Exploring the experiences of fathers who have a child with a learning disability

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Abstract
Children with learning disabilities often require greater levels of support from their parents than other children. However, there can be differences in the caring experiences of mothers and fathers. This literature review aimed to develop an understanding of fathers’ experiences of caring for children with learning disabilities in the UK. Analysis of seven UK studies identified two overarching themes – gender stereotypes in parenthood and loss of imagined future.

Findings suggest that parenting a child with a learning disability can be a positive experience for fathers but can involve a journey through loss and grief before eventual acceptance of their child’s condition. Tailored interventions, such as male-only support groups, might help fathers as they move through this journey.

Background
Having a child with a learning disability can be challenging, with parental responsibilities often continuing long after the child’s adolescence (Auriemma et al. 2022, Oakes and Douglass 2023). More than half of people with learning disabilities in England continue living with their families into adulthood, resulting in parents providing care and support into old age (Atkinson 2017). This can affect parents’ physical and psychological well-being, leading to poor family relationships later in life (Enea and Rusu 2020).

Fathers have a significant role in caring for their children and are integral in the family support system (May and Fletcher 2013, Panico et al. 2019). Fathers of children with learning disabilities are more likely to remain involved in their child’s life if they have early active engagement (Flippin and Crais 2011). However, barriers such as the traditional gender expectation that men should provide financially prevent some fathers from contributing equally to childcare (Brown et al. 2012, Grau Grau et al. 2022). Also, while paternity rights, such as standardised paternity leave, are increasingly recognised through legislation and policy initiatives, the financial burden of parenting often rests with the father.
This can force fathers back into employment, reducing the support they can provide at home. Cohen et al (2016) emphasised the often significant differences in mothers’ and fathers’ experiences of parenting children with learning disabilities, while Potter (2017) noted that, in many cases, support is tailored towards mothers, while fathers’ needs and experiences are not considered as important, which means a significant person in the child’s support system is overlooked.

A UK literature review exploring fathers’ experiences of having a child with a learning disability found that they felt excluded from services and undervalued by professionals compared with their child’s mother (Davys et al 2017a). Davys et al (2017a) suggested that the timing of any services provided should consider fathers’ potential work commitments, emphasising the importance of the father-child relationship.

A more recently published international review of fathers’ experiences of having a child with a learning disability (Marsh et al 2020) found similar themes as Davys et al (2017a), including fathers’ anxieties about the future and concerns about a lack of coping strategies. However, the transferability of international evidence to UK settings can be an issue; for example, the nationalised healthcare system in the UK can affect the accessibility and quality of services compared with countries with a private healthcare system (Papanicolas et al 2019). Additionally, there may be cultural differences in attitudes towards people with learning disabilities in different countries, which might affect fathers’ experiences (Scior and Werner 2016). Therefore, the authors of this article undertook an updated literature review focusing on fathers of children with learning disabilities in the UK.

**Aim**
To explore UK fathers’ experiences of having a child with a learning disability.

**Methods**
The literature review began in September 2022. The authors used a systematic approach following guidance by Aveyard (2018). Synonyms of keywords (Box 1) and Boolean operators (AND/OR) were used to refine and expand the search of the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), APA PsycInfo and the British Nursing Database. The search generated 293 articles.

The titles and abstracts of retrieved articles were skim-read by the first author (EC) to check if they met the eligibility criteria (Table 1). Following removal of duplicates, screening and full text read, seven qualitative research articles were selected for review. These articles were appraised by EC using the Critical Appraisal Skills Programme (CASP) (2018) qualitative research tool. Findings were thematically synthesised using Thomas and Harden’s (2008) line-by-line approach to identify common themes.

**Findings**
The seven studies included in the review are summarised in Table 2. All seven studies were determined credible through CASP (2018) appraisal.

Using Thomas and Harden’s (2008) approach, EC undertook initial coding of the studies which identified six themes – loss, bereavement, isolation, lack of support, acceptance and male stereotypes.

