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Citation: Marsh, L., Brown, M. & McCann, E. (2020). The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: Findings from a qualitative study. *Journal of Clinical Nursing*, 29(17-18), pp. 3373-3381. doi: 10.1111/jocn.15368

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The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: Findings from a qualitative study

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Abstract

Aims and objectives: To report the views and experiences of fathers following their child's diagnosis of an intellectual and developmental disability (IDD).

Background: There is a growing interest in understanding the experiences of fathers of children with IDD given the transformation of the structural change of fathers' roles within the family and wider society.

Design: A qualitative design was used to elicit the view and experiences of fathers.

Methods: A total of ten Irish fathers participated in face-to-face interviews. The data were thematically analysed. The COREQ guidelines for reporting qualitative studies were used in the development of this paper.

Results: The key themes that emerged were (a) the confirmation of the child's diagnosis (b) the impact of the diagnosis and (c) father's motivation to participate in disability research.

Conclusions: This study informs and develops a further understanding of the international evidence base of fathers receiving a confirmation of a child's diagnosis of an intellectual and developmental disability, the impact of the diagnosis on fathers and their motivation to share their stories to add to the disability research. Health and social care practitioners have important contributions to make in meeting the needs of fathers. There are specific areas to consider in terms of practice, education and research that require further attention and development to ensure fathers' distinct needs regarding their child's diagnosis of IDD are known and responded to effectively.

Relevance to clinical practice: This study highlights that when the child's disability is confirmed, fathers experience a diverse range of mixed emotions. Health and social care practitioners including nurses need to be aware of the impact of the diagnosis upon fathers. There is scope to develop the knowledge, skills and confidence of health and social care practitioners regarding the experiences of fathers and how

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they can further support fathers and their families during the critical time of a disability disclosure.

KEYWORDS

children, diagnosis, education, families, fathers, intellectual and developmental disabilities

1 | INTRODUCTION

Major transformations in the roles of mothers and fathers within families have evolved and different types of families now form part of the changing status of the social construct of the family, for example, families may comprise of heterosexual couples, single parents, couples co-parenting and same-sex couples (Carroll, 2018; Gates, 2015; Goldscheider, Bernhardt, & Lappegård, 2015; Golombok, 2015). In addition, the change from traditional family structures has been influenced by socio-political and economic factors that have seen women return to the workplace thereby necessitating the need for shared parenting (Christopher, Umemura, Mann, Jacobvitz, & Hazen, 2015; Doss & Rhoades, 2017). While it is recognised that traditional approaches to child-rearing and parenting have historically focused on the role and experiences of mothers, fathers are now playing an increasingly central and important role in child-rearing. For example, evidence highlights the positive effects that the involvement of fathers has on the child's social and psychological development and academic achievement (Cohen, Zeedyk, Tipton, Rodas, & Blacher, 2016; Jeynes, 2016).

Becoming a father is often life changing and a significant personal milestone (Gage & Kirk, 2016; Yarwood, 2011) in which a man's status changes from that of son, brother, uncle, partner or husband to that of father (Chin, Hall, & Daiches, 2011). The transition to fatherhood brings a mix of excitement and apprehension and for many is rewarding (Huang, St, Tsai, & Chen, 2011). Despite policy developments over the past 50 years, a meta-ethnographic analysis of 62 research studies found that fathers are not yet fully accepted and supported to fulfil parental roles (Wells, 2016). However, societal changes and expectations of men have witnessed fathers taking on considerable responsibility for the rearing of their child. This increased involvement is recognised more globally in the wider family context (Allport et al., 2018; Broomhill & Sharp, 2012; Shapiro, Gottman, & Fink, 2019). Indeed, this increased involvement extends to fathers of children with IDD (Davys, Mitchell, & Martin, 2017; MacDonald & Hastings, 2010; Takataya, Yamazaki, & Mizuno, 2016).

