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ORIGINAL ARTICLE

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Fathers' experiences as carers for autistic children with learning disabilities

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Accessible Summary

- This research explored the experience of four fathers of autistic children who also have learning disabilities.
- Fathers' experiences as carers are increasingly recognised in the literature; however, the studies of parental experience tend to centre mothers. The current research builds upon the recent and important focus upon fathers' experiences.
- The fathers in this study sometimes felt helpless and unable to fulfil the traditional role as protectors and providers, but they also had strong feelings of closeness with their children and developed new identities through the challenges and joys they experienced alongside their children.

Abstract

Background: This small study explores the lived experience of four UK-based fathers (one black British, one white Polish and two white British) caring for at least one child with a dual diagnosis of learning disability and autism. The key aim was to get as close as possible to understanding the experience of these fathers in their role as carers.

Methods: The study makes use of interpretative phenomenological analysis (IPA) as an approach to gathering (via interview) and making sense of the fathers' experiences.

Findings and discussion: We co-constructed three themes following analysis of the interview transcripts: "fatherhood: not doing enough, not doing it right"; "crossing worlds: relearning how to communicate and reclaiming fatherhood"; and "uncertain futures." We found that, for these fathers, the experiences of anxiety and helplessness were balanced with the appreciation of their value as protectors, their shifting sense of identity and of their closeness with their children. Relationships were central throughout.

Conclusions: The exploration of fathers' experiences helps to highlight the less-measurable, nuanced aspects of the joys and challenges of caring for children with dual diagnoses of learning disability and autism which might be used to enhance the support provided and to inform new approaches.

KEYWORDS
autism, experiences, fathers, learning difficulties, parents

1 | INTRODUCTION AND LITERATURE

In the UK, "learning disabilities" are characterised by "lower intellectual ability … significant impairment of social or adaptive functioning and onset in childhood" (National Institute for Health and Care Excellence (NICE), 2020). (For "learning disabilities," we are following the journal guidance on using person-first language in this article, but recognise that for many in the autistic community, "autistic person" is preferred to "person with autism" [e.g. Sinclair, *Loud Hands: Autistic people speaking*, The Autistic Press, 2012]). This diagnosis is broadly commensurate with the DSMV definition of "intellectual ability" (APA, 2013). "Autism spectrum disorder" is characterised by difficulties in "social communication and social interaction," and by "restrictive, repetitive patterns of behaviour, interests, or activities" (according to the DSM-5, APA, 2013). Diagnosis with both learning disability and autism spectrum disorder is common (Boucher, 2009). The authors of the current paper recognise that children come to receive diagnoses of autism and learning disability in accordance with the definitions described above. However, the authors consider autism and learning disability to be largely socially and culturally constructed (Burr, 2003; McGuire, 2016); thus, in the current paper, the experiences of diagnosed children, and their families, are understood to be situated, shifting and relational (Mallett & Runswick-Cole, 2012). Feelings of distress, for example, are therefore theorised as emerging from a network of social, and material contexts, not simply as an inevitable product of a "disorder" or because of ineffective intervention (Sinclair, 2012).

There is a significant amount of literature which attends to parental experiences of caring for autistic children and/or children with learning disabilities: evidence suggests that these parents can experience particularly high levels of stress (especially fathers: Dardas & Ahmad, 2015), depression, anxiety, grief, guilt, isolation and sorrow (e.g. Benderix et al., 2007; Dumas et al., 1991; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Brown, 2002; Koegel et al., 1992; Lu et al., 2015; Martins et al., 2013; McKinney & Peterson, 1987; Selmann et al., 2017; Sivberg, 2002; Woodgate et al., 2008). There is also a little attention to some of the positive experiences of fathers in caring for children with a dual diagnosis of learning disabilities and autism; for example, fathers have expressed feelings of closeness, affection and joy in their child's honesty, humour and intelligence (Potter, 2017), they have taken joy in the caring role (Hannon et al., 2018) and have recognised the value of their journey towards acceptance (Burrell, Ives, & Unwin, 2017). However, much of the research centres the mothers' experiences (DePape & Lindsay, 2015; Hurtubise & Carpenter, 2017; Hwang, Kearney, Klieve, Lang, & Roberts, 2015; Markoulakis, Fletcher, & Bryden, 2012; Van Wyk & Leech, 2016; Shu, 2009), with a few exceptions (e.g. the father-only stories presented in Harrison et al.'s (2007) edited collection; and Marsh et al.'s narrative enquiry around fathers' experiences (2018), as well as work by Burrell et al., 2017; Lashewicz et al., 2016; Cheuk & lashewiz, 2015). This is perhaps partly because mothers still take on the majority of the responsibility for direct care, and because the fathers defer to the presumed greater emotional capability of the mother, unless there is a need to act "tough": one dad of a child with disabilities is quoted in an edited collection of father's experiences:

