONDENT: Yeah, I mean I think we’ve been very lucky from the beginning because Abi is now two and a half but from the beginning we were in the position where Sarah could work part-time at school (***right***) and I could work part-time, I was a contractor so I had quite long periods of time off work (***right***) so we’ve never been in the situation where both of us have worked (***course***) so they’ve had a lot of our time erm and I just think that’s a bit, I don’t know how families that have to both work would would deal with it (***sure***) but I guess they just would.

***INTERVIEWER: So what other dads have talked about is in terms of their adjustment consisting of***

*Hypothesis 2: The more co-morbidities/health challenges the child experiences, the harder fathers find it to adjust*



**Interviews**

| Name | Nodes | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| Participant 001 | 73 | 409 | 31/07/2015 13:10 | AR | 12/06/2016 10:00 | AR |
| Participant 002 | 114 | 851 | 31/07/2015 13:12 | AR | 12/06/2016 10:02 | AR |

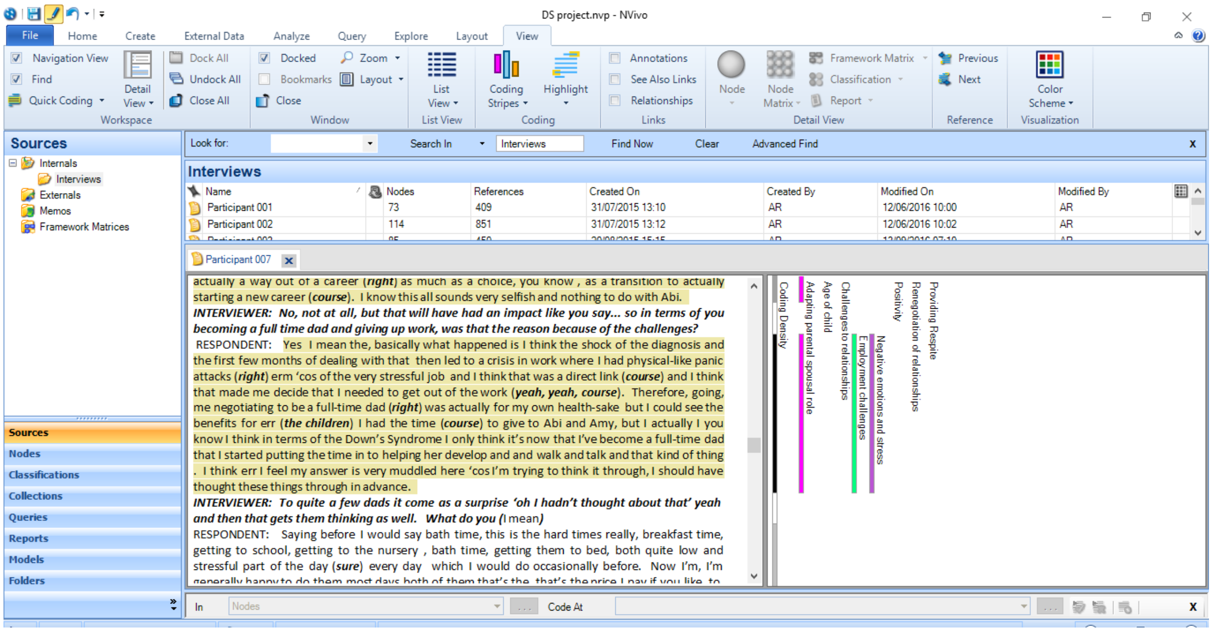
we've just been really lucky (***sure***) that we just trust that she's going to develop because she wants to and she's quite smart (***yeah, ah***) you know you can see that she's quite a smart cookie and works things out for herself really quickly .

