



The experience of being a father of a son or daughter with an intellectual disability: Older fathers' perspectives

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Abstract

Background: As life expectancy for people with an intellectual disability increases, there is a growing cohort of older father carers. This study aimed to gain a more in-depth understanding of older father carers' experiences of parenting.

Methods: Semi-structured interviews were conducted with 7 older fathers ($M = 63.9$ years) and analysed using constructivist grounded theory.

Results: Three conceptual categories were identified. "Wearing different hats: how fathers' sense of identity had altered over the years. "Family comes first": importance placed on the family unit. "Getting on in years": the challenges faced by ageing fathers parenting their son/daughter.

Conclusions: Fathers re-evaluated their priorities and found a new identity in their parenting role, although they continued to see themselves as secondary carers. Fathers worried about the future as their health declined but drew strength from the benefits they had derived and the challenges that they had overcome to do their best for their son/daughter and their family.

KEYWORDS

ageing, fathers, intellectual disability, older, parent carer

1 | INTRODUCTION

People with an intellectual disability are now living longer than ever before (O'Leary, Cooper, & Hughes-McCormack, 2018) and this increase in lifespan has resulted in many parents caring for their son/daughter with an intellectual disability into old age, sometimes even up until their own death (Cairns, Tolson, Brown, & Darbyshire, 2013; Emerson & Hatton, 2008). In the UK, there are approximately 29,000 people with an intellectual disability who live with a family member over the age of 70. The World Health Organisation (2000) identified ageing family carers of people with an intellectual disability as a vulnerable group since they are affected by the ageing process while also fulfilling a caregiving role. Ageing carers of a son/daughter with an intellectual disability are more likely to experience social isolation

and financial strain than other types of carers (Argyle, 2001; Black & McKendrick, 2010; McConkey, 2005). These challenges, in combination with a growing cohort of parents caring into old age, have led to an increased interest in the experiences of older parents of a son/daughter with an intellectual disability.

While ageing parents continue to care for their offspring in the face of challenges related to old age, there is evidence that many parents benefit from help, assistance and companionship provided by their son/daughter with an intellectual disability (Gant, 2010). A recent systematic review of literature on the experiences of carers aged 75 years and over reported that some studies suggested caring was potentially less challenging for older carers as they adapt to their role (Greenwood & Smith, 2016). However, given the limited number of studies identified in the review which directly compare

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the experiences of older and younger carers, it is difficult to draw firm conclusions from this review about the impact of ageing on caring experience.

Previous research into the experiences and well-being of older parents (age 60 years and over) of a son/daughter with an intellectual disability has largely focussed on mothers, as they have been traditionally viewed as the main caregiver within the family unit (Dillenburg & McKerr, 2009). While carers are generally more likely to be female than male, there is evidence that men participate more in caregiving as they age. A study of older carers reported that between 75 and 84 years of age the numbers of male and female carers are similar, while nearly three in five (59%) carers are male after 85 years of age (Carers & Age, 2015). This change in role for older fathers may occur when their partner who had previously provided the bulk of caregiving tasks is unable to continue caring either due to ill health or death. There is a growing body of evidence suggesting that traditional gender roles within the household are changing and that while fathers may often remain the secondary carer, their participation in childcare has increased over time (Altintas, 2016; Essex & Hong, 2005; Sullivan & Gershuny, 2001). The role that fathers play in their son/daughter's development has also now been acknowledged, both within research and at the governmental level (Ferreira et al., 2016; Flouri & Buchanan, 2002; Flouri & Buchanan, 2004; Meuwissen & Carlson, 2018). This in turn has led to a growing awareness of the need to include fathers in research.

Older fathers of a son/daughter with an intellectual disability may experience particular challenges in their caring role as they are from a generation where men were not traditionally expected to participate in childcare tasks. It has been suggested that more stigma is associated with men who transgress traditional gender norms than women (Coleman & Franiuk, 2011; Gaunt, 2013; Goldscheider, Berhardt, & Lappegard, 2015). These societal attitudes may have affected the ability of fathers to serve as main caregivers of their son/daughter with an intellectual disability prior to retirement. For example, fathers who seek work leave to care for a relative are less likely to be granted leave than a mother who seeks time off for the same reason (Coleman & Franiuk, 2011). A number of other gender specific issues differentiate the experiences of male and female carers. Older male carers have been found to be less likely to ask for necessary help and support than older female carers, and report feeling excluded from support groups or services which are predominantly attended or accessed by women (Milligan & Morbey, 2013). This lack of flexibility within gender roles is especially difficult for ageing fathers who take on the primary caregiving role when the death or declining health of the mother makes this alteration necessary (Essex & Hong, 2005).