> "She goes to all the meetings and I just turn up when I'm needed or told that I'm needed"; "I go to the meetings when things are bad and I have to act tough to get what we want." (Harrison et al., 2007: p. 9).

It is also likely to be connected to traditional (Western) expectations around father's role in the family (as provider and protector, rather than carer nurturer). As a result, professionals may be more likely to place the burden of caring responsibility onto the mother (Flippin & Crais, 2011), so that fathers feel excluded (Frye, 2016; Potter, 2017). There is also a concern that fathers may feel their worries are less legitimate (Ives, 2014).

There is also little research which attends particularly to the experiences of parents or carers from black or minority ethnic backgrounds in white majority countries, nor to the experiences of parents in the global South (though, see Selmann et al., 2017, for an insightful exploration of the experiences of British Somali parents of autistic children; Hannon et al. (2018) for a discussion of the parenting styles of Black American fathers of autistic children; and Sarrett (2015) for parental sense-making in India). In summary, there is good reason to consider that the gendered and culturally specific constructions of and around "race," gender, parenthood, the "ideal" family and disability interact with the ways caring for children can be experienced, and consequently with the parent's sense-making and identity (Ives , 2014, 2015; Sarrett, 2015; Selmann et al., 2017). Such constructions are also very likely to mediate what parents mean by and experience as "stress," "guilt" or "depression" (e.g. Cvetkovic, 2012) to the extent that these feelings are not quantitatively measurable. This is another reason why research which focuses upon in-depth conversations around experience using IPA is valuable.

2 | METHODS

2.1 | Recruitment

One of the co-authors of the current paper (Louise Cooper) works as a senior learning disability nurse within the NHS. A leaflet advertising the research was distributed by this researcher to fathers of autistic children with learning disabilities following clinic and home visits via a single Learning Disability Nursing Service. To avoid the risk of coercion, fathers on the caseload of the researcher were not given leaflets. To be included, fathers were required to be the father of a child aged under 18 with a formal diagnosis of autism spectrum condition and learning disability. Initially, five fathers expressed interest in taking part. Once eligibility was confirmed, these fathers were invited to read a participant information sheet, were given the opportunity to ask questions and share concerns. Four fathers then decided to take part. Participants offered informed consent, and subsequently, interviews were arranged. It was made clear in the information sheet, consent forms and in person that the participants could withdraw at any point during the data collection and analysis period (Table 1).

2.2 | Data collection

The four interviews took place in the participants' homes, at their request, and following arrangement by phone and email communication. A risk assessment was undertaken and the interview location and procedure agreed both by NHS and by university ethics panels. The interviewer (Louise Cooper) did not know the participants prior to the interview. All interviews were undertaken in English, were audio-recorded and were approximately one hour long. Interviews were semi-structured, and after initial greetings, reminders and introductions, began with a question "can you tell me a little bit about your child/children?" (approximate wording). The interview continued with questions which enabled discussion of the positives and challenges of fatherhood and caring with follow-up questions such as "can you tell me what that was like?" and "can you say a bit more about that?" as appropriate. The audio interviews were transcribed, and the audio was deleted as soon as transcription was complete. During transcription, names of people and places and other identifying information were removed or obscured. The transcripts and any personal details were stored according to the UK's General Data Protection Regulation (GDPR).

2.3 | Analysis

Interpretative phenomenological analysis (IPA) is a methodological approach suited to small scale, detailed exploration of human experiences (Smith et al., 2009). The aim is to come as close as possible to understanding how a particular phenomenon is experienced by someone. Interview discussions are one means of achieving this aim. Key in this approach is the understanding that is it not possible to come to a singularly "true" understanding of another's experience, because human understanding of others is always achieved via a particular perspective and through reference to the listener's lived experience and knowledge. As such, as researchers we were not looking for the "essence" of participants' experiences, so to speak, but aimed to construct a thorough interpretation of their experiences through the lenses of our own knowledge and expertise. The aims and analysis were broadly rooted in a social constructionist paradigm (Burr, 2003).

