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Title Page

“Yeah that made a big difference!”: The importance of the relationship between
health professionals and fathers who have a child with Down syndrome

Freyja Docherty¹ and Rebecca Dimond²

¹ School of Medicine, Cardiff University, U.K, ² School of Social Sciences, Cardiff University, U.K.

Corresponding author:

Freyja Docherty

Department of Clinical Genetics

Northern General Hospital

Herries road

S5 7AU

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Abstract

Evidence suggests that medical services do not reflect the increased involvement of fathers in childcare, a discrepancy that can often lead to feelings of exclusion and inequality. Fathers who have a child with Down syndrome may encounter many different health professionals during their child's life, therefore it is important to consider this relationship, and investigate the factors that influence their experiences. This is particularly important because the limited research focusing on fathers suggest that those who have a child with Down syndrome can experience increased stress levels and lasting feelings of loss and grief. It is therefore important to address their relationships with health professionals, as these may be a significant resource to prevent these feelings. This study used interpretative phenomenological analysis (IPA) to explore the experiences of seven fathers who have a child with Down syndrome, focusing on their interactions with health professionals. The analysis showed that the major factors associated with negative experiences were feelings of exclusion, receiving overly negative information about the condition and a perceived lack of on-going support. Positive experiences were associated with being made to feel like an equal parent, being given direct/clear information and being congratulated on the birth of their child. These results provide an insight into what fathers expect in terms of their own and their child's care and highlight that health professionals have an important and extensive role in influencing fathers' experiences of Down syndrome.

Key words: Down syndrome, Fathers, Interpretive phenomenological analysis, Health professionals, Diagnosis.

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Introduction

Down syndrome (DS) is one of the most common chromosomal alterations with an estimated prevalence of 1 in every 1,000 births in England and Wales (Down's Syndrome Association 2016). Living with DS can present diverse and complex medical and social needs (Karmiloff-Smith et al. 2016). As such, caring for a child with DS can present particular challenges for parents and families, therefore it is important to understand the needs of these families in order to increase parental and also child wellbeing. However, despite the prevalence of the condition, families who have a child with DS are often included in research studies under the umbrella of families who have a child with a number of disabilities (e.g. Minnes & Steiner 2009; Pelchat, Lefebvre, & Perreault, 2003; Rice, Gray, Howlin, Taffe, Tonge, & Einfeld, 2015). Furthermore, the majority of studies looking specifically at DS are presented from the female perspective, with research tending to focus on reporting data solely from mothers (e.g. Pillay, Girdler, Collins and Leonard, 2012; Gabel & Kotel, 2015; Choi & Van Riper, 2016). This means that despite there being an identified need, fathers who have a child with Down syndrome are frequently under-represented in current literature (Buckley, 2002; Cuskelly, Hauser-Cram, & Van Riper, 2008).

Research that is focused on fathers is important because fathers' involvement in childcare has increased in the past 10 years (Boström & Broberg, 2014; Burgess, 2008; Yogman, Garfield & Committee, 2016). Therefore, more research is needed into this group to reflect this more modern parenting practice. Although this increase may be attributed to a number of factors, such as an increase in paid paternity leave, a greater focus on mothers returning to the workplace and a shift in societal perceptions of gender roles, fathers involvement in child rearing is not always reflected in policy and social attitudes (Burnett, Gaterell, Cooper & Sparrow, 2012; Yogman,

1 Garfield & Committee, 2016). Indeed, in a health care setting research suggests that this
2 changing dynamic is not always supported and many studies report that fathers often feel
3 excluded or side-lined by health professionals (Berlyn, Wise, & Soriano, 2008; O'Brien, 2005).
4 For fathers who have a child with a disability, who often come into contact with many different
5 health professionals during the care of their child, reports of feeling marginalized and excluded
6 are unfortunately common (Huang, Tsai & Kellett 2012; Locock & Alexander 2006; Robson,
7 2002; Towers, 2009,). The impact of feeling excluded and undervalued should not be
8 underestimated. Feelings of helplessness, isolation and even panic have been reported by fathers
9 as a result of feeling excluded during hospital visits (Bacsrom & Hetfelt Wahn 2011; Deave &
10 Johnson, 2008). Furthermore, despite the fact that fathers often report a high level of respect for
11 health professionals and an appreciation of their potential as a source of support, frequently
12 feeling disregarded or ignored by health workers can act as a barrier to this support (Salzmann-
13 Erikson & Eriksson, 2013). This may be particularly important for fathers who have a child with
14 additional needs. Skotko, Levine and Goldstein (2011) for example found that fathers were less
15 likely to utilize 'non-profit organizations' as a means of support than female respondents. This
16 means that there is a greater need for health professionals to ensure these fathers are receiving
17 adequate care and attention in order to support their positive wellbeing.

18 **Purpose of the study**

19 Although the importance of these interactions is well understood, the contributing factors
20 to these feelings have not been extensively explored. For fathers who have a child with Down
21 syndrome their interactions with health professionals may be particularly important as feelings of
22 exclusion or isolation may worsen or contribute to the higher reported stress levels of parents
23 who have a child with the condition compared to parents of typically developing children

1 (Hodapp, 2007). Furthermore, studies report that fathers who have a child with DS can
2 experience initial feelings of trauma at the diagnosis (Hornby, 1995) and also on-going feelings
3 of loss and grief (Fleming, 2013), which may be worsened by feelings of exclusion.