Existing studies which include fathers within their sample generally have a very small proportion (Cairns et al., 2013; Foster, Kozachek, Stern, & Elsea, 2010; Rowbotham, Carroll, & Cuskelly, 2011) or have removed fathers from their analysis due to low participant uptake (Thomson, Glasson, Roberts, & Bittles, 2017). Small numbers of older fathers (age 60 years and over) were included

in only two of these studies (Cairns et al., 2013; Rowbotham et al., 2011). A meta-synthesis of studies on the experience of carers of people with an intellectual disability found that the majority of studies did not separately report the experiences of fathers and mothers (Griffith & Hastings, 2014). Yet there is some evidence that mothers and fathers have different experiences of caregiving, in terms of perceived benefits and challenges (Hastings et al., 2005; Olsson & Hwang, 2006; Saloviita, Itäläinen, & Leinonen, 2003; Taunt & Hastings, 2002). It is unclear how generalisable these findings are to older fathers as only Saloviita et al. (2003) included this group in their study, with an age range of 23–84 years and a mean age of 45 in the sample. A survey of 609 male carers, which included 119 fathers, was conducted by the Carers Trust and the Men's Health Forum in 2014 (The Carers Trust, 2014). This survey was open to carers of all ages, with just over one-third of participants aged 65 years and over. A number of issues were identified in this survey which participants considered to be unique or different for male carers. These included a lack of recognition of their role by society, professionals and services. The balance between work and care was further identified as a challenge that was different for male carers. These results suggest that the experience and impact of caring are not the same for mothers and fathers. If this is the case, research which does not separately report fathers' experiences of caring provides an incomplete picture.

Where fathers' experiences have been separately considered, there are also significant gaps. A recent review of the literature related to fathers of children with an intellectual disability included only fathers of a son/daughter from birth up to age 22 (Davys, Mitchell, & Martin, 2017). The themes identified in this review included response to diagnosis, varied response to intellectual disability, concern for the future, work, roles and relationships, impact of fathers upon child development, fathers and service providers, and fathers needs and coping strategies. While these studies provide insights into the experiences of fathers of children and young adults, they do not capture all fathers, namely fathers who are ageing and have older children with an intellectual disability.

The current study aims to provide a more in-depth understanding of older fathers' experiences of parenting a son or daughter with an intellectual disability. This type of study may help services to provide more targeted support to older fathers.

2 | METHODS

2.1 | Participants

The inclusion criteria for the study were as follows: having a son/daughter with an intellectual disability and being at least 60 years of age. Seven Caucasian fathers (father mean age: 63.9 years; son/daughter with an intellectual disability mean age: 31.0 years) were recruited through charities and organizations providing services or supports to people with an intellectual disability and/or their families in Scotland. Further demographic information is provided in Table 1.

TABLE 1 Participant demographic information

Father pseudonym	Age of father	Father employment status	Number of children in family	Age of offspring	Gender of offspring	Severity of offspring's ID	Father & child live in same house
Mr Walker	64	Retired	1	28	Female	Moderate	Yes
Mr McKay	68	Retired	2	37	Female	Profound	Yes
Mr Thomson	64	Full-time employment	3	28	Female	Moderate	Yes
Mr Hughes	64	Retired	3	29	Male	Severe	No
Mr Murphy	60	Full-time employment	3	34	Male	Mild	Yes
Mr Kendall	61	Retired	1	28	Male	Mild	Yes
Mr Lampton	66	Semi-retired	3	33	Female	Severe	Yes

Abbreviation: ID, Intellectual disabilities.

Identifying fathers for this study was challenging as the majority of charities and organizations supporting recruitment were in contact with the person's mother and often did not have details for fathers. When fathers were identified and approached, very few wished to participate in the study. The charities who assisted with recruitment did not disclose how many fathers were approached. Despite being sent detailed information on the purpose of the study, two interested fathers provided contact information for their wives, rather than themselves, as they assumed that the researchers would be most interested in talking to their son/daughter's mother. Once the researchers confirmed that it was actually the father that was of interest for the study, both fathers were keen to participate.