An interpretative phenomenological analysis (Smith et al., 2009) of the interview data was undertaken using a three-layer coding process: descriptive, linguistic and interpretative. The descriptive layer of the analysis involved coding each line, sentence or sentence part with a couple of words or a short phrase to summarise what the speaker appears to be saying about their experience, about what something was like or how something felt. An example might be "feeling isolated" or "taking joy in son's moment of learning" or "worrying about the future." This is always an interpretation, but the analyst tries to use the words of the speaker as far as possible in the summary codes, as a way of being as representative as they can. The second analytical layer was concerned with discourse, specifically, with the choice of words, the use of metaphor and the structure of utterances. The analysts were interested in how the father's caring role was presented, how it was described in literal and metaphorical language, and how this language conjured a particular world of experience. The third layer was more explicitly interpretative. In this final layer, both researchers wove in their personal experiences and professional knowledge to ask themselves questions such as "what does it seem to me is going on here?" and "How can I make sense of the sense this

TABLE 1 Details of participating fathers and their children

Father	Age range	Race/ ethnicity	Relationship status	Education and employment	Age range[a] and gender of child	Diagnoses of child/ children
Ethan	50–59	Black British	Married	University degree. Employed (shared caring responsibilities)	1 boy, age range 10–14	Mild learning disability and autism
Pete	30–39	White Polish	Living with partner	University degree. Unemployed (full-time carer)	2 boys, age range 5–9	Learning disability and autism
Ali	40–49	White British	Married	GCSEs. Unemployed (full-time carer)	1 boy, age range 5–9	Learning disability and autism, Down syndrome and thyroid problems
Tom	40–49	White British	Living with partner	Details not given on education. Employed (shared caring responsibilities).	1 girl age range 5–9	Learning disability and autism

[a] The ages of the children have been given as a range to protect against their identification.

father is making of their experience?" The analytical process was also characterised by repeated zooming in and out: stepping back to look at the whole, to notice and question our human responses, and stepping in to spend time with specific sections, sentences or words in the text. We worked together each stage of the analysis, meeting to discuss each of our interpretations, to reflect and share thoughts on the potential themes. Louise Cooper undertook and transcribed the interviews, and she also undertook the initial line-by-line analysis (with regular and focused discussion and support). Together,Harriet Cameron and Louiseanalysed the discourse used by the fathers. Harriet provided methodological guidance and worked with Louise to share interpretations and co-construct the final themes. Harriet led in the connection of the findings to the literature and completed the writing of the current paper. Each of the four fathers' experiences, as well as our own experiences and interpretations as researchers and practitioners, contributed to the production of the four themes.

2.4 | Ethics

The study received ethical approval both from the NHS (via the Health Research Authority) and from an appropriate higher education institution.

3 | FINDINGS AND DISCUSSION

As an approach, interpretative phenomenological analysis necessarily recognises research findings as a product of the interaction between the participants, data, authors and context, rather than a set of objective results which might be discussed after their presentation (Wagstaff et al., 2014). There is no clear distinction, therefore, between "findings" and "discussion" in this kind of work. As such, the authors have chosen to combine the findings with the discussion.

3.1 | Fatherhood: not doing enough, not doing it right?

Each of the fathers in this study appeared to have to reflect upon, and sometimes to doubt, their identities as men and as fathers against a complex ideological backdrop which questions the "masculinity" of men in "caring" roles (Connell, 2005). Some of the fathers were more successful than others in weaving their parental roles into a new and positive identity for themselves, but three of the four appeared to experience some disjuncture between an idealised fatherly role and the realities of their day-to-day lived experiences. This was an intensely emotional experience for them. Here is a short extract from one of the fathers, whom we shall call Pete:

> I had to give up working and not working err…it is…and for a man deciding not to work to care, to care for the children, and understand our biology and how we are shaped you know and understand social pressure on males being a provider and things like that and so it's, for me as a person, it's like, it's like having an accident and someone ends up with a scar on their face, it is a totally different experience for a male having a scar on the face than a female having a scar on the face.

Pete's use of a facial scar as a metaphor for the ways in which his "decision" to leave employment and become the main carer is socially judged and gendered is powerful. This father arguably experiences his parental role as robbing him of worthiness as a man.