4 An investigation of the factors that influence interactions with health professionals would
5 be useful to enhance parental experiences and prevent feelings of exclusion acting as a barrier to
6 good supportive relationships. Focusing specifically on fathers prevents the lack of or loss of
7 their voice in studies that look at both parents but often have an overwhelming, yet unintentional,
8 female respondent bias (e.g. Hippman, Inglis, & Austin, 2012; Lockock & Alexander, 2006). In
9 order to build a more comprehensive picture about what fathers who have a child with DS
10 require from health professionals, the current study explored the experiences of fathers around
11 the time of receiving a diagnosis of Down syndrome in their child and also their experiences in
12 the on-going care of their child. In-depth interviews were utilized to understand their broad
13 experiences and to examine the links that fathers themselves made between positive and negative
14 experiences and the behaviors of health professionals. During the interviews participants were
15 asked to describe a positive and negative experience they had with health professionals. This
16 article focuses on their responses.

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1 **Methods**

2 **Participants**

3 The target sample were participants who met the following inclusion criteria: a male who
4 assumes a paternal parenting role to a child with Down syndrome and was in contact with the
5 child at the time of diagnosis. A suggested target of between 6 and 10 interviews to be conducted
6 and analyzed was set in accordance with guidelines for IPA in Turpin, Barley and Scaife (1997).
7 IPA is a highly descriptive method guided by three core concepts, *phenomenology*, *hermeneutics*
8 and *idiography* (Smith et al. 2009). Therefore, small sample sizes allow the idiographic focus on
9 the *particular*, allowing the experiences of each individual participant to be analyzed and
10 explored in depth. Fathers were recruited via a U.K city Down syndrome support group. An
11 email was circulated via the support group administrator with a participant information sheet and
12 consent form attached. Participant information sheets were also handed out, by the researcher, at
13 the monthly support group meetings. Seven, out of the eight fathers who met the inclusion
14 criteria and were approached, agreed to be interviewed.

15 All seven of the participants were given pseudonyms: **Steve, James, Tim, Neil, Harry,**
16 **David** and **Max**. The age of participants ranged from 36 to 48 years old. The average age was 41
17 years old. The average age of their child with Down syndrome was four years, with the ages
18 ranging from two to seven years old. All of the participants were biological fathers to their
19 children and were currently co-habiting and in a relationship with their child's mother. For three
20 of the participants their child with DS was their first and only child, for two of the participant
21 their child with DS was their oldest child with a younger sibling without DS and for the final two
22 participants their child with DS was the youngest of multiple older siblings without DS. All of

1 the participants were currently in employment; two worked part-time, five worked full-time.
2 Two of the participants received a pre-natal diagnosis of Down syndrome in their child; the
3 remaining five received a post-natal diagnosis.

4 **Data collection**

5 Semi-structured face-to-face interviews were conducted at a location of the participants
6 choosing. An interview guide was constructed composed of 15 open ended questions following
7 guidelines in Smith, Flowers and Larkin (2009) (Appendix 1). All interviews were conducted by
8 the first author. Additional questions were asked to follow up interesting points mentioned by
9 the participants and the participants were asked to clarify any points that they had made to ensure
10 that the interviewer understood their accounts. Of the seven interviews, three were conducted in
11 the participants' home, three in a local café of the participants choosing and one was conducted
12 at the support group meeting in a quiet room. The interviews ranged in length from 42 minutes to
13 one hour 33 minutes

14 Ethical approval for this study was obtained via the Cardiff University School of medicine
15 research and ethics committee.

16 **Analysis**

17 Interpretive Phenomenological Analysis (IPA) was used to explore fathers' accounts of
18 their interactions with the health professionals involved in their child's care. IPA is a qualitative
19 research method concerned with the exploration of how individuals experience and interpret a
20 given phenomenon and has been effectively used in previous studies to explore the experiences
21 of being a parent to a child with a genetic condition (e.g. Forrest Keenan, van Teijlingen, McKee,

1 Miedzybrodzka, & Simpson, 2009; Rivard & Mastel-Smith, 2016). The following analysis
2 methodology was constructed for this project based on recommendations for IPA in Smith,
3 Flowers and Larkin (2009), Smith and Eatough (2012) and Turpin et al. (1997).

4 The interviews were transcribed after the interview at the soonest possible convenience.
5 Reading and re-reading of the transcript was then performed followed by initial noting of
6 thoughts and interpretations in the margins. These thoughts were then processed into emergent
7 topics or *subordinate themes*. These subordinate themes were then clustered into groups
8 representing *basic themes* that have a similar meaning. After all the interviews were conducted
9 and all the transcripts had been analyzed, the basic themes for all of the interviews were
10 constructed under superordinate themes. This was achieved by further clustering based on
11 identifying links and patterns between basic themes.

12 Following the completion of all interviews the participants were provided with a document
13 summarizing the research findings via email. Participants were each asked to comment on the
14 findings to increase the validity of the research results. Where appropriate, the results of this
15 feedback are included in this article.

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1 Results

2 Three superordinate themes were identified: *Evaluations of health care experiences*,
3 *Expectations of care* and *Health professionals' attitudes towards Down syndrome* (**Table 1**).

4 Superordinate theme 1: Evaluations of health care experiences

5 The first theme describes how participants evaluated an experience as positive or negative.
6 Feelings of exclusion and inequality were common and contributed to the participants feeling
7 under-valued by health professionals and were associated with negative experiences.