2.2 | Qualitative approach

Data collection and analysis procedures were informed by Charmaz's (2000) account of grounded theory. The aim was to gain a rich and in-depth understanding of the experience of fathers parenting their son or daughter with intellectual disabilities, taking into account the multiple perspectives and circumstances of fathers. As the existence of multiple socially constructed realities is acknowledged in grounded theory, this approach is well suited to the study.

2.3 | Data collection and analysis

The first stage of the study involved semi-structured interviews using broad and open-ended questions to allow themes to develop. A historical approach was taken to questions, with the interviewer asking questions about their son or daughter's early years up to the present day. This style of interview was chosen to put participants at ease and allow them to tell the story in their own words. An initial interview guide was developed which included questions such as "Tell me about your son/daughter and your family life", "What was it like when your son/daughter started

school?" Rather than following a step by step process, grounded theory involves moving back and forth between various stages of data collection and analysis. Therefore, after each interview, the data were analysed and coded, with subsequent interview schedules being informed by the themes from the analysis of the previous interview(s). One interview was conducted per participant, with interviews lasting between 60 and 112 minutes. Interviews were audio-recorded, with participants' consent, and transcribed verbatim by the researcher. A written summary of each interview was produced and sent to the participant for review. Participants were invited to make any corrections where their meaning had been misinterpreted and to add any further information. All fathers responded and were largely happy with the account of the interview, with only one father asking that a quote from the bible be included to summarize his experiences.

In keeping with grounded theory, an inductive approach to analysis was used to develop categories and themes from the data, rather than trying to fit data into prescribed categories. Two stages of coding were used in Charmaz's (2000) grounded theory; initial coding which involved analysing the data to search for the participant's meaning; and focussed coding when the most useful or pertinent codes were selected to represent the themes emerging from the data. The researcher moved between stages of coding and between transcripts to compare the codes and themes that had been identified. In keeping with Charmaz's account of grounded theory analysis, a core category was developed to explain the phenomenon under study. NVivo 10 (QSR International, 2012) was used to assist with the organization of codes and themes. Theoretical sampling was used in the current study to inform which themes or ideas would be focussed on in each interview, allowing for incomplete categories to be filled with new data. Data collection and analysis in constructivist grounded theory are usually stopped once saturation is reached. Saturation was not reached in all themes, due to the aforementioned issues with recruitment, but this was achieved for most themes in the theoretical framework.

Ethical approval for this study was obtained from the University of Glasgow's Ethics Committee.

3 | RESULTS

3.1 | Life through a different lens

While fathers' experiences were unique, analysis of the data revealed common themes. Fathers provided rich details of their lives from the birth of their son/daughter to the current day. These fathers reflected back upon their caring journey and felt that their lives had been changed by parenting a child with an intellectual disability. Their experiences had impacted their sense of identity and altered their outlook on life. They felt that they viewed their lives and the world around them in a different manner, as if through a different lens. Therefore, the theoretical model which encapsulates all themes was named "life through a different lens." A narrative summary of the subsequent theoretical model is provided below, detailing the themes and subthemes, and represented in Figure 1. Quotations from fathers are presented to provide support for interpretation of themes, and pseudonyms are used to protect the fathers' identities.

3.2 | Wearing different hats

Fathers described many aspects of their identities, which included that of parent, expert in their son/daughter's care, and main breadwinner. Switching between these identities as the situation demanded, or "changing hats" as one father described it, was commonly reported by fathers. Which of these "hats" or identities were most salient to them tended to change over time. Fathers discussed how some "hats" were maintained, gained or lost while parenting their child with an intellectual disability. These different "hats" are discussed in the subthemes below.

3.2.1 | A parent not a carer

Many fathers did not identify with the label of carer and rejected this term when it was used by the interviewer. As is discussed later in this paper, fathers felt that they had a strong bond with their son/daughter and so the term "carer" may have been seen as underrepresenting the importance of their parental relationship, and implying that they were not close:

I would say we don't see it as being carers. Carers are somebody else. That's no us. You know? We're just her parents.