***INTERVIEWER: Do you think that would have been different if, if she had of erm had health issues or other difficulties?***

RESPONDENT: Err I think from what I understand health issues can you know can delay development and it's obviously another thing to worry about (***sure***) we probably would be worried about that and erm and what we have friends in town here who have children with Downs with autism or emotional behavioural complications and we can see how much more challenging that is (***yeah, yeah***) you know (***course***). Just like Abi adjusts to change really generally quite easily you can take her somewhere (***ah***) spontaneously and maybe just tell her beforehand that you're going just like any child so that's made life easy for us too so we can actually continue life pretty much as normal (***brilliant***) and I really think the only major challenge is is is getting her around, getting her mobile (***sure***) but maybe as time goes on and she moves into school and when she's, we come up with a whole new set of challenges I just think she's at a nice age where we can help her (***course***). Maybe when you have to hand her over to other people to help her and we have to rely on them (***sure***) I can imagine that's another level of stress.

***INTERVIEWER: It might be different and that's something that I've heard from other dads in terms of the development stages as kind of the child grows things get a little bit easier in terms of***

*Hypothesis 3: Fathers renegotiate employment in order to overcome challenges with full-time work that impact on their adjustment*



**Interviews**

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| Participant 001 | 73 | 409 | 31/07/2015 13:10 | AR | 12/06/2016 10:00 | AR |
| Participant 002 | 114 | 851 | 31/07/2015 13:12 | AR | 12/06/2016 10:02 | AR |

actually a way out of a career (***right***) as much as a choice, you know , as a transition to actually starting a new career (***course***). I know this all sounds very selfish and nothing to do with Abi.

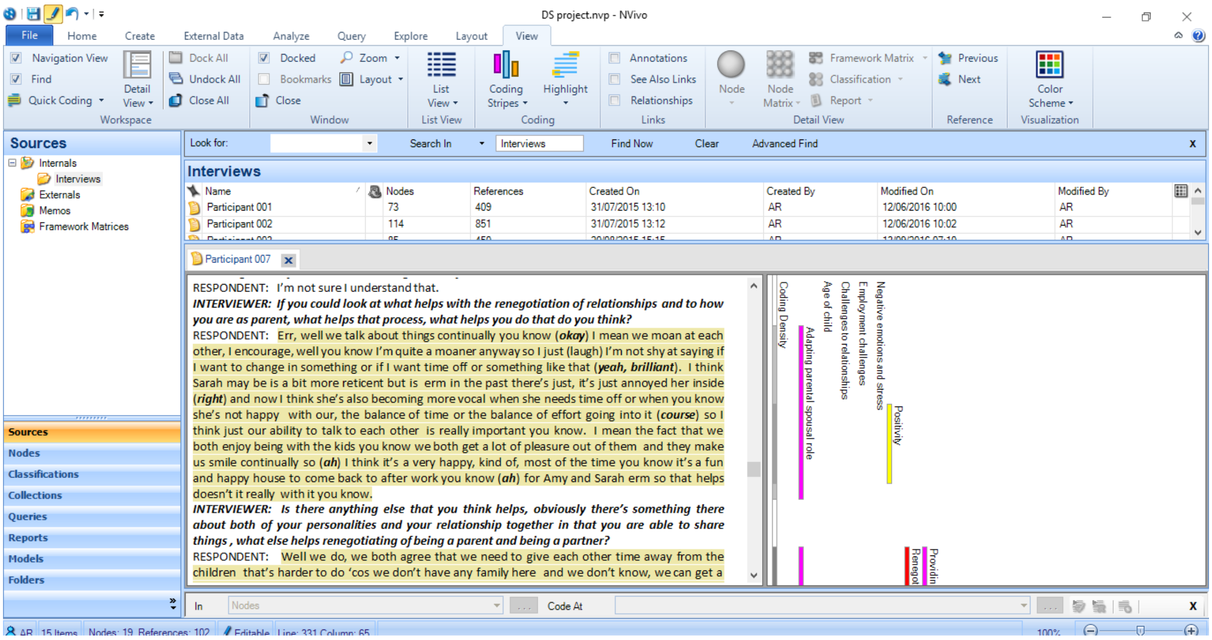
***INTERVIEWER: No, not at all, but that will have had an impact like you say... so in terms of you becoming a full time dad and giving up work, was that the reason because of the challenges?***