8 Basic theme: Feelings of exclusion.

9 Feelings of exclusion were reported by seven out of the seven participants and stemmed
10 from a number of sources. One significant way these feelings were created was by being
11 excluded from discussions about their child's care. As described by **David**:

12 *"All the questions are always directed to the mother. But you just do what*
13 *you do. Any time there's anything involved with needles I'm the one that*
14 *does it. The nasal tube, I'm the one that does it. All the nasty stuff I do but*
15 *when they are discussing it they are always talking to her mother!"*

16 During his interview David spoke at length about his involvement in his child's care. In the
17 above extract David highlights how his role in practical aspects, such as using needles or
18 inserting a nasal tube is often not acknowledged by health professionals. This reflects an overall
19 trend shared by five out of the seven participants that feelings of exclusion were particularly
20 frustrating as although they took an equal parenting role this did not seem to be recognized by

1 health care staff. For many of the participants being involved in their child's care also meant
2 being listened to. **Steve** made this suggestion when asked what advice he would give to health
3 professionals:

4 *“Listen to the parents for fucks sake listen to the parents. They usually know*
5 *what's going on, or they've got a pretty good idea. It's all about good*
6 *communication and listening to dads, to mums, to the children”.*

7 Steve is obviously frustrated by the fact that he feels he is not listened to, indicated by his
8 choice of language. But as Steve points out, it is not just fathers who need to be listened to it is
9 also mothers and the children themselves.

10 Feelings of exclusion were also caused by instances when the participants had felt their
11 presence was seen as a negative by health professionals:

12 ***Neil:** “Well at the birth, I've already spoken about it but, dads are seen as*
13 *inconvenience really, mothers are...well I was speaking to (name of partner)*
14 *about it and talking about you and coming round and she said she felt like a*
15 *bit of an inconvenience too. So she does have similar feelings but it's*
16 *obviously a lot more explicit with dads as they are explicitly telling you, you*
17 *are not welcome here.”*

18 Drawing on his own experiences, Neil describes how fathers can be made to feel
19 not welcome at the birth of a child. Although Neil acknowledges that this may also be
20 the case for his partner, he suggests that fathers in particular are more vulnerable to

1 being seen as an inconvenience, and that this might be more explicit for fathers than
2 mothers.

3 **Basic theme: A sense of inequality.**

4 Feelings of inequality were associated with negative experiences and were demonstrated
5 by a number of factors. For four out of the seven participants, a sense of inequality was often
6 associated with times when the participants had felt that *practically* they were not being made to
7 feel comfortable and their wellbeing was not being considered in the same way that is was for
8 their female partner. **James** talked about his experience during the birth of his child:

9 *“I couldn’t use the facilities, I couldn’t make myself a cup of tea, I*
10 *wasn’t allowed to make toast. She (partner) was sleeping on a bed, I*
11 *was sleeping on some chairs. I mean we were both there for the same*
12 *reason but she was treated like she was supposed to be there and I*
13 *was treated like I wasn’t”.*

14 James describes how he was treated differently from his partner. Several of the fathers
15 mentioned a difference in how they were treated compared to their wives, and many pointed to
16 this difference leading them to feel that they were not viewed by health staff as of equal worth or
17 importance.

18 Participants also talked about how they disliked being made to feel in some way a lesser
19 parent than their child’s mother:

20 **Tim:** *“Although it has changed so much in the last 10 or 20 years the*
21 *services don’t really reflect that, they are sort of lagging behind in the way*

1 *that attitudes and practices of some professionals. I'm working pretty much*
2 *full time now but when the kids were growing up I was around more than*
3 *(name of partner) but yeah I sometimes do feel that services are skewed*
4 *towards the Mother and you are just seen as the stand in carer”*

5 This statement reflects a common theme discussed by five of the participants that
6 the changing roles of fathers are not appreciated by services and staff. As a result,
7 participants felt they were continually treated as secondary carers even though their
8 involvement in their child’s care was equal to that of their partner.

9 **Superordinate theme 2: Expectations of care**

10 The second theme illustrates what the participants expected from health professionals in
11 terms of care for their child and also for themselves. When the participants were asked to
12 describe a negative experience they described instances when the care their child had received
13 was disjointed or they had felt there was a lack of on-going support for themselves as new
14 parents. Positive experiences were associated with instances when health professionals had
15 provided a sense of care-coordination and information was clearly and directly communicated.

16 **Basic theme: Continuity of care.**

17 Participants talked about how a lack of on-going support for themselves as new parents was a
18 major contributor to poor experiences:

19 **David:** *“We were kicked out basically. ‘Here you go enjoy’!”*

1 **Neil:** *“The really bad part of it was that you didn’t feel that you were part*
2 *of a system of care after”.*

3 All of the fathers in this study suggested that a large amount of distress is caused by the feeling
4 that they don’t know what is coming next and what will be available to them and suggest that
5 continuing care was an important factor in their diagnostic journey.

6 The participants also described how a lack of on-going care for their child was associated
7 with negative experiences with health professionals:

8 **Max:** *“We just feel a little out of the loop in terms of his general health and*
9 *who will be in charge of that. We just feel a bit let down as we don’t really*
10 *know what’s happening”*

11 For Max not knowing what care or support would be provided for his child was
12 very disappointing and this continued lack of appropriate information has led to him and
13 his partner feeling disillusioned with the services they have encountered. A need for
14 clear communication from health professionals about what care their child would
15 receive was a preference expressed by many of the participants.