Research evidence highlights some of the negative aspects of parenting a child with IDD, such as increased levels of stress (Findler, Jacoby, & Gabis, 2016; Giallo et al., 2015; McConnell & Savage, 2015), marital disharmony (Namkung, Song, Greenberg, Mailick, & Floyd, 2015; Robinson & Neece, 2015) and financial pressures (İnanç, Topal, & Topal, 2018; Isa et al., 2016; Trentacosta, Irwin, Crespo, & Beeghly, 2018). However, there is also a growing body of evidence regarding acceptance, resilience and personal growth, offering an insightful and balanced view of family caregiving experiences (Caples et al., 2018; Mohan & Kulkarni, 2018). To date however, much of the

What does this paper contribute to the wider global clinical community?

- This study highlights the importance of a range of health and social care practitioners need to recognise the emotional impact of a diagnosis of IDD and how the process of assessment and disclosure can influence how fathers adapt over time.
- Fathers can be reticence to talk to others about their experiences and as a result may find it difficult to access supports such as counselling and disability support groups.
- Fathers need to be afforded the opportunity to discuss their experiences of receiving a confirmation that their child has an IDD and the impact of such a diagnosis. This will allow an opportunity for health and social care practitioners to further understand and improve support across the care trajectory when disclosing a child's IDD.

existing research evidence is presented through the lens of mothers (Findler et al., 2016) with less attention from perspectives of fathers (Davys et al., 2017; Marsh, Leahy-Warren, & Savage, 2018; Marshak, Lasinsky, & Williams, 2019), despite the growing recognition of fathers increased involvement of providing care for their children with IDD over the previous three decades in particular (Hornby, 1992; Towers & Swift, 2006). Given that an IDD diagnosis requires fathers to reposition themselves as a parent of a child with a disability (Davys et al., 2017), the full impact of their experiences remains unclear. Therefore, this is an area that requires further exploration.

1.1 | Aim

To report on the views and experiences of Irish fathers following their child's diagnosis of an intellectual and developmental disability (IDD).

2 | METHODS

This paper presents a secondary analysis of the original master qualitative data set to identify new insights into the views and

experiences of ten fathers of young children with IDD in relation to the confirmation of a disability diagnosis (Long-Sutehall, Sque, & Addington-Hall, 2011; Ruggiano & Perry, 2019). This qualitative descriptive study was conducted between March and May 2013 following institutional review board approval by the participating organisations. All research ethics and governance procedures were adhered to throughout the study. Previous findings were reported elsewhere (Marsh et al., 2018). The paper was developed using the COREQ guidelines for reporting qualitative studies (see File S1).

2.1 | Study questions

1. What are the views and experiences of fathers' regarding the diagnosis of their child's IDD?
2. What are the implications for nursing practice, education and future research?

2.2 | Data collection and recruitment

Convenience sampling was considered as an appropriate method to recruit participant fathers (Haber, 2013). Twenty-five postal invitations were sent by a gatekeeper employed in the early intervention services, to fathers of children availing of these services in the Republic of Ireland. The gatekeeper verified that fathers met the inclusion criteria as they were living with their child with IDD, their child was younger than six years of age and that fathers were able to speak and understand English. If fathers were willing to participate in the research, within this invitation, they were asked to directly contact the first researcher who was undertaking this study as part of her Doctoral degree programme. Ten fathers consented to participate. None of the participants or their children were known to the researcher prior to the interviews. Fifteen potential participants did not contact the researcher and their specific reasons for non-participation remain unknown.

The primary author, a female, conducted semi-structured individual face-to-face interviews with participant fathers in a place of their choosing. Interviews were conducted in fathers' own homes ($n = 3$), the researcher's office ($n = 4$), an office in the early intervention service ($n = 2$) and a participant's workplace ($n = 1$). All interviews were digitally recorded and lasted for between 49 and 76 min, with the average lasting for one hour. Following transcription, pseudonyms were assigned to ensure anonymity and confidentiality.

2.3 | Data analysis

Thematic analysis was used to identify the key themes across and within transcripts (Clarke & Braun, 2017; Ruggiano & Perry, 2019) in which fathers shared their stories of their experiences of the disclosure of their child's IDD. All interviews were transcribed

verbatim by a professional transcribing company. They were then analysed individually, and then collectively, using an analytical framework developed by the three members of the research team to address the new research questions. QSR NVivo 12 software was used to manage all of the data and support the systematic approach to analysis (QSR International, 2018). During the interviews, field notes were produced to aid with the analysis. Immersion in the data allowed for the generation of key themes achieved through repeated listening to the audio-recordings and re-reading the transcripts (Long-Sutehall et al., 2011). Emergent themes were identified independently by all researchers and following a discussion, three themes were agreed.