RESPONDENT: Yes I mean the, basically what happened is I think the shock of the diagnosis and the first few months of dealing with that then led to a crisis in work where I had physical-like panic attacks (***right***) erm 'cos of the very stressful job and I think that was a direct link (***course***) and I think that made me decide that I needed to get out of the work (***yeah, yeah, course***). Therefore, going, me negotiating to be a full-time dad (***right***) was actually for my own health-sake but I could see the benefits for err (***the children***) I had the time (***course***) to give to Abi and Amy, but I actually I you know I think in terms of the Down's Syndrome I only think it's now that I've become a full-time dad that I started putting the time in to helping her develop and and walk and talk and that kind of thing . I think err I feel my answer is very muddled here 'cos I'm trying to think it through, I should have thought these things through in advance.

***INTERVIEWER: To quite a few dads it come as a surprise 'oh I hadn't thought about that' yeah and then that gets them thinking as well. What do you (***I mean***)***

RESPONDENT: Saying before I would say bath time, this is the hard times really, breakfast time, getting to school, getting to the nursery , bath time, getting them to bed, both quite low and stressful part of the day (***sure***) every day which I would do occasionally before. Now I'm, I'm

*Hypothesis 4: In order to overcome challenges to relationships, fathers seek to renegotiate relationships with their spouse/ other children*



| Name | Nodes | References | Created On | Created By | Modified On | Modified By |
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| Participant 001 | 73 | 409 | 31/07/2015 13:10 | AR | 12/06/2016 10:00 | AR |
| Participant 002 | 114 | 851 | 31/07/2015 13:12 | AR | 12/06/2016 10:02 | AR |

RESPONDENT: I'm not sure I understand that.

***INTERVIEWER: If you could look at what helps with the renegotiation of relationships and to how you are as parent, what helps that process, what helps you do that do you think?***

RESPONDENT: Err, well we talk about things continually you know (***okay***) I mean we moan at each other, I encourage, well you know I'm quite a moaner anyway so I just (laugh) I'm not shy at saying if I want to change in something or if I want time off or something like that (***yeah, brilliant***). I think Sarah may be is a bit more reticent but is erm in the past there's just, it's just annoyed her inside (***right***) and now I think she's also becoming more vocal when she needs time off or when you know she's not happy with our, the balance of time or the balance of effort going into it (***course***) so I think just our ability to talk to each other is really important you know. I mean the fact that we both enjoy being with the kids you know we both get a lot of pleasure out of them and they make us smile continually so (***ah***) I think it's a very happy, kind of, most of the time you know it's a fun and happy house to come back to after work you know (***ah***) for Amy and Sarah erm so that helps doesn't it really with it you know.

***INTERVIEWER: Is there anything else that you think helps, obviously there's something there about both of your personalities and your relationship together in that you are able to share things , what else helps renegotiating of being a parent and being a partner?***

RESPONDENT: Well we do, we both agree that we need to give each other time away from the children that's harder to do 'cos we don't have any family here and we don't know, we can get a