16 **Basic theme: Clear and direct communication.**

17 Clear and direct communication from health professionals was seen as vital to providing a
18 sense of continuity of care:

1 **Harry:** *“we saw (name of doctor) in the morning and he told us exactly*
2 *what was happening and you just felt reassured that everything was in*
3 *place”.*

4 Having an awareness of what was coming next established this feeling of continuity, which
5 for Harry in particular led to feelings of reassurance and a sense that this was a positive
6 experience. Many of the participants described how being kept up to date with what is going on
7 and what is going to happen, could actually make their experiences more manageable:

8 **Steve:** *“When you know what is going on no matter how bad things*
9 *are going, clearly you want things to go well, but if people*
10 *communicate with you well what’s going on you can almost manage*
11 *anything”*

12 Direct statements from health professionals was also the participants’ preferred method of
13 communication when discussing their child’s diagnosis:

14 **Steve:** *“There was no kind of ‘there might be some doubt about this’*
15 *any false hope. ‘Your child has got Downs’ and he went through it*
16 *and he was straightforward and to the point and I just thought that*
17 *was great”*

18 The importance of clear communication was confirmed by **Harry** after reading the
19 participant feedback sheet: *“Yes, definitely a clear approach by a professional that knows what*
20 *they are talking about is best”.*

1 For the participants interviewed, feeling as if you and your child were part of a system of
2 care and that this would be clearly communicated was of high importance. These findings, and
3 those mentioned above, were validated by feedback from the participants:

4 **Neil:** *“Yeah, the feeling of being left with no support after the*
5 *diagnosis is probably one of the worst aspects of my experience and*
6 *one that can be quite easily remedied by doctors, midwives, health*
7 *visitors, charities etc.”*

8 This confirms the importance of on-going support for fathers and the important role that health
9 professionals have to alter their experiences.

10 **Superordinate theme 3: Health professionals’ attitudes towards Down syndrome**

11 **Participants** talked about the attitudes and perceptions of DS that they had encountered
12 from health professionals and how this affected them. Although they were not directly asked
13 what they believed health professionals thought about people with DS, the participants
14 interpreted the attitudes of health professionals by how they conveyed information about the
15 condition and how they reacted to their child. Importantly, health professionals’ attitudes towards
16 Down syndrome was actually found to affect the participants’ own perceptions of the condition
17 and the way they responded to the diagnosis.

18 **Basic theme: How information is presented**

19 A really striking topic that was discussed by three of participants was their experiences of
20 the way in which information about DS was presented to them by health professionals e.g.

21 **David:**

1 *“We’ve had so many scare tactics and this was prior to the birth, ‘we want*
2 *you to terminate’ and all this and you just think we’ll do what we do. To me*
3 *I’d say, too much information at times but I understand they have to give it*
4 *but you not want to hear really massive scare tactics all the time. We were*
5 *expecting a monster, before she’s born we’re expecting someone who’s*
6 *going to be sat there as a 12-year-old well as an adult she’ll have the*
7 *intelligence of a 12-year-old and she’ll be dying of leukemia”*

8 For David the information that he was given by health professionals vastly affected the
9 way in which he perceived Down syndrome and his daughter, particularly striking is how he
10 describes his expectations as a “*monster*”. This interpretation was confirmed by David when
11 giving feedback on the results summary: “*The report portrayed my experiences very*
12 *accurately*”. In terms of information giving **Tim** talks about getting the balance right as “*not*
13 *necessarily focusing on all the positives but just not painting the blackest picture*”. For Tim this
14 means having an awareness of the personal limits of the couple:

15 *“[I suggest] looking at the couple how they interact, I know that’s a tall*
16 *order for health professions as they don’t necessary have the time, but I*
17 *think people have got different thresholds for information”*.

18 The importance of not painting the “*blackest picture*” was discussed by **James** who when asked
19 to talk about a particularly positive care experience gave this example of a consultant they
20 encountered:

21 *“(name of doctor) was really positive and upbeat and cheery about*
22 *everything and ‘you’re going to have a great time being parents!’ and*

1 *made us see beyond the diagnosis and the immediate stresses He helped us*
2 *to be excited about the fact that we had a baby and not to be stressed*
3 *about the fact that we had a baby with Down syndrome. He reminded us*
4 *that this was a tremendous thing to be excited about and he really helped*
5 *us to focus on that. Yeah that made a big difference”*

6 The attitude of the consultant is described by James as being genuinely positive and
7 demonstrates the important way in which health professional attitudes to the condition are
8 perceived.

9 **Basic theme: Reactions of health professionals to their child**

10 Another way in which attitudes towards DS are demonstrated by health professionals is in
11 their reaction to the participant’s child. For **Neil**, the fact that immediately after the birth of his
12 child he was “*walking around with (name of child) and no one wanted to congratulate me*” lead
13 to feelings of dissatisfaction with the care him and his partner received. A more positive
14 experience is described by **Steve** about a particular doctor they met:

15 *“He was amazing you know. He walked into the room and his immediate*
16 *reaction was ‘beautiful baby, beautiful boy’. And it just set the tone”.*

17 For Steve the fact that the doctor acknowledged that his baby was beautiful was really
18 important for establishing a positive relationship with this doctor and demonstrates how more
19 positive reactions to Down syndrome from health professionals can not only affect their patients’
20 perspectives, as illustrated earlier by David and James, but also their relationship with families.