**Key points**
- Fathers have a significant role in caring for their children and are integral in the family support system
- Stigma is a potentially important issue in fathers’ experiences of having a child with a learning disability
- Improved understanding of fathers’ experiences may better equip learning disability nurses to support the wider family through the stages of grief, adaptation and acceptance

**Box 1. Synonyms of keywords**

| "learning disab*" |
| "intellect* diasb*" |
| "intellect* impair*" |
| "Child*" |
| "Son*" |
| "Daughter*" |
| "Father" |
| "Dad*" |
| "Paternal" |
| "Parent*" |
| "Experience*" |
| "View*" |
| "Perception*" |
Following reflection and supervisory discussions with the second author (ED), these themes were combined to form two overarching themes – loss of imagined future and gender stereotypes in parenthood.

**Loss of imagined future**
This theme was identified in all seven studies and focused on fathers’ feelings of loss and grief for the future they had imagined for themselves and their child. Participants in three studies (Davys et al 2017b, Ridding and Williams 2019, Cameron and Cooper 2021) discussed the grief they experienced over the loss of a ‘perfect’ child, as well as their ongoing acceptance of their child’s diagnosis, adjusting to their new life and the loss of traditional developmental milestones.

This theme included fathers’ relationships with their partners. One participant in Thackeray and Eatough’s (2018) study commented that they could understand why parents were prone to divorce after they had a child with a learning disability, due to the challenges involved. A participant in Davys et al (2017b) suggested they felt like the ‘third person’ in the relationship dynamic between themselves, their partner and the child. In other studies, participants commented on the strain and psychological effects on their wives, such as guilt, which left them feeling that they had to ‘hold back’ their own emotions to protect the relationship (Cameron and Cooper 2021, Dunn et al 2021). In contrast, participants in Ridding and Williams’ (2019) study stated that their child had brought them closer to their spouses, albeit with a conscious mutual effort to improve communication and share caring responsibilities. This could suggest that having a child with a learning disability can strengthen spousal relationships by encouraging partnership working.

Participants in some studies emphasised how stigma about learning disabilities was a challenge in wider society and among family and friends (Batchelor et al 2021, Frizell 2021). Some fathers felt anxious about telling others about their child’s diagnosis and experienced shame. One father commented on his wider family’s negative response to his child’s diagnosis and the isolation this caused (Batchelor et al 2021). Cameron and Cooper (2021) also identified that some fathers felt judged by others’ perceptions of their child’s behaviour. Some fathers discussed their sense of loneliness, feeling that they were unable to make meaningful connections with others because no one understood their experiences (Thackeray and Eatough 2018, Batchelor et al 2021, Frizell 2021). In contrast, Ridding and Williams (2019) commented on how societal views on people with learning disabilities had improved and how this helped counteract some of the fathers’ negative experiences.

Five studies identified fathers’ anxieties about the future, three of which identified a specific anxiety about the standard of services available to children with learning disabilities later in life (Davys et al 2017b, Cameron and Cooper 2021, Dunn et al 2021). Some fathers also expressed anxiety about their child’s comorbidities and the constant fear that their child’s health might decline (Thackeray and Eatough 2018, Cameron and Cooper 2021).

<table>
<thead>
<tr>
<th>Table 1. Eligibility criteria</th>
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<tbody>
<tr>
<td><strong>Inclusion</strong></td>
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<tr>
<td>» Focus on fathers with a child with a learning</td>
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<tr>
<td>disability</td>
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<tr>
<td>» UK-based research</td>
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<tr>
<td>» Articles published between 2017 and 2023</td>
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<td>» Primary, qualitative research</td>
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<tr>
<td><strong>Exclusion</strong></td>
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<tr>
<td>» Focus on mothers with a child with a learning</td>
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<tr>
<td>disability or parents where a father’s data</td>
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<tr>
<td>cannot be extrapolated</td>
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<tr>
<td>» Non-UK research</td>
</tr>
<tr>
<td>» Published before 2017</td>
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<tr>
<td>» Secondary and/or quantitative research</td>
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All seven studies identified positive aspects of parenting a child with a learning disability. For example, some fathers described the ‘strong bond’ they felt with their child and the joy they brought to their lives (Davys et al 2017b, Thackeray and Eatough 2018, Dunn et al 2021). Others commented on their personal growth as a result of having a child with a learning disability (Davys et al 2017b, Ridding and Williams 2019, Batchelor et al 2021, Cameron and Cooper 2021, Frizell 2021), how much their parenting ‘journey’ had taught them and the value of being able to ‘give back’ to their children (Batchelor et al 2021).