# Appendix O

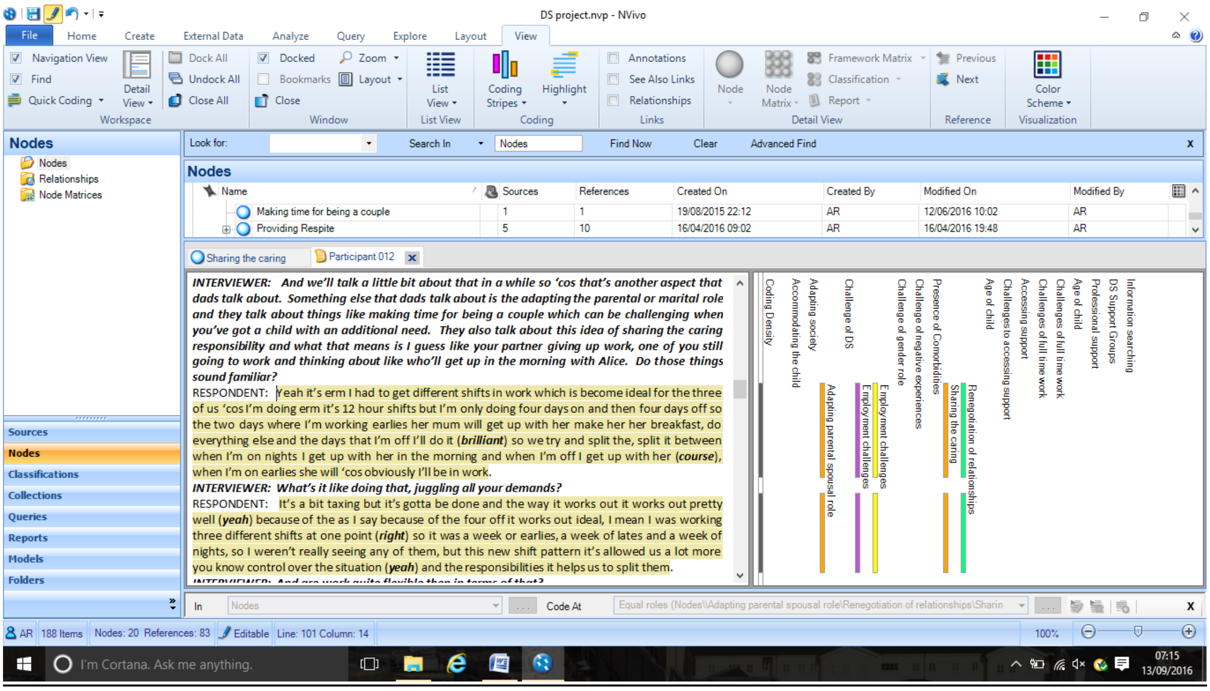
## Phase 3: Selective Coding

Selective coding was used to establish if there was ‘priority’ between the categories in terms of fathers’ overall adjustment (i.e. if one category was more important than the other). This led to the refinement of the final theoretical model.

An example of this is highlighted below in an excerpt from a transcript (Participant 12). For this participant, ‘Adapting Society’ also played an important part. However, as noted in the main thesis, for the majority of fathers, this was not the case and this category was described instead as the “icing on the cake”.

***INTERVIEWER: Out of all those three if you had to rate them which would you say is the most important that you've found so far with Alice that you've done the most of or that really resonates like with what you've told me?***
RESPONDENT: Accommodating the child.
***INTERVIEWER: So you think that's probably the most important?***
RESPONDENT: Yeah.
***INTERVIEWER: What comes next or parallel?***
RESPONDENT: Well the other two are basically gotta be side by side because your parental role and adapting society's gotta be basically the same (*yeah*) because you've gotta come to terms with it and then you've gotta try and get other people in Alice's life to come to terms with it as well so to me the adapting parental and the adapting society are basically side by side (*yeah*) but the main thing is you accommodate your child before anything.
***INTERVIEWER: So accommodating the child is first and then would you say then these other two happen just exactly the same time or do they come shortly after or when do you think they come?***
RESPONDENT: Shortly after 'cos after, once you've accommodated your child then you've gotta try and sort yourself out and and try help other people understand what she's got and (*sure*) how to help her.
***INTERVIEWER: Are there any out of these that just are just icing on the cake or do you think all three are fundamental to how you've adjusted to parenting Alice?***
RESPONDENT: All three are fundamental (*yeah*).
***INTERVIEWER: Are there any other things that you, that we've not talked about that you would add to those three, or that don't kind of fit under each one of them?***
RESPONDENT: Erm no not really, not that I can think of.
***INTERVIEWER: Brilliant, is there anything else that you've not told me about adjusting to Alice that you think might be important for other dads to know or professionals to know?***
RESPONDENT: Well there is one for professionals what they need to learn is a dad's got just as much responsibility as the mum so they need to be able to talk to the dads the way they talk to the mums and not turn round and hold stuff back from the dad (*yeah*) until the mum's there (*course, yeah*). I mean I can't go into Alice's doctor and change her address without her mum doing it (*really*) because the receptionist won't accept that I'm her dad. It's like that with most doctors and err receptionists and everything else they don't wanna they don't wanna err associate with the dad (*right*) 'cos dads get all this bad press about oh they leave, or they don't wanna know but the dads that do wanna know are there (*yeah*) and they're fighting like hell to be accepted (*course*) by the professionals but they're just turning, turning away because you're not the mother (*sure*).
***INTERVIEWER: How do you think we could change that as professionals, what would make a difference, how could we involve dads more or approach dads?***