21 These themes were confirmed in the participant feedback from **Max**:

1 *“I think that it is important for parents to be aware of certain potential*
2 *health problems but these don't need to be concentrated on immediately*
3 *after diagnosis. As your findings say, it would be nice to be congratulated on*
4 *the birth or impending birth of your child.”*

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Discussion

This study aimed to explore the experiences of fathers with a child diagnosed with Down syndrome, at a time when their child was being cared for by hospital staff or by health professionals in the community. The role of health professionals in the lives of families with a child with a disability should not be underestimated. Health professionals act as a significant source of support for fathers (Salzmann-Erikson & Eriksson, 2013) but evidence suggest that this support can be undermined by feelings of exclusion or inequality (Berlyn, Wise, & Soriano, 2008; O'Brien, 2005). As fathers are less likely to utilize non-profit support or advice organizations (Skotko et al. 2011), the role for health professionals, as the frequent first port of call for fathers seeking support and information is particularly crucial. Although there have been several key studies exploring parent's experiences of having a child with a disability (Douglas, Redley, & Ottmann, 2016; Pelchat et al., 2003), this study stands out for two particular reasons. Firstly, it focused on Down syndrome. This is important as research suggests that parents who have a child with Down syndrome experience higher stress levels and lower-wellbeing than parents of typically developing children (Cunningham, 1996; Hodapp, 2007). However, the complexities of having a child with DS are often overlooked and parents are often included in more general studies that investigate parenting experiences of children with a range of disabilities. Secondly it explored the experience of fathers, as opposed to mothers or more generally parents. This is a particular strength of the study because while many studies report that they are including the voice of fathers, this is often relayed by the female partner (e.g. Hornby, 1995) or lost in studies that have a majority female respondent bias (e.g. Hippman et al., 2012). Although this study is based on a small number of respondents, by focusing on DS and on

1 the experience of fathers, it provides a valuable insight into an important yet neglected area of
2 health and wellbeing.

3 A significant finding of this study was that fathers who have a child with Down syndrome
4 reported feeling excluded during interactions with health professionals. These feelings of
5 exclusion have been reported elsewhere and can have significant negative implications for
6 fathers (Deave & Johnson, 2008; Backstrom & Hetfelt-Wahn, 2011; Cosson & Graham 2014).
7 Combined with reports that fathers can experience shock and despair when confronted with an
8 often unexpected diagnosis of DS (Fleming, 2013; Takataya, Yamazaki, & Mizuno, 2016),
9 evidence provided by the current study that fathers who have a child with DS experienced these
10 feelings is particularly worrying. Fathers can feel excluded at the birth of their child, and in the
11 on-going care of their child. An interesting finding is the clarity with which these participants
12 can recall their feelings and their interactions with health professionals around the time of
13 diagnosis. However, a potential caveat to this is that fathers may only be recalling and analyzing
14 their experience because they have been explicitly questioned about them, this may represent a
15 limitation of the interview guide.

16 Whereas Locock and Alexander (2006) found that the male partner often chose to leave the
17 room during prenatal screening, the participants interviewed in this study all expressed a desire
18 to be present at the birth and the ongoing hospital appointments. Yet several felt they were not
19 being listened to by health professionals, and were made to feel like they were not meant to be
20 present at the birth of their child. For the fathers in this study, exclusion was implicit in the
21 organization of healthcare services and not only a matter of interpersonal
22 communication. Overall fathers suggested that they felt neglected in their interactions with
23 health professionals and would have benefitted from greater efforts to include them. This would

1 support the call for changes to female-orientated prenatal and postnatal services (Brajenović-
2 Milić and Dorčić 2016).

3 A further significant finding was that fathers often felt undervalued by being placed as
4 secondary to their child's mother. Feelings of inequality were created by not being given access
5 to the same facilities as mothers and more crucially not being recognized for their important and
6 equal parenting role. A number of reports from the Fatherhood Institute (Burgess, 2008;
7 Fatherhood Institute, 2014), a UK initiative set up to publicize and promote father's rights and
8 responsibilities, echo an overall increased level of paternal involvement. Crucially, based on the
9 responses of the seven fathers interviewed in this study it appears that fathers want to be
10 involved, but there are barriers to their participation that surround feelings of exclusion and
11 feelings of inequality.

12 One of the major contributors to a poor experience was a lack of on-going care. Concern
13 for the long-term provision of care for their children was a major concern of the fathers
14 interviewed by Hornby (1995). Despite the length of time that has elapsed between this study
15 and our own, the similarities between our own findings and other recent studies suggest that
16 improvements could still be made in terms of the awareness of the experiences of fathers, and
17 continuity of support (Marshall, Tanner, Kozyr, and Kirby 2015).

18 Another important finding of the current project was that the attitude of health
19 professionals about DS affected fathers' experiences. The fathers involved in this study believed
20 that the health professionals involved in their child's care held negative views about the
21 condition, manifest by presenting an overly medicalized or negative clinical picture. The impact
22 of health professionals' attitudes and styles of information giving are not unique to parents of

1 children with DS (see for example, Wesley, Zhao, Carroll, & Porter, 2016; Hall, Abramsky, &
2 Marteau, 2003) however, this issue has been galvanized by the Down's Syndrome Association
3 who launched the 'Tell It Right, Start It Right' campaign in May 2016 (Bryant, Puri, Dix, &
4 Ahmed, 2016). This initiative aims to increase awareness for the condition amongst health
5 professionals and promote the delivery of balanced information to new parents. .

6 Overall, these results suggested that health professionals have a pivotal role in affecting fathers'
7 experiences and what it meant to have a child with DS. Greater collaboration between health
8 professionals and charitable organizations for DS has been suggested to help raise awareness and
9 acceptance of the condition in health services and wider society (Jain, Thomasma, & Ragas,
10 2002), the results of the present study may help to strengthen this argument further and suggest
11 how for fathers in particular positive attitudes can have a significant impact.

12 These findings could have significance to the field of genetic counselling as given increased
13 father involvement in childcare (Burgess 2008; Fatherhood Institute 2014) more and more
14 fathers may attend genetic counselling appointments with their children than in previous years.
15 In addition, the advent of new genetic technologies such as whole genome sequencing makes the
16 testing of mother-father-child trios the gold standard in diagnostics (e.g. Hunt et al. 2014)
17 therefore it is likely that fathers will continue to attend genetic counseling clinics in increasing
18 numbers.