(Mr Walker)

On the other hand, the role of father was one that was taken very seriously. As far as they were concerned, all caregiving tasks that they completed were due to being a father and not a carer. It was clearly important to these men that they were a good father

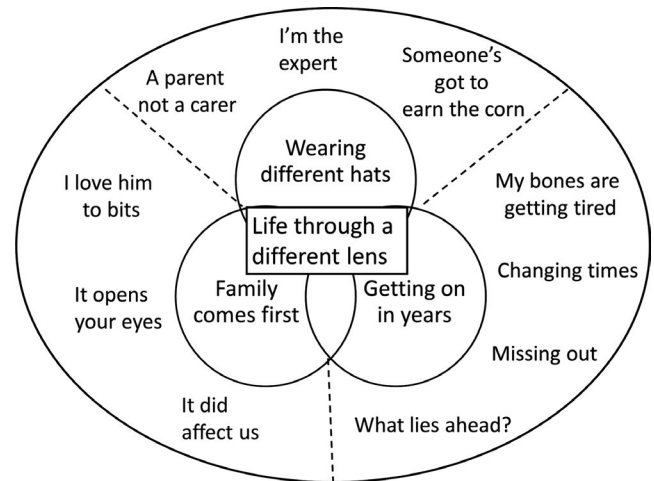


FIGURE 1 Grounded theory model of "Life through a different lens"

and they were determined to do all they could for their son or daughter:

I mean, one of the things we've always said is 'she's our daughter, same as her elder sister. We do our best for her elder sister and we're doing our best for Jessica'.

(Mr McKay)

3.2.2 | Someone's got to earn the corn

Providing for their family financially was another important part of fathers' identities, particularly when their wife had to stay home to look after their son/daughter full-time. As fathers were usually the main breadwinner within their family, most acknowledged that their wife provided the majority of the care for their son/daughter. Fathers used language such as "filling in" and "allowing her to take a break" to describe their contribution to their offspring's care. This suggests that they did not consider caring to be their main role and that they were caring on a temporary basis to assist their wife. This was even true of fathers who explicitly described themselves as dividing care 50/50 as well as those who had retired and were just as available as their retired wife. The acknowledgment that their wife was most involved was often followed by a justification that this division of tasks was common among families:

I'm more of an aide de camp for Amy. I think most husbands are. (Mr McKay)

... and whilst I was there as much as I could be for Laura, somebody's got to go out and earn the corn.

(Mr Thomson)

One father even admitted that he had had a more traditional view of the division of household tasks in the beginning but that this had changed over time:

I think in the early days I was probably, I'll not say chauvinistic but old fashioned in the way that the kids were for Laura, I went out and made the money.

(Mr Thomson)

Mr Thomson was the only father to explicitly state this but the idea of traditional gender roles ran throughout the interviews. When asked for specifics about how they cared for their son/daughter and what that involved, most identified certain physical tasks as their domain, while others "belonged" to their wife.

My wife does the primary care and then I do the fetching and so on, and help at the end.

(Mr Lampton)

A different pattern emerged for two fathers who had originally been the main breadwinners in the family but had to give up their jobs in order to help more with their son/daughter's care. These fathers had previously held high-status jobs with large salaries and appeared to struggle with letting go of these identities. One father spoke about feeling like a "second class citizen" now that he was unemployed. They expressed sorrow at leaving these previous lives behind and felt that this change had a negative impact on their sense of self and social status. Both fathers did not feel that they had a choice about giving up work but thought it a necessary move, for fear of what would happen to their child if they did not stay at home full-time to look after them:

So, I always knew there would come a day when I would have to give up my former life and sort of become a full-time carer. And at that time, it was 'Is this my life for the next 20/30 years?' And I think that's the most difficult thing to come to terms with.

(Mr Kendall)

3.2.3 | I'm the expert

While fathers initially experienced challenges navigating the social care system, many had come to view themselves as an expert in both the system and how to care for their son/daughter. In various instances, fathers had spoken up to medical professionals to safeguard their child, using their expertise to ensure that their son/daughter received appropriate care. On one occasion, Mr Walker's daughter had gone to hospital after a fall and was about to be discharged after the doctor had made a very brief examination. Mr Walker challenged this decision and ensured that his daughter was given further attention:

And I said 'Her eyes were rolling, absolutely rolling'. I says 'Knocked to the head and she's just been sick' I

says 'Don't call me a doctor but to me that's concussion.' 'Oh, maybe we should go and have another look' Hmm....."

(Mr Walker)

This "hat" was discussed in particular detail by fathers who had given up work to look after their son/daughter, suggesting that this identity provided them with status or purpose they felt they had lost after leaving employment. One such father took great pride at being the one who other parents sought out for advice. By becoming an expert who was looked up to by other parents, fathers appeared to have reclaimed a position of high status:

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

(Mr Kendall)

3.3 | Family comes first

Family played a key part in the lives of all fathers. The bond that fathers had formed with their son/daughter was discussed at length in the interviews. Fathers spoke enthusiastically about who their son/daughter was and what they meant to them. Fathers acknowledged that there were stresses associated with having a son/daughter with an intellectual disability but also emphasized the positives that their son/daughter had brought into their families' lives. These different aspects of family life with a son/daughter with an intellectual disability are discussed in the subthemes below.