The screenshot below highlights how many of the sub-categories within ‘Adapting the Parental/Spousal Role’ relate to each other (e.g. ‘Employment challenges’ and strategies such as ‘Renegotiation of relationships’ and ‘Sharing the caring’)



Nodes

| Name | Sources | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| Making time for being a couple | 1 | 1 | 19/08/2015 22:12 | AR | 12/06/2016 10:02 | AR |
| Providing Respite | 5 | 10 | 16/04/2016 09:02 | AR | 16/04/2016 19:48 | AR |

***INTERVIEWER: And we’ll talk a little bit about that in a while so ‘cos that’s another aspect that dads talk about. Something else that dads talk about is the adapting the parental or marital role and they talk about things like making time for being a couple which can be challenging when you’ve got a child with an additional need. They also talk about this idea of sharing the caring responsibility and what that means is I guess like your partner giving up work, one of you still going to work and thinking about like who’ll get up in the morning with Alice. Do those things sound familiar?***

RESPONDENT: Yeah it’s erm I had to get different shifts in work which is become ideal for the three of us ‘cos I’m doing erm it’s 12 hour shifts but I’m only doing four days on and then four days off so the two days where I’m working earlies her mum will get up with her make her her breakfast, do everything else and the days that I’m off I’ll do it (***brilliant***) so we try and split the, split it between when I’m on nights I get up with her in the morning and when I’m off I get up with her (***course***), when I’m on earlies she will ‘cos obviously I’ll be in work.

***INTERVIEWER: What’s it like doing that, juggling all your demands?***

RESPONDENT: It’s a bit taxing but it’s gotta be done and the way it works out it works out pretty well (***yeah***) because of the as I say because of the four off it works out ideal, I mean I was working three different shifts at one point (***right***) so it was a week or earlies, a week of lates and a week of nights, so I weren’t really seeing any of them, but this new shift pattern it’s allowed us a lot more you know control over the situation (***yeah***) and the responsibilities it helps us to split them.

