

“They don't think I can cope, because I have got a learning disability...”: Experiences of stigma in the lives of parents with learning disabilities

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Abstract

Background: Parents with learning disabilities report facing a widely held ‘presumption of incompetence’, placing them under pressure to prove their parenting competence. In collaboration with a learning disability theatre company, an inclusive research methodology explored experiences of parenting with learning disabilities, with a specific focus on the operation of stigma in parents' lives.

Method: Interviews with 17 mothers and 5 fathers who self-identified as having learning disabilities were co-facilitated by learning-disabled co-researchers, and analysed using thematic analysis, with input from people with learning disabilities.

Results: Thematic analysis generated four key themes; (1) positions of powerlessness, (2) assumptions of incompetence, (3) challenging assumptions and proving competence and (4) claiming power.

Conclusion: Parents reported experiencing stigma and disempowerment within their networks, yet continued to embrace their valued parental identity and drew strength from involvement with self-advocacy organisations. The research informed arts-based performance pieces and resources aimed at training professionals and raising public awareness.

KEY WORDS

inclusive research, intellectual/learning disabilities, parenting, qualitative, thematic analysis

1 | INTRODUCTION

With increasing recognition of the rights of people with learning disabilities¹ to live fulfilling and purposeful lives (McGaw, 1998), the number of those becoming parents has unsurprisingly grown (Emerson et al., 2005) and with it a small yet detailed literature on parents' experiences. Such parents are likely to have complex needs that have the potential to impact their role as parents (Stewart &

MacIntyre, 2017); they may have difficulties with literacy and activities of daily living, self-esteem or emotional needs (Tarleton & Heslop, 2020) and are likely to face multiple social disadvantages in their parenting role, including significantly greater socioeconomic disadvantage, environmental adversity, poorer mental health and less intergenerational support (Emerson et al., 2015; Llewellyn & Hindmarsh, 2015). Whilst the number of parents with learning disabilities in the United Kingdom is not known, such parents commonly face formal assessment of their parenting ability by social care services (McGaw & Candy, 2010), and it seems that these families are disproportionately likely to be subject to child protection intervention

¹Also known as ‘intellectual disabilities’ in the academic literature, the terms ‘learning disability’ and ‘learning-disabled’ have been used throughout this paper as the favoured terms of the co-researchers and reference groups involved with this study.

or child removal (Tarleton & Turney, 2020). It has been reported that it is not the learning disability per se that can result in poorer outcomes for children and families where parents have learning disabilities, but the social disadvantage faced by these families (Collings & Llewellyn, 2012). Despite these challenges, research suggests parents can and do offer 'good enough' parenting when appropriate support is in place (MacIntyre et al., 2019; Tarleton & Porter, 2012; Tarleton & Ward, 2007). There are many examples in the literature that promote best practice for professionals when working with parents with learning disabilities, including the need for proactive, ongoing and individualised support through coordinated multi-agency working (Tarleton & Turney, 2020), with an emphasis on relationships-based support (Tarleton & Heslop, 2020). Good Practice Guidance published by the Department of Health and Department for Education and Skills (2007), and updated by the Working Together with Parents Network (2016), offers clear principles to support professionals in providing an equitable service to families where one or more parent has a learning disability. Yet, there remain concerns that these principles are not being consistently applied.