2.4 | Validity, reliability and rigour

A transparent process of decision-making was established by the research team to ensure confirmability the findings. To enable this, a detailed analysis of participant experiences was undertaken, thereby establishing the potential transferability of the findings (Graneheim, Lindgren, & Lundman, 2017). From a credibility perspective, robust data collection methods, data analysis and synthesis were employed throughout. The application of the principles of qualitative rigour was fully applied throughout the data analysis process to ensure the trustworthiness of the findings (Noble & Smith, 2015).

2.5 | Ethics statement

Ethical approval was granted by the participating organisations with all research ethics and governance procedures adhered to throughout. Consent was gained from all participant fathers and pseudonyms are used in reporting the findings.

3 | RESULTS

The demographic characteristics of the participants and their children with IDD included eight fathers who were married and two who were co-habiting, ranging from 31 to 48 years of age. Of the 10 children with IDD, 6 were boys and 4 were girls, between 13 months and 5 years of age. One boy had a severe physical and intellectual impairment, and one boy was going through the assessment process for autism. Six children had Down syndrome and one boy was diagnosed with a Global Developmental Delay, while one girl remained without a specific diagnosis. A total of eight children with IDD had one other sibling, one was the youngest of three siblings and one was an only child (Table 1).

Following analysis of the qualitative data, three themes emerged: (a) confirmation of their child's diagnosis and (b) the impact of the diagnosis and (c) fathers' motivation to participate in disability research.

3.1 | Theme one. Confirmation of their child's diagnosis

The narratives presented by fathers clearly articulated the emotions of learning their child's IDD and resonated across all the participants' experiences. Recalling the experience of receiving the diagnosis remained highly emotive and sensitive. One father, Andy, explained how he was "*reliving the experience as if it were yesterday*" and this sharing of his personal story about Molly's diagnosis of Down syndrome was "*not easy*." Andy then went on to describe how he was "*heartbroken*" when the doctor confirmed within a half hour of his daughter's birth that she had Down syndrome. For Charlie, the confirmation for him was when the doctor went on to describe the visible and typical features of Down syndrome such as the low ears and the eyes within minutes of Lucy's birth.

Eoghán was present in the delivery room at the birth of his first child. The midwife confirmed that Leo had Down syndrome almost immediately, which he appreciated as he could see the visible features of Down syndrome in Leo's eyes:

I sort of knew it straight away you know when I saw the eyes... the midwife actually said it straight away... which was good...

Charlie and Eoghán described how the diagnosis of Down syndrome described by the doctors was based on the clinical features of the syndrome in a way that they understood. However, for Andy the power of the perceived negative language used by one doctor who provided a second opinion to confirm the diagnosis of Down syndrome was unsupportive:

I will never forget it he kept using the term limp and I hated it at the time, I just wanted to kill him...she is very limp, and he kept repeating it...

For five of the six fathers of children with Down syndrome, a conclusive diagnosis of Down syndrome was made within a few hours of birth, while for one father the diagnosis was made at a routine 13-week scan. Jack recounted how he was not present at the time his wife was told that their baby had Down syndrome which he perceived to be a "*harsh*" way of sharing such a diagnosis:

...they told her at the scan when she was on her own... I thought it was a bit harsh but then when was she going to be told ... we got an awful shock...