19 Further research should seek to expand on this study by investigating the experiences of a larger
20 and more geographically diverse set of fathers. These studies should aim to build a more
21 comprehensive list of recommendations for health professionals that would contribute to more
22 positive experiences.

1 **Study Limitations**

2 This is a small study, drawing on the accounts of seven fathers, which might not be generalizable
3 to a much larger population. As specific demographic material is not provided, to protect the
4 anonymity of this small sample, how the results may have been impacted by a number of
5 variables including parenting history and experience, the parents' occupation, the age and health
6 of child, is not explored but may have been an interesting area to investigate. A further
7 limitation lies in the 'self-selection' of participants, where fathers might have agreed to
8 participate because they had particularly positive or negative experiences.

9 Furthermore, all of those interviewed for this study utilized the support group, which is unusual
10 for fathers (Skotko et al. 2011), In addition, as participants were recruited from a single U.K
11 support group this might suggest that their experiences are particular to the local professional
12 support system and cannot be generalizable to a wider population.

13 **Conclusions**

14 It is important to note that the experiences of the fathers interviewed in this research project were
15 both positive and negative. Each participant had a range of experiences to discuss and their
16 views about health professionals were overwhelming positive, while the more negative
17 experiences were clearly significant to the participant and were useful to illuminated areas for
18 improvement. The key findings were that fathers who have a child with Down syndrome can
19 experience feelings of exclusion during interactions with health professionals. The factors
20 contributing to these feelings were not being involved in discussions about their child's care and
21 not being listened to. Fathers also felt that health professionals did not acknowledge their role as
22 equal parents. Feelings of inequality were caused by not being given equal access to facilities in

1 the hospital. Clear and direct communication when confirming the diagnosis of Down syndrome
2 and when organizing on-going care was preferred by the fathers in this study. An overall lack of
3 on-going care was seen as a major contributor to negative experiences. The pivotal role of health
4 professionals to affect fathers' perceptions about Down syndrome was also demonstrated in this
5 study. Attitudes were revealed by how information about the condition was presented and how
6 health professionals reacted to their child, particularly whether the fathers were offered
7 congratulations.

8 These results offer, for the first time, a detailed insight into the factors and behaviors that
9 contribute to the perceptions of these experiences of fathers with intense involvement in health
10 care services. It highlights potential for change that would promote more positive interactions
11 between fathers who have a child with Down syndrome and the health professionals involved in
12 their child's care.

13 **Compliance with Ethical Standards**

14 All procedures followed were in accordance with the ethical standards of the responsible
15 committee on human experimentation (institutional and national) and with the Helsinki
16 Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for
17 being included in the study

18 **Conflicts of Interest**

19 Freyja Docherty and Rebecca Dimond declare that they have no conflict of interest.

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References

- 1
2 Backstrom, C., & Hertfelt Wahn, E. (2011). Support during labour: first-time fathers'
3 descriptions of requested and received support during the birth of their child. *Midwifery*,
4 27(1), 67-73. doi:10.1016/j.midw.2009.07.001
- 5 Berlyn, C., Wise, S., & Soriano, G. (2008). Engaging Fathers in Child and Family Services:
6 Participation, Perceptions and Good Practice. *Family Matters*, 80, 37-42.
- 7 Boström, P. K., & Broberg, M. (2014). Openness and avoidance—a longitudinal study of fathers
8 of children with intellectual disability. *Journal of Intellectual Disability Research*, 58(9),
9 810-821. doi: 10.1111/jir.12093
- 10 Brajenović-Milić, B., & Dorčić, T. M. (2016). Men's Knowledge About Maternal Serum
11 Screening for Down Syndrome and their Attitude Towards Amniocentesis. *Journal of*
12 *genetic counseling*. Advanced online publication. doi: 10.1007/s10897-016-9989-y
- 13 Bryant, L.D., Puri, S, C., Dix, L., & Ahmed, S. (2016). Tell it Right, Start it Right: An evaluation
14 of training for health professionals about Down syndrome. *British Journal of Midwifery*,
15 24(2), 110-117. doi: <http://dx.doi.org/10.12968/bjom.2016.24.2.110>
- 16 Buckley, S. (2008). Issues for families with children with Down syndrome. Retrieved from:
17 <https://www.down-syndrome.org/information/family/overview/>
- 18 Burgess, A. 2008. *The Cost and Benefits of Active Fatherhood: evidence and insights to inform*
19 *the development of policy and practice*. Retrieved from Fatherhood Institute website:
20 <http://www.fatherhoodinstitute.org/uploads/publications/247.pdf>.