Two of the fathers (Pete and Ali) had come to the point where they had little choice but to give up employment in order to become full-time carers for their children. “[M]y work stopped…it is all these appointments as well you see” (Ali). They came to experience themselves as failing in their duty to provide, economically. Ali, like Pete, found that it was not possible to fit paid work around caring responsibilities, particularly with the additional unpredictability of medical appointments and shifting pressures at home. This was a source of frustration and appeared to catalyse feelings of self-doubt and questions about self-worth.

For a third father, Ethan, full-time paid work was becoming difficult to maintain alongside his caring responsibilities. Having a discussion with his employers about the pressures of being a carer and the impacts this was likely to have on his work was very difficult for Ethan:

> It was very, very bad at one point that I had been off sick and had to really…discuss it with my employers…I found myself making excuses, not excuses but telling them what was going on and then without warning I have to leave work to go to school ohh…

Ethan's self-correction in the extract above is telling that what "was going on" might be considered as "making excuses" arguably speaks to the lack of legitimacy attached to caring responsibilities as a reason for absence from work. It would not be surprising if employers were less sympathetic to fathers requesting time out to care for their children than mothers, because of gendered expectations (Rashley, 2005). Greater challenges may also be experienced by black fathers compared with white fathers, as they will have to operate within institutionally racist environments in Western schools and healthcare environments (Gilborne, 2008).

The importance of being able to protect their children (something fathers may feel a particular social responsibility to do—see, e.g., Lamb, 2004) was also sometimes in conflict with the need to provide for their child economically. For Ethan, for example, there was a frequent need to go into school at a moment's notice, combined with a feeling that he wasn't able to protect his child from harm in the school environment. This manifested as a feeling of great emotional strain and inability to fulfil this fatherly role to the degree society expected. This emotional turmoil is reflected elsewhere in the literature (see, for example, Burrell et al., 2017; Neece et al., 2012).

Ethan explained:

> I would go in there (school) and I would have tears sometimes running down my eyes…it was really really bad.

A responsibility to be able to protect their children and the other family members was felt keenly by all of the participants, in and out of school environments; the sense that it was not always possible to protect others, that some aspects of well-being were out of their control, was a source of distress and sometimes engendered a feeling of failure in their protective duty.

> [T]he illness is all the time you just worry making sure he is breathing at night.
>
> (Ali, speaking of his unwell child)

> I have to be aware of how it is affecting her…she is struggling…it is wearing her down.
>
> I have to know how much to put on her or say to her… holding back on some things cos it may have a negative impact on her.
>
> (Ethan, speaking of his wife)

These fathers' feelings of emotional overwhelm in connection to the need to protect their children and their partners are also echoed in the literature (Pelchat, Levert, & Bourgeois-Guerin, 2009). There is likewise evidence that men consider shielding their partners from their emotional burdens as part of their protective responsibility (Lashewicz et al., 2016). What is perhaps particular about the experiences of these fathers is that two socially constructed strands in dominant conceptions of fatherhood masculinity, the ability to provide and the ability to protect, are forced into apparent conflict when the children have additional needs associated with autism and learning disability. In other words, because of the given social and economic structures in which these fathers and their children are situated, it is not always possible to care for an autistic child with learning disabilities at the same time as financially providing for them. Whilst this is similarly the case for mothers, fathers may experience a particular difficulty in taking on what may be understood as a demasculated way of life, in which two key expectations of "successful" fatherhood are under-fulfilled (Humberd, Ladge,& Harrington, 2015).

3.2 | Crossing worlds: relearning how to communicate and reclaiming fatherhood

When the four fathers talked about the challenges of managing situations in which their child behaved or communicated in ways they found difficult to cope with or which society does not accept, they were all bound and positioned by the discourses of shame and blame. The fathers talked about, or alluded to, feeling helpless, upset, trapped, judged and isolated in connection to their own and others' perceptions of their child's behaviour and communication.

"Behavioural problems" and "communication problems" are ideologically loaded phrases. The dominant discourse around the behaviour and communication of and by autistic children and children with learning disabilities constructs the disorder and the child as the root of the problems (Baggs, 2007; Yergeau, 2018). This discourse is used to justify containment of the problem and the child, and can position the children and their parents as to blame when containment or intervention "fail" (Jones, 2003).

The fathers found it particularly hard when their child did not communicate through speaking words.