For other fathers, because of the less visible features of IDD, concerns were not raised until between two and four years after their child's birth due to delays in the child reaching their developmental milestones. Father's subsequent concerns about their child were then shared with other healthcare professionals including GP's. Some of these fathers recalled how they felt the way in

TABLE 1 Demographics of fathers and their child with IDD

Participant pseudonym & age	Relationship, pseudonym and age of child	Child's diagnosis
Andy age 37	Daughter Molly 2½ years	Down syndrome
Brian age 31	Daughter Abbie 2 years	Undetermined
Charlie age 39	Daughter Lucy 3 years	Down syndrome
David age 44	Son Matthew 13 months	Down syndrome
Eoghán age 38	Son Leo 2¾ years	Down syndrome
Fionn age 41	Son Rory 2 years	Down syndrome
Greg age 43	Son Dylan 4 years	Unknown-Autism query
Harry age 48	Son Vincent 5 years	Unknown - associated severe physical disability
Ian age 35	Son Peter 3 years	Global developmental delay
Jack age 41	Daughter Jess 2½ years	Down syndrome

which the diagnosis was disclosed to healthcare professionals was particularly unhelpful. Brian recalled the inappropriate terminology and language that was used when he was not present at the appointment.

...it was just completely wrong the way it was put across, it was just blunt, and it was just thrown at [partner], she was there on her own...

Irrespective of how fathers were told of their child's disability, most fathers recalled sharing the diagnosis with mothers and sisters initially. Fathers described being too emotional to share the news personally. Andy said:

I just broke down and I put my arms around my Mom and I just said it, that was it. I just said I don't want to tell anybody. I said you can tell people...

Reticence to disclose their child's diagnosis to wider family and friends was a difficult experience for some participants, a situation further compounded by a later and lengthier diagnosis. Some fathers, like Brian and Greg, did not want to be constantly asked about their child once the news was made public. This was related to needing more time to come to terms with their child's diagnosis and to adapt to being the father of a child with IDD. Greg, whose son was four when autism was suspected, was just "*not ready*" to tell people. Yet, there was a sense of acceptance and adapting to his view of fatherhood as time went by. He said:

I don't talk about it with anyone else ... now I am ready to tell people, 6 months ago I wasn't...

3.2 | Theme two. The impact of the diagnosis

The impact of the diagnosis resulted in fathers having to change their initial personal views and expectations of fatherhood through a lens of disability. The experiences of fathers in the current study were generally reflective of an excitement and expectation of the initial construct of fatherhood. Fathers used the phrase “*hands on dads*” to capture these experiences of being involved with their children and how fatherhood came naturally as captured here in Fionn's narrative:

...you go into a hospital you are just given a child and boom you are a father or boom you are a mother and when you have a typical developing child everything is just easy; you literally fall onto the roller coaster and go with it...

Fatherhood for most came with personal and societal expectations and irrespective of the child's disability. Following the diagnosis, these fathers remained “hands on dads” and provided constant and continued care to their child with IDD and the wider family. Notably, the impact of a diagnosis was not always perceived as a negative experience and is a noteworthy finding given the research to date has focused primarily on the negative impact of caring for a child with IID. Fathers articulated how they became more aware of people with disabilities because of their personal experiences with their own disabled child. In addition, they now made considerable effort to communicate with people with disabilities and acknowledged a personal growth in themselves as they became more empathetic and increasingly appreciative of others in similar situations. Previously, they may not have even noticed people with disabilities and are shaped by their entry into the world of disability. As Brian said:

...now I know the score I would actually talk to them and not talk to the person with them, but it would make you more aware of it anyway especially then when you are dealing with your own because you can appreciate more what people are dealing with...

A heightened awareness has led to changes in how fathers had perhaps previously “judged or misjudged” others with disabilities. They were now more aware of their position as fathers in the world of disabilities, a positive change acknowledged through their experiences of fatherhood.

3.3 | Theme three. Motivation to participate in disability research

While fathers' expectations of fatherhood had changed, they articulated clearly why they were motivated to be involved in the current study. David wanted to be a part of the research process as

he perceived fathers' voices were not often the focus of disability research. David said:

I believe research needs to happen and what interested me in your letter was the fact there was a focus on fathers because I know a lot of the focus is usually on mothers...

For Greg, it was an opportunity as a father to talk to someone who did not know him, his son or his family. During the interview, Greg was often upset but the desire to speak about Dylan and his subsequent journey to date appealed to him and further motivated him to be an active research participant:

I have to vent I am going have to get this off my chest I said it is building up and I have been through so much. I said I don't know the girl it will be confidential I said I just want to get it off my chest I said it is killing me...