- 1 Burnett, S. B., Gatrell, C. J., Cooper, C., & Sparrow, P. (2013). Fathers at work: A ghost in the
2 organizational machine. *Gender, Work & Organization*, 20(6), 632-646.
3 DOI: 10.1111/gwao.12000
- 4 Choi, H., & Van Riper, M. (2016). Maternal Perceptions to Open-Ended Questions about Life
5 with Down Syndrome in Korea. *The Qualitative Report* 21(2), 288-298. Retrieved from:
6 <http://nsuworks.nova.edu/tqr/vol21/iss2/7>
- 7 Cosson, B. and Graham, E. (2014). 'I felt like a third wheel': Fathers' stories of exclusion from
8 the 'parenting team'. *Journal of Family Studies* 18(2-3), 121-129.
9 <http://dx.doi.org/10.5172/jfs.2012.18.2-3.121>
- 10 Cunningham, C. (1996). Families of children with Down syndrome. *Down Syndrome Research*
11 *and Practice* 4(3), 87-95. doi:10.3104/perspectives.66
- 12 Cuskelly, M., Hauser-Cram, P., & Van Riper, M. 2008. Families of children with Down syndrome:
13 What we know and what we need to know. Retrieved from: [https://www.down-](https://www.down-syndrome.org/reviews/2079/reviews-2079.pdf)
14 [syndrome.org/reviews/2079/reviews-2079.pdf](https://www.down-syndrome.org/reviews/2079/reviews-2079.pdf).
- 15 Deave, T., & Johnson, D. (2008). The transition to parenthood: what does it mean for fathers?
16 *Journal of Advanced Nursing*, 63(6), 626-633. doi:10.1111/j.1365-2648.2008.04748.x
- 17 Douglas, T., Redley, B., & Ottmann, G. (2016). The first year: the support needs of parents
18 caring for a child with an intellectual disability. *Journal of Advanced Nursing*. Advanced
19 online publication. doi: 10.1111/jan.13056
- 20 Down's syndrome association. 2016. *About Down's Syndrome: FAQs*. Retrieved from:
21 <http://www.downs-syndrome.org.uk/about/general/>.

- 1 Fatherhood Institute. (2014). *Father-inclusiveness training can improve health visitors' practice*.
2 Retrieved from: [http://www.fatherhoodinstitute.org/2014/father-inclusiveness-training-for-](http://www.fatherhoodinstitute.org/2014/father-inclusiveness-training-for-health-visitors-can-improve-practice/)
3 [health-visitors-can-improve-practice/](http://www.fatherhoodinstitute.org/2014/father-inclusiveness-training-for-health-visitors-can-improve-practice/).
- 4 Fleming, S. A. (2013). *Fathers' experiences after their child has been diagnosed with Down*
5 *syndrome: A phenomenological study*. (Doctoral thesis). Retrieved from:
6 <http://gradworks.umi.com/35/87/3587086.html>.
- 7 Forrest Keenan, K., van Teijlingen, E., McKee, L., Miedzybrodzka, Z., & Simpson, S. A. (2009).
8 How young people find out about their family history of Huntington's disease. *Social*
9 *Science and Medicine*, 68(10), 1892-1900. doi:10.1016/j.socscimed.2009.02.049
- 10 Gabel, S., & Kotel, K. 2015. Motherhood in the Context of Normative Discourse: Birth Stories
11 of Mothers of Children with Down Syndrome. *Journal of Medical Humanities*.
12 Advanced online publication. doi: 10.1007/s10912-015-9367-z
- 13 Hall, S., Abramsky, L., & Marteau, T. M. (2003). Health professionals' reports of information
14 given to parents following the prenatal diagnosis of sex chromosome anomalies and
15 outcomes of pregnancies: a pilot study. *Prenatal diagnosis*, 23(7), 535-538. doi:
16 10.1002/pd.637
- 17 Hippman, C., Inglis, A., & Austin, J. (2012). What is a "balanced" description? Insight from
18 parents of individuals with Down syndrome. *Journal of genetic counseling* 21(1), pp. 35-
19 44. doi: 10.1007/s10897-011-9417-2
- 20 Hodapp, R. M. (2007). Families of persons with Down syndrome: New perspectives, findings,
21 and research and service needs. *Mental Retardation and Developmental Disabilities*
22 *Research Reviews*, 13(3), 279-287. doi:10.1002/mrdd.20160

- 1 Hornby, G. (1995). Fathers' views of the effects on their families of children with Down
2 syndrome. *Journal of Child and Family Studies*, 4(1), 103-117. doi:10.1007/BF02233957
- 3 Huang, Y. P., Tsai, S. W., & Kellett, U. (2012). Fathers of children with disabilities: Encounters
4 with health professionals in a Chinese context. *Journal of Clinical Nursing*, 21(1-2),
5 198-206. doi: 10.1111/j.1365-2702.2011.03826.x
- 6 Hunt, D., Leventer, R. J., Simons, C., Taft, R., Swoboda, K. J., et al. (2014). Whole exome
7 sequencing in family trios reveals de novo mutations in PURA as a cause of severe
8 neurodevelopmental delay and learning disability. *Journal of medical genetics*, 51(12),
9 806-813.
- 10 Jain, R., Thomasma, D., & Ragas, R. (2002). Down syndrome: still a social stigma. *American*
11 *Journal of Perinatology*, 19(2), 99-108. doi:info:doi/10.1055/s-2002-23553
- 12 Karmiloff-Smith, A., Al-Janabi, T., D'Souza, H., Groet, J., Massand, E., Mok, K., et al. (2016).
13 The importance of understanding individual differences in Down syndrome.
14 *F1000Research*. doi: 10.12688/f1000research.7506.1
- 15 Locock, L., & Alexander, J. (2006). 'Just a bystander'? Men's place in the process of fetal
16 screening and diagnosis. *Social Science & Medicine*, 62(6), 1349-1359. doi:
17 10.1016/j.socscimed.2005.08.011
- 18 Marshall, J., Tanner, J. P., Kozyr, Y. A., & Kirby, R. s. (2015). Services and supports for young
19 children with Down syndrome: parent and provider perspectives. *Child: Care, Health*
20 *and Development*, 41(3), 365-373. doi: 10.1111/cch.12162