3.3.1 | I love him to bits

Fathers spoke with enthusiasm about their son/daughter's personality and interests. They clearly loved their son/daughter and derived much joy from their relationship:

I think I just like him the way he is now. All his little idiosyncrasies shall we say. He's my son and I love him to bits.

(Mr Kendall)

Many fathers expressed a fierce pride in all that their son/daughter had achieved and how they had overcome the odds to exceed medical professionals' expectations. They were eager to describe their son/daughter's skills and abilities in great detail. Fathers

recounted times when their son/daughter's achievements were celebrated, not just by the family but by their whole community. Mr Murphy's son had recently competed in the Special Olympics and won a bronze medal. This was an incredible experience for Mr Murphy and his family:

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

(Mr Murphy)

Fathers also spoke of the difficulty of seeing other people's offspring doing well and achieving things that their son/daughter could not, and of unfavourable comparisons being made. The level of enjoyment the fathers clearly derived from emphasizing all their son/daughter's achievements during these interviews might have been because they were aware that their son/daughter was not always able to achieve the same milestones as other people:

There's no sense in masking that, and it's hard, and it is. It's harder when you see the likes of my nephews and my nieces and they're going forward, and they're going away and that's never going to happen.

(Mr Walker)

Fathers appeared to take particular pleasure in observing ways in which their son/daughter's personality resembled their own, and this seemed to strengthen their bond. For example, Mr Murphy described himself and his son as pranksters who enjoyed playing tricks on one another, and this was an important element of their relationship:

The relationship I've had with Mark has always been, there's always been an element of teasing and fun.

(Mr Murphy)

Some fathers felt that the relationship they had with their offspring had not changed much over time. This seemed to be because they felt that their son/daughter continued to need a similar level of parental support when they reached adulthood or because they felt that the strength of their relationship remained undiminished:

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

(Mr Thomson)

3.3.2 | It opens your eyes

In addition to the unique bond that fathers shared with their son/daughter, their parenting journey had significantly changed the way that fathers looked at the world and had opened their eyes to the experiences of others. According to these fathers, realizing that their son/daughter had a disability had been something of a reality check and had made them more aware of the difficulties that others faced:

In the past, before Jessica, you see people with disabilities and you just (shrug) 'It's just a disability' but now when I see somebody with a disability I wonder how they're getting on.

(Mr McKay)

Most fathers felt that they had grown as a person, as a result of having a son/daughter with an intellectual disability. Fathers believed that they had become a better and more caring individual through their experiences:

I suppose to a certain extent through Jessica, I'm a more caring person than I might have been, you know?

(Mr McKay)

Many had made choices that had enriched their lives, which they attributed entirely to the presence of their son/daughter with an intellectual disability. For example, as his teenage daughter had trouble making friends, Mr Thomson founded a peer mentoring charity to bring teenagers with and without intellectual disabilities together socially. This became a big part of his life. Yet, on reflection, he was surprised that he had taken this initiative and felt that it was rather out of character. As Mr Thomson had particular difficulties obtaining appropriate services for his daughter, setting up this charity appeared to have been an empowering experience:

I would never have done that, I'd really never have done it. And I thrived on it.

(Mr Thomson)

For many fathers, their experiences caused them to reevaluate what was really important in life and many felt that they had adjusted their priorities:

Makes you think of the values in life that are important, and I think you adjust your perspective. I think it, it stops you in your tracks.

(Mr Murphy)

3.3.3 | It did affect us

While fathers emphasized their personal growth, they also recognized that having a son/daughter with an intellectual disability had

impacted the family, both positively and negatively. Some fathers struggled with the idea that by reducing their hours or giving up work entirely to help look after their offspring, they had somehow let their family down by failing to provide for them properly. This was a particular concern among fathers who had been high earners and whose family had a comfortable lifestyle prior to the birth of their son/daughter with an intellectual disability. Given the importance they had placed on their role as the main breadwinner, fathers were upset by the impact that their loss of earnings had on the family:

So, it does make me feel really, really guilty... the fact that giving up work meant that she's had to, you know When other people are going out and decorating the house we've had to make do with what we've had.

(Mr Kendall)

While fathers did admit that they had been negatively affected at times, the majority felt that their wives had actually experienced more of the psychological impact of parenting a son/daughter with an intellectual disability.