Charlie's drive to participate in the study stemmed from his curiosity as to why after three years anyone would want to talk to him about his experiences as a father of a child with IDD:

I think Dads are put in the background as such ...there was nobody ever said anything to me about do you want to talk to somebody or whatever... I was a bit weary because nobody has ever in 3 years wanted to talk to me and I thought why now...

4 | DISCUSSION

This study documented the experiences of fathers' experience of receiving a diagnosis of their child's IDD. The findings from the current study reflect the existing body of international research that highlights how from the time the diagnosis of a child's disability is confirmed fathers' emotional responses are varied as this disclosure is life changing (Carpenter & Towers, 2008; Foundation for People with Learning Disabilities, 2005; Hannon & Hannon, 2017). While fathers were not specifically asked about their child's diagnosis in the original interviews, all of them began their story at that point, which for them was the central tenet of becoming a father of a child with IDD.

Fathers spoke in-depth about the initial confirmation of the child's diagnosis of IDD, the words that were used and who was involved in the disclosure, a finding resonating across many studies (Foundation for People with Learning Disabilities, 2005; Huang et al., 2011). In Huang et al.'s (2011) phenomenological study with 16 Taiwanese fathers of children with a developmental disability, for some, being informed by healthcare professionals of their child's diagnosis, was direct and an approach that was favoured by these fathers. This directness was also favoured by many Japanese fathers who received the diagnosis of Down syndrome following their child's

birth (Takataya et al., 2016). For others, the provision of a diagnosis in later months or years by healthcare professionals was found to be at times, almost insensitive and blunt (Huang et al., 2011), a finding resonating across this and other studies in which parents were dissatisfied with healthcare professionals' disclosure of a child's disability (Close, Sadler, & Grey, 2016; Coons, Watson, Schinke, & Yantzi, 2016; Crane, Chester, Goddard, Henry, & Hill, 2016; Nelson Goff et al., 2013).

Positive terminology and appropriate language is therefore an important practice consideration at the time of a disability disclosure and warrants further research attention (Cadwgan & Goodwin, 2018). Thus, it is critical that all health and social care practitioners are aware of how they can positively or negatively influence parents' experiences when disclosing a child's IDD. Prior research has demonstrated that a disclosure of a child's disability can be life changing and requires health and social care practitioners to share information that is relevant, timely and sensitive (Foundation for People with Learning Disabilities, 2005). Therefore, education of best practice guidelines such as *Informing Families of a Child's Disability* (National Federation of Voluntary Bodies, 2007) or the National Institute for Health and Care Excellence (NICE, 2011) guidance in relation to recognition, referral and diagnosis of autism spectrum disorder in children is key. This will help to better ensure that parents, including fathers, are appropriately supported and signposted at this emotional and critical juncture in their lives (Byrne, Noritz, & Maitre, 2017).

Within the theme of *the impact of the diagnosis*, there was an assumption that fatherhood would come naturally and the anticipation of a "healthy" child in keeping with societal expectations and cultural norms (Petts, Shafer, & Essig, 2018). Similar to prior research, fatherhood, for most, was being present at the birth of their "perfectly healthy" child (Riley & Rubarth, 2015). In the current study, fathers clearly articulated the excitement of being present at their child's birth but once the diagnosis was confirmed, fathers were often unprepared and transitioned from being a father, to being a father of a child with IDD. This change in status resulted in taking on caring giving roles across the child's lifespan, roles that were neither anticipated nor expected, a finding reflected by American fathers of children with disabilities (Bonsall, 2018). Consequently, fatherhood was repositioned through a new lens of disability (Bonsall, 2018). Thus, evolving societal beliefs and attitudes regarding fatherhood requires a fresh understanding of the different forms fatherhood takes and that no single view of fatherhood exists. Rather, transition within fatherhood evolves over time and time also allows for personal growth and a positive and personal perspective towards acceptance and being a father of a child with IDD.