1.1 | Parenting, learning disability and stigma

Despite policies aimed at increasing social inclusion, independence and empowerment in recent years, people with learning disabilities remain a highly stigmatised group (Scior, 2011). Stigma is defined as the 'process by which certain groups...are marginalised and devalued by society because their values, characteristics or practices differ from the dominant cultural group' (Ali et al., 2012, p. 212), and typically involves the co-occurrence of labelling, stereotyping and prejudice, leading to a loss of status and discrimination (Link & Phelan, 2001). Importantly, Link and Phelan (2001) point out that 'for stigmatisation to occur, power must be exercised' (p. 364); that is, the subjugation of people with learning disabilities as a social group is maintained by the disempowerment felt by having one's access to rights, resources and opportunities determined by 'powerful others' in the social hierarchy. The growing literature base exploring the qualitative experiences of parents with learning disabilities consistently highlights the scrutiny and opposition they routinely face from those in their social and professional network, representing a widely held 'presumption of incompetence' that places undue pressure on parents to prove their parenting abilities and 'worthiness' above that expected within the non-learning-disabled population (Booth, 2000; Gould & Dodd, 2014; Murphy & Feldman, 2002). In a review of child custody removal cases in Iceland, Sigurjónsdóttir and Rice (2016) detected two key discriminatory assumptions routinely made by professionals that resonated with the wider international literature: (a) interpreting a diagnosis of a learning disability as evidence of incompetent parenting in and of itself; and, (b) assuming parents with learning disabilities could not benefit from support, education and training. They suggested that despite progression in policies, anxieties may nonetheless be rooted in older eugenic

concerns that continue to (possibly unconsciously) shape the prism through which the reproductive rights of people with learning disabilities are viewed. Indeed, although the governance of sexuality and reproductive rights using sterilisation has notably declined in recent decades (Hamilton, 2015), parents with learning disabilities often continue to face strong opposition and disapproval from family and professional networks when disclosing pregnancies (Aunós & Feldman, 2002).

Emerging research exploring how parents with learning disabilities adopt and value their parental role suggests this represents a highly desirable identity (Mayes et al., 2011; Shewan et al., 2014). Adults with learning disabilities continue to be at the mercy of others' perceptions of them as 'child-like' or 'asexual' (Wilkinson et al., 2014), and therefore, the parenting identity offers a much-valued 'adult' status (Booth & Booth, 1994) that acts as a rebuttal against the 'enforced primary identity' of being learning disabled (Edmonds, 2000, p. 21). It has been suggested, however, that where this comes under threat, such as when children are removed from a parent's care (Edgerton, 1967), or where the parent identity is 'attacked' through opposition, scrutiny and presumptions of incompetence (Edmonds, 2000; McConnell & Strike, 2002), this may act to negate the positive self-evaluation associated with the parental role, and further emphasise the stigmatised status of being 'learning disabled'. Crucially, this can lead to an increased vulnerability to psychological distress and a rejection of the perceived 'attacker' (Edmonds, 2000), which has important implications where the individuals and systems being rejected are the very services designed to provide parents with support.

Research into the role of social and professional networks in supporting learning-disabled mothers has highlighted the inherent power imbalance that exists between the mothers and more powerful 'others' (Traustadóttir & Sigurjónsdóttir, 2008). Upon accessing support services, it appears that mothers remain dependent on non-learning-disabled 'allies' within their social network, who hold stronger positions of power relative to themselves, to negotiate with the service providers and advocate on their behalf, without usurping their position as the central figure in their baby's life (Mayes et al., 2011). However, the quality of informal support varies widely; the mere presence of a social network does not guarantee support received will be helpful (Stenfert Kroese et al., 2002), and can even inhibit parenting when offered in a manner that assumes parental incompetence (Tucker & Johnson, 1989). Furthermore, parents with learning disabilities are often socially isolated (Schuengel et al., 2017) and excluded within their communities (Llewellyn & McConnell, 2002), and thus may even be entirely reliant on the professional network for support. Taken together, the existing research literature, therefore, highlights a crucial need to understand what parents' experiences tell us about the operation of stigma in their lives, and specifically exploration of how this might impact on parents' experiences of accessing appropriate support within their social and professional networks to enable them to develop the competence to fulfil their valued parental role.

1.2 | Limitations of existing research literature

Despite providing valuable insight into the challenges faced by parents with learning disabilities, the conclusions that can be drawn from the existing literature on parents' experiences have been limited by a number of methodological issues (Emerson et al., 2015). The majority of studies have relied on samples already known to services (IASSID, 2008), potentially biasing inclusion of parents with a higher degree of disability and/or need. This not only limits the generalisability of the findings but potentially overestimates the impact that having a learning disability has upon parental competence and child outcomes (Emerson et al., 2015). This is further compounded by an almost exclusive focus on mothers' experiences, with the exception of a few small studies of fathers with learning disabilities in recent years (Dugdale & Symonds, 2017; Shewan et al., 2014).