I think that generally having a disabled child has a far greater effect on the mother. You know? Because you know the mother's with the child, a lot more.

(Mr Thomson)

Fathers were also very aware of and, at times, concerned by the consequences of having a son/daughter with an intellectual disability on their other offspring. Many fathers expressed a sense of guilt at the thought that their other sons/daughters may have been negatively affected, either through receiving less attention or because it limited their opportunities. However, fathers were quick to emphasize the positives. Fathers were clearly proud of the resilience that their other offspring had demonstrated and commended them for being more mature and caring than they themselves had been at a similar age:

They're better people if you like. They know through experiences that there are other people less fortunate. They're more tolerant of people.

(Mr Thomson)

Despite the challenges, fathers felt that the whole family had benefited in a multitude of ways due to their son/daughter with an intellectual disability:

Mark is Mark, and Mark has enriched our family in a way that would never have happened had he not been Mark. So, it's not a It can never be, I suppose is what I'm saying... it can never be a regret, it can never be a regret.

(Mr Murphy)

3.4 | Getting on in years

Thinking about how they and their family had been impacted by caring caused fathers to consider how their experiences had or would change as they entered retirement age.

They were now beginning to face what their retirement would have in store for them and to tackle the issue of what would happen to their son/daughter once they were no longer able to continue looking after their son/daughter. The fathers' growing concerns about the future are addressed in the subthemes below.

3.4.1 | My bones are getting tired

Fathers stressed the prolonged nature of their caring role and how it wore them down over time. This was felt at an emotional and a physical level, with fathers feeling the weight of their dependent offspring on their well-being:

It's just like bringing up any normal child, except Jessica's childhood shall we say has continued right through to the now, you see? Doing everything for her.

(Mr McKay)

It is just hard work, constant attention.

(Mr Lampton)

Some fathers were initially resistant to admitting that they needed to adjust the tasks they performed for their son/daughter as they aged and were reluctant to ask for help. This appeared particularly difficult for fathers when they struggled to complete physical tasks. Given that fathers often considered physical tasks to be their domain, while their wives were more involved in emotional care, this change in their ability to shoulder such tasks may have left fathers feeling redundant:

As she got older I refused to consider myself getting older and it took me a long while to start using the hoist and things that were provided. But I realised, after a few problems with health wise, that meant I better start using the hoist.

(Mr McKay)

While most fathers wanted to continue looking after their son/daughter, it was unclear how much choice they had in the matter. Language such as "carrying on" was frequently used, which captured the need to continue and cope as best as possible. After years of experience with the social care system, many fathers felt more able to navigate the system to obtain necessary supports and services. Yet, some fathers did not appear to feel this way and spoke of reaching out to social work for assistance but being told to carry on while they could. Feeling that they were just left to get on with things as best

they could, or even that they had been abandoned by the social care system came up frequently throughout the interviews:

Oh, well I'm getting older and my bones are getting more tired. That's what I keep saying to social work but they say 'well, you're coping'.

(Mr Kendall)

3.4.2 | Changing times

Despite initial resistance to accepting extra help, fathers appreciated receiving high-quality services. Reflecting back on their experiences over the years, all fathers used language such as "fight" and "battle" to describe the process of obtaining such services. Some fathers continued to take this view and spoke of the restrictions that their caring role placed on their social life. Others described their current situation as much improved, although it was unclear whether this view reflected an actual increase in support or merely gratitude for whatever they could obtain at this stage in their lives. Those who felt that they had recently gained more freedom often experienced guilt:

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

(Mr Kendall)

Reflecting back, fathers noted how their experiences differed from new parents nowadays. There was a general feeling that new parents had far more support than they had been given in the early days of their offspring's life and many appeared resentful of this lack of support:

... but that's what it was like in those days. Well that's it, just get on with it. No support, no nothing.

(Mr Lampton)

3.4.3 | Missing out

Reflecting back on how things had changed during their parenting journey, most fathers began to express that they had often missed out on opportunities due to their caring role. While fathers did not regret caring for their son/daughter, they felt that they had made significant personal sacrifices in order to do so. They appeared to feel torn between these ideas and at times had to battle to focus on the positives:

I've had my moments where I've said 'Why me?' When my mates are all off to a golf weekend and I

can't go. Or off to a stag weekend and I can't go on a stag weekend.