While it is recognised that fathers' participation in research remains a considerable challenge for researchers, these findings highlight the importance of not making assumptions that all fathers are uninterested in sharing their stories or in contributing to the research agenda. Ten fathers participated in this research and this current study provides some tangible reasons for fathers' motivations to be involved which have been largely underreported. Rather

many of the reasons purporting why fathers' voices are absent are largely speculative. However, an important and recurring theme from this study was that while some fathers perceived themselves to be in the background, once invited they were extremely motivated to talk about their child. When presented with that opportunity, motivation stemmed from a multitude of factors including a realisation that most of the research focuses on mothers, a belief that research needs to happen with fathers, curiosity about why they were invited as well as a significant desire to talk to someone unknown to them. The term the "*forgotten man*" was coined by Paynter, Davies, and Beamish (2018) in which fathers reported how they were ignored by healthcare professionals and removed from decision-making processes about their children, a finding resonating across our study and the international research (Takataya et al., 2016). While policy attention with fathers is now growing, a key learning point is that fathers have to be asked and included on the decisions that affect themselves, their child and family. Thus, fathers must be provided with these opportunities to share their experiences of receiving a child's disability diagnosis as it is from these shared narratives an increased understanding by health and social care practitioners will develop allowing a more supportive and interdependent relationship across the caregiving trajectory to be fostered and nurtured.

4.1 | Limitations

This current study expands the evidence base relating to fathers' responses to their child's diagnosis of intellectual and developmental disability (IDD), their expectations of fatherhood and their motivation for participating in research. The authors recognise that the study has several limitations including the restriction to one country and limited to one service provider; therefore, the findings may not be reflective of fathers experiences elsewhere. Additionally, as all fathers in this study had young children a future comparison study of experiences between such fathers and those with older adult children with IDD would be helpful. However, an important strength of this qualitative study is the inclusion of the unique subjective experiences of fathers of children with IDD.

5 | CONCLUSION

It is evident from our findings and the wider international research that fathers of young children with IDD require nurses and other healthcare professionals to be knowledgeable and responsive to their needs particularly at the time of a disclosure of IDD and are therefore required to embrace a culture of respect, inclusivity and collaborative working with all members of the family, including fathers. Changes in family structures and societal beliefs and values have witnessed a reframing of the concept of fatherhood. While becoming a father is a major life transition, fathers are now more involved in their child's care, an involvement that transcends to fathers

of children with IDD. There is scope for health and social care practitioners including nurses to work with fathers as they are well placed to make an important contribution to meeting the needs of fathers. Specific areas of practice, disability education and research will contribute to a shared understanding of fathers distinct needs which can be responded to effectively with these healthcare professionals across the life course of caring.

6 | RELEVANCE TO CLINICAL PRACTICE

It is vital that future research priorities should include studies that increase our knowledge and understanding of the needs of fathers. There is now an ever growing opportunity to add to the body of research evidence regarding fathers by understanding, for example, how parents should be informed about a child's disability diagnosis. While fathers are often reticent to talk to others, researchers could also undertake further studies that focus on both mothers and fathers thereby recognising and responding to the distinct individual needs of parents, and as a couple.

It is apparent from the wider literature and the findings from the current study, that there is a need for health and social care practitioners to develop their knowledge, skills and confidence in supporting fathers and the family of children with IDD across the caregiving trajectory. This is required to recognise the role of fathers in all aspects of their child's life. Therefore, collaborative alliances with fathers to meet their individual needs and those of their family can be created and fostered from the moment a child's disability is diagnosed. From the perspective of undergraduate and postgraduate nurse education, the specific needs and concerns of fathers and the families need to be embedded in the curriculum, thereby ensuring their aspirations and hopes are included and responded to by future health and social care practitioners at a clinical, educational, research and policy level.

ACKNOWLEDGEMENTS

The authors would like to thank the fathers who kindly participated in the study. In addition, the authors would like to thank Professor Eileen Savage and Dr Patricia Leahy-Warren for their support.

CONFLICT OF INTEREST

The authors declared no potential conflict of interest with respect to the research, authorship and/or publication of this article.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Marsh L, Brown M, McCann E. The views and experiences of fathers regarding their young child's intellectual and developmental disability diagnosis: Findings from a qualitative study. *J Clin Nurs*. 2020;29:3373–3381. <https://doi.org/10.1111/jocn.15368>