### Table 2. Summary of studies included in the review

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Sample and location</th>
<th>Data collection and analysis</th>
<th>Relevant findings</th>
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<tbody>
<tr>
<td>Batchelor et al (2021)</td>
<td>» Exploration of fathers’ experiences of a support group for men caring for children with disabilities and/or developmental delay</td>
<td>» 15 fathers » South Wales</td>
<td>» Semi-structured interviews » Thematic analysis</td>
<td>» Fathers discussed the benefits of all-male support groups » Fathers felt understood and ‘connected’ for the first time » Fathers discussed issues with modern male identity, such as struggling to make ‘connections’ » Findings showed a lack of appropriate services for fathers</td>
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<td>Cameron and Cooper (2021)</td>
<td>» To understand fathers’ experience of being a carer for autistic children with learning disabilities</td>
<td>» Four fathers » Manchester</td>
<td>» Semi-structured interviews » Interpretive phenomenological analysis</td>
<td>» Fathers felt a sense of loss of identity and fear for the future » Fathers experienced difficulties in managing social stigma and feelings of shame » Fathers reported challenges in accepting their child’s diagnosis</td>
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<tr>
<td>Davys et al (2017b)</td>
<td>» To understand the concerns of being an older father of a child with a learning disability</td>
<td>» Seven fathers » Manchester</td>
<td>» Semi-structured interviews » Interpretive phenomenological analysis</td>
<td>» Fathers had varied responses to their child’s diagnosis and the effects of this on their lives » Fathers felt the need to adhere to traditional gender stereotypes</td>
</tr>
<tr>
<td>Dunn et al (2021)</td>
<td>» To understand the experience of being an older father of a child with a learning disability</td>
<td>» Seven fathers » Scotland</td>
<td>» Semi-structured interviews » Grounded theory</td>
<td>» Fathers reported that their sense of identity changed over time » Participants discussed positive aspects of being an older father, such as strong bonds with their child, but also identified stressors, such as fear of the future and negative experiences with services</td>
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<td>Frizell (2021)</td>
<td>» To explore parents’ feelings about discovering their child had Down’s syndrome</td>
<td>» Five mothers and three fathers (only fathers’ data were synthesised in the literature review) » England</td>
<td>» Semi-structured interviews » Interpretive phenomenological analysis</td>
<td>» Fathers reported challenges in accepting the reality of their child’s diagnosis » Fathers felt unsupported and isolated and experienced stigma from family and friends</td>
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<tr>
<td>Ridding and Williams (2019)</td>
<td>» To understand fathers’ experiences of parenting a child with Down’s syndrome</td>
<td>» 15 fathers » North west England</td>
<td>» Semi-structured interviews » Grounded theory</td>
<td>» Fathers found it challenging to accept the reality of their child’s diagnosis » Fathers needed to adapt the parent/spousal role to accommodate their child » Fathers felt that society’s views of learning disabilities were improving</td>
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<tr>
<td>Thackeray and Eatough (2018)</td>
<td>» Exploration of the paternal experience of parenting a young adult with a developmental disability</td>
<td>» Five fathers » London</td>
<td>» Semi-structured interviews » Interpretive phenomenological analysis</td>
<td>» Fathers had ongoing concerns for their child’s well-being and reported limited available opportunities for their child » Fathers felt their child brought joy to their lives » Fathers reported struggling to connect with painful emotions</td>
</tr>
</tbody>
</table>
Gender stereotypes in parenthood