***INTERVIEWER: And are work quite flexible then in terms of that?***

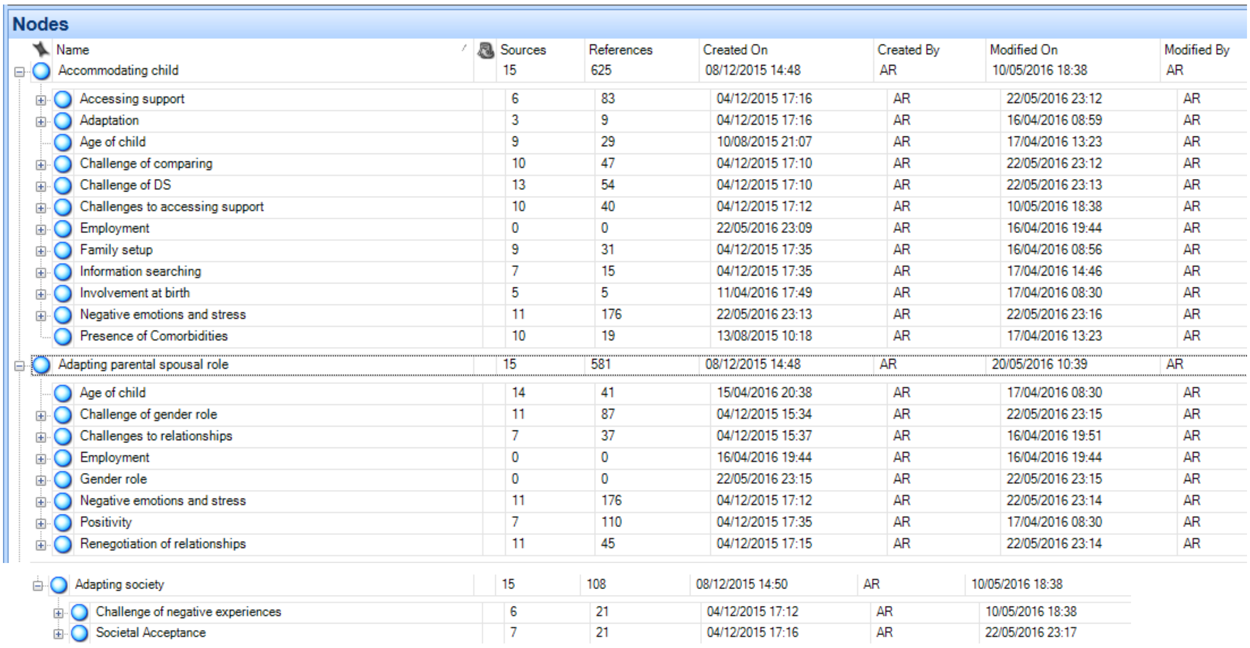
In: Nodes

Code At: Equal roles (Nodes\\Adapting parental spousal role\Renegotiation of relationships\Sharin