(Mr Kendall)

Having adjusted to their caring role and developed a good grasp on how to navigate the social care system, fathers were suddenly faced with a new stage in their lives for which they were not prepared. The realization that their retired life would be quite different from their peers had also started to sink in and fathers were grappling with what this would mean going forward:

What do most couples do when they retire? They see themselves having the freedom to do the things they would like to do. Now I'm not saying Carolyn and I won't be able to do that, but with certain things we won't be able to do it unless we make provision for Mark.

(Mr Murphy)

3.4.4 | What lies ahead?

Fathers were starting to plan for their offspring's future and accept that there would eventually come a time when they could no longer look after their son/daughter. This brought with it a number of concerns, such as anxiety about the quality of care that their offspring would receive. Feeling that they were unable to rely on the system to care properly for their son/daughter appeared the main cause of stress for parents when they tried to envision their offspring's future:

We're always scared she'll get her own place and they'll bring people in You hear horror stories.

(Mr Lampton)

The concern about what might lie ahead for their son/daughter often motivated fathers to begin the planning process to secure their offspring's future. Most fathers had taken some steps to put a plan in place for their son/daughter, although these ranged in nature, as well as in degree of development. The length of time that it took to put things in place had taken fathers by surprise and most were highly frustrated by the bureaucracy involved:

Amy and these other parents have been at this for over 10 years, nearly 12 years since the first started making the first enquiries.

(Mr McKay)

Even with plans in place, there was a feeling that they could not control what actually happened in their offspring's future:

...but again, there's not a lot you can do about it. You can only put things in place. We've tried to put things

in place, financial wise and different things and what have you.

(Mr Walker)

Having been let down by the system many times in the past, fathers were reluctant to trust that health or social care services would do the best for their son/daughter when the time came. However, fathers did not appear to be completely panicked by this prospect and seemed to feel that they still had enough time to develop a concrete plan.

4 | DISCUSSION

The theoretical model of "Life through a different lens" captured fathers' experiences as an older parent to a son/daughter with an intellectual disability and how their lives have changed as a result. Most fathers in the current study spoke at length of the positive impact that their offspring had on their lives and felt that they had become more considerate and caring people. While fathers admitted that there had been periods of extreme stress and that their other offspring had perhaps received less attention, most emphasized that the positives had far outweighed the negatives. This supports previous research which has found that many parents re-evaluate their lives and perceive themselves and their families to have benefited from having a son/daughter with an intellectual disability. For example, mothers and fathers commented not only on the challenges, but on the happiness, joy, pride and greater appreciation of life that their families had experienced (Beighton & Wills, 2017; Chadwick et al., 2013).

The results of the current study demonstrate that an overemphasis on stress and coping models in the existing literature may fail to take account of the numerous other aspects of a fathers' experience, and ultimately do not provide complete pictures of fathers' parenting journeys. The finding that fathers experience both positive and negative outcomes of parenting a son/daughter with an intellectual disability provides support for the Two Factor Model of Psychological Well-being (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991), which proposes that both positive and negative outcomes from looking after their offspring may be experienced simultaneously due to the operation of two different appraisal processes operating in parallel. In this study, fathers linked negative experiences, such as fighting social services for adequate support with negative emotional outcomes such as heightened anxiety. Unsurprisingly, positive relationships with their son/daughter were regarded as life enhancing. Rather than focussing on vulnerability to mental health, future research should also consider how such positive experiences of parenting a son/daughter with an intellectual disability can be supported.

While the majority of fathers emphasized the positive aspects of life with a son/daughter with an intellectual disability, two fathers took a different view. These fathers appeared to be worn down by their caring role and spoke of life as a constant struggle to get their needs met. These were fathers whose offspring had a severe or profound intellectual disability, one of whom also regularly

exhibited challenging behaviour. These fathers had experienced particular difficulties in obtaining the supports and services they felt that their son and daughter required. The type of support tasks that they needed to perform were also physically demanding. However, the only other father in the sample whose son/ daughter had more significant support needs maintained a more positive outlook and his account of life with his daughter was full of laughter. An important difference from the other two fathers was that he described receiving a high degree of support from formal and informal sources. While other factors may also be at play, this highlights the importance of everyday support, particularly when someone has significant support needs to be met.