> We try to talk to him like so he will say a few words back or whatever but he won't be able to say anything at all.
>
> (Ali)

Concerns around communication were apparently inseparable from the social meanings constructed around isolation and separation from social norms (theirs and their children's). The fathers appeared to find it hard to imagine a world in which "nonverbal" means of communication alone might be socially acceptable or accepted as "enough"; this seemed at times to be devastating for the fathers. Melanie Yergeau (2018) considers that the dominant stories of autism construct "[t]he figure of the autistic as unknowable, as utterly abject and isolated and tragic…" (p. 3) and she argues instead for autism as valuable defiance of the normal, and autistic people's nonconformation, asociality, gestures and stimming as discomforting assumptions about humanness. "[N]orms need destroying," writes Yergeau (2018: 78). This is an exciting idea, in our view as researchers, but we recognise that this may not be of practical help in dealing with the relentlessness of social expectation, on the ground, as it were.

> You have a crowd and all the eyes on you and, and… you may fail and you may succeed and people may judge you.
>
> (Pete)

Being stared at is an intense, often social rule-breaking interaction; the "staring relationship" is one in which, according to Garland-Thompson (2006, p. 176), "we recognise and misrecognise the inner lives of one another." Having "all the eyes on you," being judged as "extraordinary," "failing" and "succeeding" under public and institutional gaze, all recall a history of the control of bodies, especially those which do not conform to the norm: racialised bodies, disabled bodies, poor bodies and unruly bodies (Foucault, 1997). Being, doing and having an acceptable body, under the ablist, racist and sexist discursive epoch of our times are not achievable for everyone in every space: "humanness [is] realizable only through proper bourgeois behaviour, status and the embodiment of whiteness" (Ansfield, 2015: p. 131). Autistic children with learning disabilities and their families can become especially visible, because they cannot always adhere to normative social expectations. The fathers in this study were accustomed to being stared at, and so lost some control over the interactions they experienced in public places. "Visual anonymity is a form of cultural capital that allows us to orchestrate the visual encounters in which we seek to recognize and be recognized" argues Garland-Thompson (2006, p. 178). These fathers could not remain invisible and anonymous.

Unspoken rules governing social performances of personhood, including rules for doing "joy," "gratitude" or "sadness" at appropriate times and in appropriate contexts, can intrude even in the absence of the public gaze. For example, there was some sadness expressed by the fathers as they came to accept they were less able to share joy with their children during social rituals such as unwrapping gifts at Christmas, or taking part in other festive and family events. There was a sense of isolation here:

> So basically, you're locked in, it's another day, its like it doesn't exist you know. Christmas is exactly the same…he doesn't unwrap anything.
>
> (Ali)

"[Y]ou're locked in," practically, in this case, the father was talking about being locked into the sameness of the everyday routines which their child lived within; but the metaphor also conjures a border between a space of "normal" events and related performances like gift-giving, and a space of "abnormal" joy in routine, and, sometimes, disinterest in socially sanctioned rituals. The father is a code-switcher: he adapts his communication to the context. However, he cannot help but carry through a strong, but unreasonable feeling that people are supposed to enjoy opening presents. The power of the "supposed" is isolating, not, arguably, the child's disinterest in itself. The fathers seemed to carry a sense of loss and sadness about what could or should have been, a "grief over a fantasised normal" (Sinclair, 1993/2012: p. 15).

> Family life is the same as it is everyday… get up in the morning everything is set at a set time……Everything is the same at night time after school … (Ali)

The fathers understood their children's need for sameness, but this did not necessarily help to reduce their feelings of loneliness (c.f. similar findings in Lashewicz et al., 2016; Martins et al., 2013). One father, Pete, felt that he was losing some of his social skills because he spent increasing amounts of time with his child away from mainstream social settings:

> About 90% of my time is with the children and I feel that there are social skills that I am losing, and so interaction with other people it is emm…its just very little.

However, strongly connected to these feelings was a shared experience of re-connecting and relearning to interpret their child's "behaviour" as a means of communication (Clements, 2005). This relearning required a lot of hard work, and resistance to the ongoing messages from others that their child, and by extension, the carer, was not welcome and should be contained. The fathers had learnt how to interpret what they felt to be challenging behaviour as one of the ways their children communicated with them. This relearning seemed to be continually checked by the perception of other people's opinions.

The fathers also felt they had to learn how to better to understand and moderate their own reactions and feelings, and in some cases, they felt they were better able to communicate and with (professional) others in a way they had not had to in the past and that this was seen by the fathers as a source of personal growth.