# Appendix P

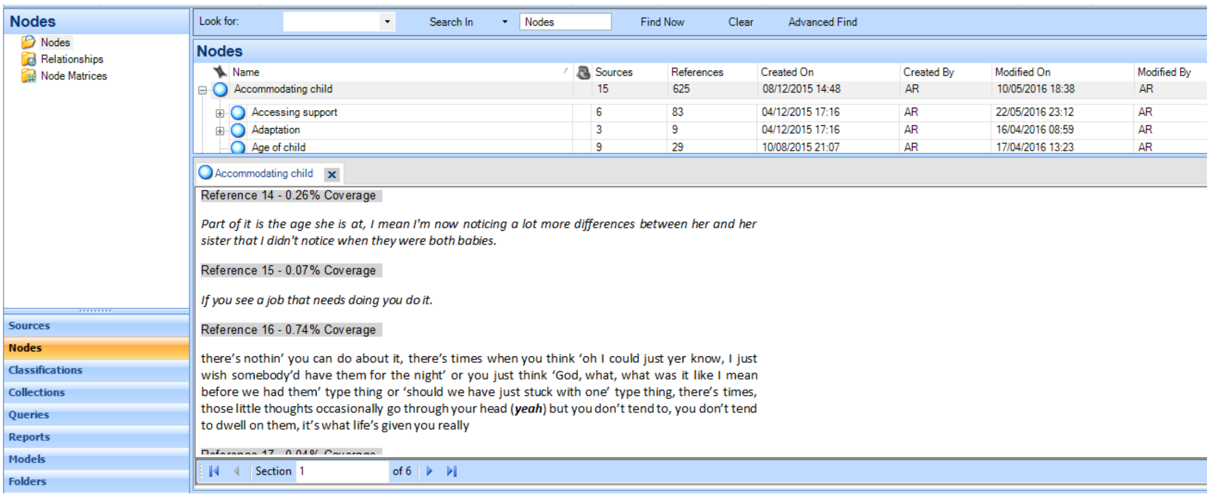
## Final Coding Structure

## (screenshot with example quotes)



| Name | Sources | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| Accommodating child | 15 | 625 | 08/12/2015 14:48 | AR | 10/05/2016 18:38 | AR |
| Accessing support | 6 | 83 | 04/12/2015 17:16 | AR | 22/05/2016 23:12 | AR |
| Adaptation | 3 | 9 | 04/12/2015 17:16 | AR | 16/04/2016 08:59 | AR |
| Age of child | 9 | 29 | 10/08/2015 21:07 | AR | 17/04/2016 13:23 | AR |
| Challenge of comparing | 10 | 47 | 04/12/2015 17:10 | AR | 22/05/2016 23:12 | AR |
| Challenge of DS | 13 | 54 | 04/12/2015 17:10 | AR | 22/05/2016 23:13 | AR |
| Challenges to accessing support | 10 | 40 | 04/12/2015 17:12 | AR | 10/05/2016 18:38 | AR |
| Employment | 0 | 0 | 22/05/2016 23:09 | AR | 16/04/2016 19:44 | AR |
| Family setup | 9 | 31 | 04/12/2015 17:35 | AR | 16/04/2016 08:56 | AR |
| Information searching | 7 | 15 | 04/12/2015 17:35 | AR | 17/04/2016 14:46 | AR |
| Involvement at birth | 5 | 5 | 11/04/2016 17:49 | AR | 17/04/2016 08:30 | AR |
| Negative emotions and stress | 11 | 176 | 22/05/2016 23:13 | AR | 22/05/2016 23:16 | AR |
| Presence of Comorbidities | 10 | 19 | 13/08/2015 10:18 | AR | 17/04/2016 13:23 | AR |
| Adapting parental spousal role | 15 | 581 | 08/12/2015 14:48 | AR | 20/05/2016 10:39 | AR |
| Age of child | 14 | 41 | 15/04/2016 20:38 | AR | 17/04/2016 08:30 | AR |
| Challenge of gender role | 11 | 87 | 04/12/2015 15:34 | AR | 22/05/2016 23:15 | AR |
| Challenges to relationships | 7 | 37 | 04/12/2015 15:37 | AR | 16/04/2016 19:51 | AR |
| Employment | 0 | 0 | 16/04/2016 19:44 | AR | 16/04/2016 19:44 | AR |
| Gender role | 0 | 0 | 22/05/2016 23:15 | AR | 22/05/2016 23:15 | AR |
| Negative emotions and stress | 11 | 176 | 04/12/2015 17:12 | AR | 22/05/2016 23:14 | AR |
| Positivity | 7 | 110 | 04/12/2015 17:35 | AR | 17/04/2016 08:30 | AR |
| Renegotiation of relationships | 11 | 45 | 04/12/2015 17:15 | AR | 22/05/2016 23:14 | AR |
| Adapting society | 15 | 108 | 08/12/2015 14:50 | AR | 10/05/2016 18:38 | |
| Challenge of negative experiences | 6 | 21 | 04/12/2015 17:12 | AR | 10/05/2016 18:38 | |
| Societal Acceptance | 7 | 21 | 04/12/2015 17:16 | AR | 22/05/2016 23:17 | |

### *‘Accommodating the child’*



| Name | Sources | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| Accommodating child | 15 | 625 | 08/12/2015 14:48 | AR | 10/05/2016 18:38 | AR |
| Accessing support | 6 | 83 | 04/12/2015 17:16 | AR | 22/05/2016 23:12 | AR |
| Adaptation | 3 | 9 | 04/12/2015 17:16 | AR | 16/04/2016 08:59 | AR |
| Age of child | 9 | 29 | 10/08/2015 21:07 | AR | 17/04/2016 13:23 | AR |

Reference 14 - 0.26% Coverage

*Part of it is the age she is at, I mean I'm now noticing a lot more differences between her and her sister that I didn't notice when they were both babies.*

Reference 15 - 0.07% Coverage

*If you see a job that needs doing you do it.*

Reference 16 - 0.74% Coverage

there’s nothin’ you can do about it, there’s times when you think ‘oh I could just yer know, I just wish somebody’d have them for the night’ or you just think ‘God, what, what was it like I mean before we had them’ type thing or ‘should we have just stuck with one’ type thing, there’s times, those little thoughts occasionally go through your head (***yeah***) but you don’t tend to, you don’t tend to dwell on them, it’s what life’s given you really

Section 1 of 6