- 1 Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their
2 children with fragile X syndrome, autism or Down syndrome. *Child: care, health and*
3 *development*, 35(2), 250-256. doi:10.1111/j.1365-2214.2008.00931.x
- 4 O'Brien, M. (2005). *Shared caring: bringing fathers into the frame*. Retrieved from
5 http://dera.ioe.ac.uk/5299/1/1.73363!shared_caring_wp18.pdf.
- 6 Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers'
7 and fathers' experiences of parenting a child with a disability. *Journal of child health*
8 *care*, 7(4), 231-247. doi: 10.1177/13674935030074001
- 9 Pillay, D., Girdler, S., Collins, M., & Leonard, H. (2012). "It's not what you were expecting, but
10 it's still a beautiful journey": the experience of mothers of children with Down syndrome.
11 *Disability and rehabilitation*, 34(18), 1501-1510. doi: 10.3109/09638288.2011.650313
- 12 Rice, L. J., Gray, K. M., Howlin, P., Taffe, J., Tonge, B. J., & Einfeld, S. L. (2015). The
13 developmental trajectory of disruptive behavior in Down syndrome, fragile X
14 syndrome, Prader–Willi syndrome and Williams syndrome. *American Journal of*
15 *Medical Genetics Part C: Seminars in Medical Genetics*, 169 (2), 182-187. doi:
16 10.1002/ajmg.c.31442
- 17 Rivard, M. T., & Mastel-Smith, B. (2016). The Lived Experience of Fathers Whose Children Are
18 Diagnosed with a Genetic Disorder. *Journal of Obstetric, Gynecologic, & Neonatal*
19 *Nursing*, 43(1), 38-49. doi:10.1111/1552-6909.12268

- 1 Robson, F. M. (2002). 'Yes!—A Chance to Tell My Side of the Story': A Case Study of a Male
2 Partner of a Woman Undergoing Termination of Pregnancy for Foetal Abnormality.
3 *Journal of health psychology* 7(2), pp. 183-193. doi: 10.1177/1359105302007002457
- 4 Salzmann-Erikson, M., & Eriksson, H. (2013). Fathers sharing about early parental support in
5 health-care - virtual discussions on an Internet forum. *Health and Social Care in the*
6 *Community*, 21(4), 381-390. doi:10.1111/hsc.12028
- 7 Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a Son or Daughter With Down
8 Syndrome: Perspectives From Mothers and Fathers. *American Journal of Medical*
9 *Genetics Part A*, 155A (10), 2335-2347. doi:10.1002/ajmg.a.34293
- 10 Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis Theory,*
11 *Method and Research*. London: Sage Publications.
- 12 Smith, J. A., & Eatough, V. (2012). Interpretive Phenomenological Analysis. In G. M.
13 Breakwell, J. A. Smith, & V. Eatough (Eds.), *Research Methods in Psychology* (Vol. 4,
14 pp. 439-460). Los Angeles: Sage.
- 15 Takataya, K., Yamazaki, Y., & Mizuno, E. (2016). Perceptions and Feelings of Fathers of
16 Children With Down Syndrome. *Archives of Psychiatric Nursing*. Advanced online
17 publication. doi: <http://dx.doi.org/10.1016/j.apnu.2016.04.006>
- 18 Towers, C. (2009). *Recognising Fathers: A National Survey of Fathers Who Have Children with*
19 *Learning Disabilities*. Retrieved from:
20 http://www.learningdisabilities.org.uk/content/assets/pdf/publications/recognising_father
21 [s_briefing.pdf?view=Standard](http://www.learningdisabilities.org.uk/content/assets/pdf/publications/recognising_father_s_briefing.pdf?view=Standard)

- 1 Turpin, G., Barley, B., & Scaife, J. (1997). Standards for research projects and theses involving
2 qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology*
3 *Forum (108)*, 3-7.
- 4 Wesley, K., Zhao, M., Carroll, Y., & Porter, J. (2016). Caregiver Perspectives of Stigma
5 Associated With Sickle Cell Disease in Adolescents. *Journal of Pediatric Nursing, 31*(1),
6 55-63. <http://dx.doi.org/10.1016/j.pedn.2015.09.011>
- 7 Yogman, M., Garfield, C. F., & Committee on Psychosocial Aspects of Child and Family Health.
8 (2016). Fathers' roles in the care and development of their children: the role of
9 pediatricians. *Pediatrics, 138*(1), e20161128.
- 10

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Tables

Superordinate theme	Basic themes
Evaluations of health care experiences	Feelings of exclusion A sense of inequality
Expectations of care	Continuity of care Clear and direct communication
Health professionals' attitudes towards Down syndrome	How information is presented Reactions of health professionals to their child

Table 1. Superordinate themes and basic themes.

Appendices

Appendix 1: Interview guide

1. Can you tell me a bit about you and your family?
2. Can you tell me about your experience of receiving a diagnosis of Down syndrome in your child?
3. How do you feel you were treated by healthcare professionals when you received that diagnosis?
4. Is there anything that sticks out in your mind that either a doctor, nurse or other care worker did that you found particularly helpful at the time of getting this diagnosis?
5. Is there anything that stands out as particularly stressful?
6. What advice would you like to give to health professional about talking to fathers about diagnosis?
7. Thinking about your experiences now, what can you tell me about being a father to a child with Down syndrome?
8. Do you feel you are treated differently by friends and family or wider society because your child has this diagnosis?
9. Do you feel you have the support you need?
10. Recently what have been your experiences of health professionals regarding your child?
11. Is there a particular occasion where you felt you were treated poorly by health professionals?

12. A particular occasion when you felt you were treated very well?
13. How do you think your experiences with health professionals compares to that of your partner/wife/ your child's mother?
14. What advice would you give to other dads who have a child with Down syndrome?
15. What advice would you give to health professional or care workers who come into contact with dads who care for a child with Down syndrome?