> I will chat to myself on the back there or listen to my music or I will review the situation and inject a bit of humour.
>
> (Tom)

> The coping for me behind this is trying to understand other people, where they are coming from.
>
> (Pete)

In recognising and practising different means of communicating (with their children, themselves and others), the fathers came to appreciate their children in ways some of them felt they might not have done had their child not been autistic or learning disabled. This was linked to a closeness, a particular bond with their children, which the fathers greatly valued.

> [I]t helps to appreciate our children more…cos if he had not had that then I may not have been as close to him to understand him more.
>
> (Ethan)

Melanie Yergeau writes about "asocial rhetorics," which, she argues, "complicate what we have come to understand as social." She argues that asociality, or a rejection of being normatively social as necessary to being human, allows us to recognise the value of relation and communication "beyond the human" (Yergeau, 2018: p. 71). The unfolding positive experiences the fathers in this study were having were perhaps possible because, in learning to communicate with their children, they were dipping their toes into the freedoms of a normative sociality.

3.3 | Theme 3 "Uncertain futures"

Developmental psychology, partnered with a neoliberal ideal of individual productivity, pushes "normal" emotional, social and intellectual (child) development as the only "good" way of becoming. By association, parents may only be "good" if they make the "'right' choices" in supporting their children in their "normal" development

(Burman, 2011, p. 430). In many ways, being positioned as the containers for their children's autism, as the buffers between their children and the world, the future was understandably constructed as a worrying place. Considering that "normality" seemed inaccessible, the fathers expressed anxiety around how their children would manage after they had left school, and as they became adults in the world.

> Other kids grow up and they you know develop and they want independence, whereas we can't see it…
>
> so then you are thinking about her leaving school, and I am wandering what type of plan and advice and support will be around then you know.
>
> (Tom)

There seemed to be both a practical worry about the availability and quality of services for autistic young people and young people with learning disabilities post-16, and a more existential worry about who their children would or could become in the unimaginable future. Fears of a gap in health and social services for autistic adults and adults with learning disabilities are echoed elsewhere in the literature (Blacher et al., 2010; Pozzo & Sarria, 2015; Saqr et al., 2018; Sosnowy et al., 2018). However, the second category of worry we have presented here is a little harder to unpick. We have attempted to do so with reference to Melanie Yergeau's connection of autism with the "unknown" and the "unknowable" in the public imagination (Yergeau, 2018). One interpretation of the fathers' fear is that if their child is not developing according to the normative story, their future is less predictable, less containable, more leaky, more mysterious and, ultimately, less human.

> what he is going to be like when he grows up? Like I say he is probably going to be stuck to us for the majority of his life anyway…he can't sit here and watch telly all the time.
>
> (Ali)

What are the children going to do, be or *become* in the future? Why can't they sit and watch telly all the time? Yergeau (2018) argues for the need to reject the assumption of goodness in human progress and development. Things may not get better; what there is now may be as good as what is to come. This acceptance of sameness is part of what Yergeau (2018) offers as resistance to the dominance of developmental norms and to the construction of so-called unproductive people as "human waste" (Bauman, 2004: 32).

The fathers' concerns about their children's *becoming* might also usefully be understood in a context where autistic adults are constructed as "threatening," rather than merely "disruptive" (McGuire, 2016: 119). A "threat" needs containment, lest it leaks into and onto the rest of the world. In this sense, autism is

> Framed as the core of a collective crisis that begins with the individual but that, in the absence of autism services and crisis supports, leaks outward, enveloping parents, families and communities. (McGuire, 2016: 6)

But, as McGuire argues, the responsibility for the continuance of this construction is a collective one. The fathers alone cannot plug the future leaks. Part of the effort towards reconstruction of the boundaries for humanness is an explicit celebration of the "ways in which …non-normative bodies provide opportunities for emancipation" rather than reproducing disability as "lack" (Goodley & Runswick-Cole, 2013, pp. 1–2). In other words, autistic people and people with learning disabilities and their families might be best placed to "break free" from normalisation and to help shake "normal" others from their illusion of autonomy (Goodley & Runswick-Cole, 2013; p. 11). Garland-Thompson (2006) alludes to the same idea: a "productive unruliness" (p. 181) and possibility created through the disruption of "normal" social rules.