This theme was present in all seven studies, with fathers identifying their need to be the breadwinner and ‘protector’ figure in the family. Some participants discussed their roles in terms of traditional male ideology, in that their experience of giving up work to care for their child led to feelings of guilt and failure because they were unable to provide financially for the family (Batchelor et al 2021, Cameron and Cooper 2021, Dunn et al 2021). Additionally, gender stereotypes were discussed in relation to the division of tasks. Fathers in four studies (Davys et al 2017b, Thackeray and Eatough 2018, Ridding and Williams 2019, Dunn et al 2021) identified the mother as the main carer of the child, with one participant stating that he only helped with childcare when the mother was unavailable (Davys et al 2017b). Another father felt that the uneven division of tasks between himself and his wife resulted from his tiredness after work, which affected his ability to care for their child (Ridding and Williams 2019).

In some studies, fathers discussed struggling to accept help or share their emotions (Thackeray and Eatough 2018, Batchelor et al 2021). One father felt that accepting their child's diagnosis made him a ‘lesser man’ (Davys et al 2017b), while another stated that they were not given the opportunity to express their concerns and that feelings of isolation were exacerbated by poor communication between themselves and their partner. Some fathers also commented on their difficulties in communicating more generally, for example with healthcare professionals and members of the wider family (Davys et al 2017b).

The effect of having a child with a learning disability on fathers’ employment was discussed in all the studies. Some fathers felt the need to give up work entirely to support the family (Cameron and Cooper 2021, Dunn et al 2021), while others gave up their careers for jobs that better suited the needs of their child (Davys et al 2017b, Thackeray and Eatough 2018). One study emphasised the need for parents of a child with a learning disability to have a reasonable employer who would provide flexible work patterns (Ridding and Williams 2019).

Fathers also identified a lack of availability of appropriate services for their child (Davys et al 2017b), with some saying they felt let down by doctors and nurses (Ridding and Williams 2019). Some fathers specifically commented on how support for their child was female-dominated and was not appropriate for men (Davys et al 2017b, Batchelor et al 2021, Frizell 2021).

Participants in one study were members of a fathers’ support group and commented how this helped them to feel ‘connected’ and understood for the first time, and gave them the opportunity to be open without fear of judgement or embarrassment, which emphasised the importance of tailored support (Batchelor et al 2021).

Five of the studies touched on a perceived male need to ‘problem solve’ and become the expert in their child's care. Batchelor et al (2021), for example, emphasised the difference between genders on this topic, with fathers describing their observations that women typically accepted information provided by healthcare professionals where men felt compelled to examine it and look for resolution. Fathers in three studies (Davys et al 2017b, Batchelor et al 2021, Dunn et al 2021) discussed the sense of purpose they gained from becoming the expert on their child's learning disability and offering support to other parents.

Discussion

The findings suggest that parenting a child with a learning disability can be a positive and rewarding experience. However, it also affects all areas of a father’s life, often involving a journey through loss and grief before eventual acceptance of their child's condition. The findings also suggest that tailored support, such as male-only support groups, may be beneficial in helping fathers move through this journey (Batchelor et al 2021).
Stigma
While Davys et al (2017a) did not identify stigma as a primary theme in their UK literature review, it was mentioned in the findings of some of the studies they reviewed, including Hornby (1995), in which participants discussed their trauma at their child’s diagnosis, and West (1998), where participants discussed the reactions of family and friends. Stigma was not a primary theme in Marsh et al’s (2020) international review, however one of the studies they reviewed (Huang et al 2012) identified cultural stigma about learning disabilities in Taiwan.

The findings of the studies in the present literature review suggest that stigma is a potentially important issue in fathers’ experiences of having a child with a learning disability (Thackeray and Eatough 2018, Frizell 2021). Stigma can lead to fathers experiencing feelings of guilt and shame following their child’s diagnosis, as well as social isolation due to judgement from the wider public and, in some cases, family and friends (Thackeray and Eatough 2018, Cameron and Cooper 2021, Dunn et al 2021, Frizell 2021). Conversely, fathers of children with Down’s syndrome in the study by Ridding and Williams (2019) believed that society’s attitudes towards people with the condition was improving. This finding was restricted to one study with a small sample size, so should be viewed with caution. However, these contrasting attitudes about stigma could be attributed to the recent increased representation of people with Down’s syndrome in mainstream media (Thomas 2021).