Furthermore, given the multiple disadvantages faced by parents with learning disabilities (Emerson et al., 2015), and the sense of powerlessness reported by parents who have undergone formal involvement of social care services (Gould & Dodd, 2014; Llewellyn et al., 2010), there is a risk that the inherent power differentials that exist between the researcher and 'researched' (Råheim et al., 2016) may have been amplified when interviews have been conducted by 'powerful' professionals associated with health and social care services, possibly limiting parents' ability or willingness to speak openly and honestly. Despite calls for increased research participation of people with learning disabilities (Beail & Williams, 2014; Ditchman et al., 2016), inclusive methodologies have not yet been extensively employed in research with learning-disabled parents.

1.3 | Current study

The idea for this innovative collaboration between arts and academic research came from Mind the Gap, the largest UK inclusive theatre company for people with learning disabilities, and specifically from a personal source; the experience of a learning-disabled parent-to-be who was undergoing a parenting assessment, and facing some of the challenges outlined in the literature. Upon researching the subject matter, the company quickly established that not only was it difficult to access for non-academics and non-professionals, but that there was an absence of the voices and perspectives of learning-disabled parents in the information available and accessible to them. They wanted to bring this hidden subject to a 'mainstream' audience using their creative means and base their project on 'real lives', which led them to interview parents about their experiences.

The present study, therefore, extended a preliminary research study (Theodore et al., 2018) to have a specific focus on what learning-disabled parents' experiences tell us about the operation of stigma in their lives. Specifically, the study sought to purposefully recruit a large, heterogeneous sample of both mothers and fathers who self-identify as having a learning disability, using an inclusive methodology involving learning-disabled co-researchers in the

design, data collection, analysis and dissemination of the research (Walmsley & Johnson, 2003). The project encompassed broader aims to develop arts-based resources aimed to contribute to staff training and service provision, and raise public awareness, to reduce societal stigma and increase progressive attitudes towards the parenting rights of those with learning disabilities through improved awareness of their experiences.

2 | METHOD

This qualitative study employed an inclusive research methodology involving learning-disabled co-researchers.

2.1 | Participants

Participants did not need to be eligible for specialist adult social care services, to better represent the 'hidden majority' (Emerson, 2011) of parents with less severe learning disabilities who are less likely to be known to adult services and thus more likely to be neglected in the research literature (WTPN, 2016). Participants were recruited on the basis of self-identifying as having a learning disability and were identified through seven different self-advocacy groups for parents with learning disabilities across the United Kingdom (in Yorkshire, Tyneside and Greater London). The sample included 17 mothers and 5 fathers, of varied ages, all living in the community (see Table 1). Whilst there were varied current childcare arrangements in the sample, the majority ($n = 15$) had experienced some short-term or long-term child removal; over half the sample ($n = 13$) were currently living apart from their children, and of those who were currently living with their children ($n = 9$), two were known to have experienced some previous separation from their children (e.g., children had been previously fostered).

2.2 | Data collection

In line with the inclusive 'participatory methodology' (Bergold & Thomas, 2012), participants were interviewed by one of three learning-disabled researchers (hitherto referred to as 'co-researchers'), with the support of a 'writing mentor' (a non-learning-disabled writer working with Mind the Gap). In total, three learning-disabled co-researchers were involved in the interviews, although one co-researcher (D.F.), a research intern on the project, was most prominently involved in the recruitment, interviews, analysis and dissemination. An interview guide was developed together with the co-researchers and the writing mentor prior to interviews, covering broad areas related to parents' experience of choosing to have children, pregnancy, childbirth and early parenting, as well as experiences of separation from children, and of help from others. The interview schedule was designed to be used flexibly to capture the variety of individual experiences.