4 | STRENGTHS, LIMITATIONS AND CONCLUSIONS

This study is limited because of its attention to the experiences of only four fathers. Ideally, a slightly higher number of participants would have enabled stronger conclusions and would have included insight from greater breadth of experience. However, IPA studies which include small numbers of participants can nevertheless offer valuable access to the lived worlds of those individuals. Whilst "generalisation" in the tradition scientific sense is not appropriate for such a study, the conclusions drawn can be used to illuminate the experiences of those in similar positions. "Generalisability" in qualitative research may be recognised as conceptually different to the statistical–scientific "generalisability" aimed for in quantitative research, that is a reader may recognise aspects of their own experiences of a given phenomenon reflected in a small-scale IPA study, and make use of this as a tool for making sense of their experiences (Smith, 2018). A related strength of the current research lies in its interpretation of the experiences a group who have been traditionally neglected in the literature, by researchers who, together, hold significant practitioner and research expertise.

As authors, we consider that the current research illuminates some of the everyday feelings and occurrences fathers of autistic children with learning disabilities experience. This research highlights some of the emotional strains and stresses connected to the belief they were not doing enough and that they were unable to fulfil the expected roles; it follows the emotional journeys the fathers experienced in crossing between the world of "normal" social rules and expectations and the worlds they shared with their children, and offers some nuanced acknowledgement of the fears these fathers held for their children's futures. Furthermore, the research underscores the situated, relational and interactional nature of the fathers' experiences. That is, the joys, worries and frustrations experienced were products of the dynamic interaction between the fathers, their children and the particular structures, histories, expectations and assumptions acting in each given context.

In the light of the insights arising from the current study, as authors, we would like call for practitioners, policy makers and educators to embrace relational perspectives of autism and learning disabilities, autistic people and people with learning disabilities, and, indeed, of all humans and neurodevelopmental conditions. We echo McGuire's words here, on autism:

> Autism can and must be theorised as a relational space: an interactional, historically contingent, socially mediated, and geo/political space; a space of questions and of power relations that invariably provides the terrain for encounters across race gender, class, sexuality, disability… (McGuire, 2016: p. 19).

Centring a relational perspective may be easier to achieve in theoretical discussion than it is in practice (though see Pluquailec, 2018, for an exploration of in-classroom possibilities of such a relational perspective, and Cameron (2020) for a relational approach in support for people with specific learning disabilities). However, we would like to suggest one way in which a relational perspective might offer new possibilities for fathers with experiences similar to those we have explored in the current article. The isolation, frustration, joy and hope that fathers feel in connection to their caring role do not exist because of their children's diagnoses. Rather, their experiences are dynamically produced within their daily encounters with particular normative assumptions, cultural expectations and social judgements constructed in the home, work, school and social environments that fathers have to negotiate. As such, a relational approach to building support for fathers would necessarily centre their situated and shifting experience and sense-making, rather than starting with clinical generalisations. Peer support alongside professional support would be crucial so that fathers had the opportunity to make sense of their experiences collectively, in a context where their experiences were no longer read as strange or tragic. There is some evidence that fathers of older children and adults, in retrospect, see their experience of fathering as a relational journey towards acceptance (Burrell et al., 2017). Therefore, making space for fathers to share their journeys with others in a similar context should arguably be an essential part of planned support (Ives, 2015). Indeed, there already exists research which confirms the efficacy of such an approach (Thompson-Janes et al., 2014). Tailored peer support should be built alongside greater efforts to train staff in the workplace, and in educational and support institutions, to enable better understanding of the pressures and challenges fathers experience, and to recognise the "affective economies *between* bodies" (Pluquailec, 2018, 12). This training should be led by fathers, in collaboration with experts in the autistic and learning disability communities, with the support of other relevant professionals and support networks.

We consider that further small-scale research which explores the experiences of fathers from diverse backgrounds or which examines the benefits of peer support networks for parents would be exceedingly valuable and would build upon the growing insights research is beginning to offer in these areas (e.g. Ives, 2014; Lam et al., 2016; Papageorgiou & Kalyva, 2010). We recommend practitioner–support group–service user–researcher partnerships which together might co-produce research which centres the needs and experiences of autistic people and people with learning disabilities and their families.

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DATA AVAILABILITY STATEMENT

The participants in this study agreed to take part on the understanding that their interview data would be deleted following write up of the project. As such, the original data have been deleted.

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