"Fighting the system" in order to obtain adequate support and resources was identified as the most stressful aspect of parenting an offspring with an intellectual disability. A general dissatisfaction with statutory support was expressed by all participants. This is consistent with broader surveys of carer satisfaction, which show that only a minority of working carers in the UK report that they receive adequate services to support them in their role (Brimblecombe, Pickard, King, & Knapp, 2016; Milne, Brigden, Palmer, & Konta, 2013). However, the fathers also found the experience of dealing with services highly stressful and felt that it took a significant toll on their well-being. Social and healthcare workers may genuinely struggle to provide the resources families want, particularly at a time of austerity. However, efforts should be made by statutory agencies to avoid taking an adversarial position and there should be a greater awareness that these "fights" with the system can have a negative impact on parents' well-being.

Fathers' views that it had been a "battle" to obtain services were also consistent with findings from a meta-synthesis on the experience of family caregivers of individuals with an intellectual disability and challenging behaviour (Griffith & Hastings, 2014). Taken together with findings from the current paper, this suggests that difficulties parents experience in obtaining appropriate services is a long-standing issue. It is interesting that some of these older fathers felt that they had now achieved more access to services or had figured out how to work the system. It may be that this perceived change is due to a better understanding of how to obtain services. Alternatively, after so many years caring, fathers may feel more grateful now for any services that they can obtain.

Unsurprisingly, this study showed that older fathers are involved in and concerned about their offspring's lives. However, the majority of fathers described themselves as being the main breadwinner while their wife performed the bulk of caregiving tasks. This was also true of fathers who had retired, suggesting that they still viewed looking after their son/daughter as their wife's domain. These results suggest that gender roles within the household may not have changed for older fathers (Sweeting, Bhaskar, Benzeval, Popham, & Hunt, 2014). In fact, there is evidence that mothers still take on most of the parenting tasks for their son/daughter with an intellectual disability. A study of middle-aged parents of a son/daughter with an intellectual disability found that mothers reported spending an average of 12.5 hr per day on caregiving tasks, while fathers reported

spending 7.25 hr per day (Rowbotham et al., 2011). These figures challenge the idea that fathers are taking an equal share of caregiving responsibilities within the family. While it may come as no surprise that older fathers continue to operate within traditional gender role norms, it remains noteworthy that the fathers in this study were only aged 60–68. Consequently, they and their wives are likely to continue in a parenting role for their son/daughter with an intellectual disability for years to come. If the mothers continue to take on the main parenting role, even after fathers have retired, then it may be mothers who will require the extra help as they age. Yet families are dynamic systems, take many forms and change over time. It would be important for future research to examine how patterns of parenting adult offspring with an intellectual disability change after both parents retire.

Love and concern for their offspring motivated fathers to make plans for the future. However, the degree to which fathers had taken steps to finalize such a plan varied greatly between fathers. A systematic review which included studies on the views of older carers identified fear of the future as an overarching theme (Innes, McCabe, & Watchman, 2012). While fear of the future did emerge as a theme in this study, it was not a dominant theme. There was a lack of urgency in making future plans for all but one father. This difference may be due to the fact that most previous studies have focussed on mothers' views. Fathers who expressed significant concerns about their offspring's futures were mainly those who had begun to experience health difficulties. They were aware that they would not be able to provide long-term support to their offspring. Previous research with older parents has also reported that health scares can lead parents to reevaluate their ability to continue looking after their son/daughter with an intellectual disability (Pryce, Tweed, Hilton, & Priest, 2017). The fathers in this study argued that there needed to be timely planning with families, to avoid crisis situations arising when parents were no longer able to support their offspring. Younger parents might also find it helpful to hear the views of these older parents, to help them think about future plans at an earlier stage.

This is the first known study focussing on older fathers' experiences of caring for their son/daughter with an intellectual disability. The results have added to the evidence base by focussing on a population who have been largely excluded from research around the experiences of family carers. All participants were married white Scottish fathers which may reduce the relevance of the emerging themes for other groups of fathers. There was also difficulty in recruiting fathers for the study. This has been noted in previous research and it has been suggested that this is partly due to fathers being unavailable during working hours, a lack of visibility to services, and beliefs that mothers are best able to answer questions about their son/daughter (Carpenter & Towers, 2008). The fact that two fathers tried to steer the researcher towards the mother suggests that mothers, in this older generation, still tend to be seen as responsible for the emotional and physical care of their offspring. Yet after the interviews had ended, a number of the fathers confided to the researcher that it had been a relief to talk about their

experiences as no one had ever asked them about their caring journey. A future challenge for researchers is to determine means of identifying fathers and encouraging them to participate in research, to ensure their views and experiences are heard.

CONFLICT OF INTEREST

There are no known conflicts of interest.

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