TABLE 1 Participant demographic data

Pseudonym	Gender	Age	Ethnicity	Children (ages)	Parents' living arrangements	Children's contact arrangements	Children's services involvement
Megan	Female	26	White British	1 (aged 1)	Independent	Living together	N
Kimberly	Female	31	White British	1 (aged 2)	Independent	Living together	Y
Helen	Female	36	White British	3 (aged 8–12)	Independent	Living together	Y
Kelly	Female	40	White British	1 (aged 18)	Independent	Living together	Y
Carol	Female	55	White British	2 (aged 22 and 33)	Independent	Living together	Y
Jill	Female	61	White British	1 (aged 23)	Independent	Living together	Y
Marie	Female	53	Black British	6 (ages unknown, 2 under 18)	Independent	Under 18 s living together (previously fostered)	Y
Fatima	Female	51	Indian	4 (aged 13–31)	Independent	Under 18 living together (previously fostered)	Y
Jenny	Female	43	White British	2 (aged 17 and 20)	Independent	One living together, one living in specialist housing; regular contact	N
Denise	Female	60	White British	1 (aged 23)	Independent	Living apart; regular contact (previously fostered)	Y
Khalil	Male	35	British Pakistani	3 (aged 6–15)	Semi-independent	Living separately from father; supervised contact	Y
Rick	Male	43	White British	1 (aged 1)	Independent	Living separately from father; regular contact	N
Neil	Male	44	White British	3 (aged 14–25)	Independent	Living separately from father; contact with adult children	N
Mike	Male	48	Black British/ Caribbean	4 (aged 16–29)	Independent	Living separately from father; contact unclear	Y
Amy	Female	43	White British	2 (14 and 17)	Independent	One child adopted, one child fostered; limited contact	Y
Linda	Female	-	White British	3 (ages unknown, youngest 24)	Independent	One adopted, two fostered; no contact	Y
Dawn	Female	42	White British	3 (aged 10–20)	Independent	Two fostered, one adopted; contact with eldest two, postal contact with youngest	Y
Rachel	Female	26	White British	2 (3 and 9 months)	Independent	Both adopted; postal contact with adoptive parents	Y
Alison	Female	-	White British	1 (aged 3)	Independent	Adopted; postal contact with adoptive parents	Y
Patrick	Male	-	White British	2 (aged 3 and 19)	Independent	Adopted; postal contact with adoptive parents	Y
Jessica	Female	29	Mixed White and Black Caribbean	1 (aged 7)	Independent	Adopted; no contact	Y
Julie	Female	-	White British	1 (unknown, under 18)	Independent	Adopted; no contact	Y

Mind the Gap actively approached self-advocacy groups for parents with learning disabilities, and attended group sessions to introduce the organisation and outline the aims of the project. If a parent expressed an interest in participating, the co-researcher and writing mentor met them for an initial introduction, to talk through the project and the research process. Information about the project and the research interviews was, therefore, provided verbally by the co-researcher and writing

mentor, and this was supported by an easy to understand written research information sheet. Written informed consent to take part in the research was gained from all participants. Interviews typically took place at a later date, involving reiteration of the consent and confidentiality procedures. Interviews lasted for between 16 and 97 min, averaging 51 min. After the initial interview, a narrative account was written up by the writing mentor and co-researcher and shared with the

participant at a later meeting, to reaffirm their informed consent and ensure they were happy with the information they had shared in the interview. Participants also completed a brief demographics questionnaire.

2.3 | Ethics

University ethical approval was obtained. All participants had mental capacity to give informed written consent to participate. Careful consideration was taken to ensure participants fully understood and consented to their participation in the project, with emphasis that they were free to withdraw from any element of the project at any time. Participants were interviewed individually due to the sensitive nature of the topic. Pseudonyms have been assigned to participants.

2.4 | Analysis

Verbatim transcriptions of the interviews were analysed using NVivo 11 software. An inductive thematic analysis of the data was undertaken using Braun and Clarke's (2006) six-phase method, to ensure academic rigour. Thematic analysis was considered appropriate given that it seeks to describe patterns across the data, allows for analysis of larger, heterogeneous samples (Braun & Clarke, 2006), and has been successfully employed in previous studies involving the participation of learning-disabled co-researchers (Beail & Williams, 2014; Stevenson, 2014). Thematic analysis' theoretical flexibility was also compatible with the critical-realist and inductive frameworks of the study (Clarke & Braun, 2013).