Although Davys et al (2017a) did not explicitly find differences in participants’ views on stigma, other differences were identified by the studies they reviewed. For example, in Hornby’s (1993) study, fathers of children with Down’s syndrome reported more positive than negative consequences for their marriages, while Ricci and Hodapp (2003) reported that fathers experienced more positive traits in their children with Down’s syndrome and less negative effects on their lives compared with children with other intellectual disabilities. In an article published after completion of the present literature review, Van Riper et al (2023) emphasised a change in attitude among families of children with Down’s syndrome, from negativity about their child’s condition to a feeling of strength and resilience. Further research into understanding these differences could be beneficial.

Scior and Werner (2016) emphasised the importance of people with learning disabilities appearing in the media, for example on television or in films, in reducing stigma, but also stressed the detrimental effect of negative representations of learning disabilities. Furthermore, a Mencap (2015) report suggested that interventions by charities in the learning disability field rarely reach audiences that do not already have a positive attitude towards people with learning disabilities. This suggests that work is required to promote a positive depiction of people with learning disabilities to a wider audience. One suggestion is for learning disability charities to collaborate with mainstream media organisations to tackle stigma by promoting inclusivity, for example by including actors with a learning disability as regular characters in popular television series.

Scior et al (2020) suggested that the most effective way to reduce stigma is by promoting regular interactions between people with and without learning disabilities. Examples of this might include mainstream schools pairing with local special educational needs schools to support face-to-face engagement between students and inviting guest speakers with lived experience of learning disabilities to lectures and classes.

The burden of stigma can cause fathers to socially isolate (Mitter et al 2019). Therefore, the authors of the present review recommend the development of services...
or interventions such as support groups that provide fathers with an opportunity to share experiences and receive relatable emotional support. When developing such services, it could be useful to undertake an online survey to ask fathers what they would find helpful. Survey questions could ask about optimal timing to fit with fathers’ work commitments, as well as group size, discussion topics and delivery method, for example face-to-face or online. The survey findings could provide a rationale for developing such services, which could be provided by health services or local charities.

Acceptance
In the studies reviewed, fathers reported experiencing a journey to acceptance of their child’s condition, often beginning with feelings of grief for the lost future they had imagined. These negative emotions were sometimes exacerbated by the effect of their child’s condition on daily family life, such as marital disruption and loss of identity through career loss or change. This journey to acceptance was discussed in Davys et al’s (2017a) literature review, which included reports of fathers adjusting to and eventually overcoming their initial distress at their child’s diagnosis. However, no recommendations for supporting this adjustment were provided. In a separate study exploring how parents mentally adjust to their children’s developmental diagnosis, Broski and Dunn (2020) proposed a three-stage transitional model – fear and uncertainty, frustration and adaptation and acceptance and pride – which is consistent with the findings of the present review. Participants in the support group reported by Batchelor et al (2021) suggested that the group enabled them to feel connected and understood for the first time and offered them an opportunity to be open without fear of judgement or embarrassment. Wider availability of such support groups might support fathers along the journey to acceptance.

Tailored support
Overall, the findings of this literature review emphasise the need for healthcare services to improve support for fathers of children with learning disabilities. All seven studies included comments from fathers on the lack of appropriate services, which exacerbated the natural grieving process. Tailored father-focused support, especially in the early stages of a child’s diagnosis, may improve the care fathers can provide and have long-lasting effects on family well-being, including reducing other disrupting factors such as marital strain (Flippin and Crais 2011). With improved understanding of the experiences of fathers, learning disability nurses may also feel better equipped to support the wider family through the stages of grief, adaptation and acceptance.

Conclusion
This literature review explored the experiences of fathers with a child with a learning disability. The findings show that parenting a child with a learning disability can be a positive experience for fathers but that it can also affect all areas of their life and may involve a journey through loss and grief before eventual acceptance of their child’s condition. The findings emphasise the need for tailored father-focused services or interventions to support them through this journey.

References
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