2.5 | Quality

Methodological integrity was maintained through adherence to published guidelines for qualitative research (Elliott et al., 1999), and the inclusive participatory research methodology (Walmsley et al., 2017) involved multiple credibility checks. During the initial stages of the analysis, the academic researchers introduced the co-researcher and writing mentor to the thematic analysis method, before each independently coding an interview transcript, and then reviewing together individual codes and interpretations. These ideas informed the academic researchers' coding of further transcripts. A second formal credibility check involved the preliminary thematic analysis of the full dataset being reviewed with the co-researcher and writing mentor. This supported the ongoing refinement of the themes, including adjustments to the language and interpretation.

One of the learning-disabled parent peer support groups who participated in the research was approached to be involved as a reference group, to support further credibility checking of the thematic analysis. The group consisted of 10 learning-disabled parents, six of whom had been interviewed for the research and four who had not.

During a group meeting attended by the academic researchers and writing mentor, the reference group were presented with an easy-read summary of the main emerging themes from the analysis; all fed back a strong resonance with each of the themes presented. Feedback from the group was incorporated into the final analysis, write-up and discussion of the results. Following completion of the study, eight members of this reference group also contributed to the development of the easy-read summary of the research project, to ensure it would be largely accessible to a learning-disabled audience.

Throughout the collaborative research process, the research team reflected together on their roles, assumptions and perspectives. At the time of the research, one academic researcher (L.F.), not a parent herself, was a trainee clinical psychologist with a long-standing professional interest in parenting and attachment, working clinically in a community perinatal mental health team and with previous clinical experience of working in a community adult learning disability team. The other, (K.T.), was a clinical psychologist and a mother, with particular research and clinical interests in supporting the needs of families where a parent has learning disabilities, working clinically in a community adult learning disability team alongside her concurrent role as an academic researcher. All of the learning-disabled researchers had considered future parenthood, although none were parents at the time of the research. The authors outline these various 'insider' and 'outsider' membership positions held by the research team (Corbin Dwyer & Buckle, 2009) to support the reader's understanding of how these positions may have influenced the research.

3 | RESULTS

The thematic analysis generated four substantive themes. Table 2 shows which participants contributed to which themes.

3.1 | Theme 1: Positions of powerlessness

Parents shared their experiences of being in persistent, and often inescapable, positions of powerlessness throughout their lives. This imbalance of power existed relationally, with parents often being involuntarily placed in a 'lesser' position by others, including partners, families and professionals.

Parents consistently shared early experiences of powerlessness. Some spoke about the lack of prospects that powerful others (e.g., teachers) had held for them, whilst others spoke of family overprotecting them, and how this had severely restricted their sense of independence and self-efficacy.

She [teacher] kept putting me down all the time, you know, you're not going to do too well and that (Megan)

Two-thirds spoke of enduring bullying throughout their early life, often directly attributing this to their learning disability.

TABLE 2 Summary of participants contributing to each theme

Theme	Contributing participants																					
	Kelly	Rachel	Marie	Helen	Mike	Khalil	Jenny	Rick	Kimberly	Amy	Neil	Denise	Linda	Julie	Dawn	Alison	Patrick	Carol	Jill	Fatima	Jessica	Megan
Positions of powerlessness	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Assumptions of incompetence	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Challenging assumptions and proving competence	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Claiming power	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

For many, this represented the beginning of a repeating pattern of stigmatisation and victimisation on the basis of perceived difference and vulnerability.

Special needs was not a nice thing to have. I mean, you get bullied no matter what you do (Dawn)

Early traumas were prominent in many parents' lives. Whilst seven parents explicitly shared their experiences of physical, emotional and sexual abuse growing up, others shared more implicit suggestions of trauma through their description of growing up in potentially toxic and neglectful environments, often featuring domestic abuse, parental mental ill-health and substance misuse.

Two-thirds of parents shared experiences of abuse in intimate relationships with current or past partners. There was a sense of powerlessness associated with the subjugation and victimisation they faced from their partners, which for many served as a continuation of earlier experiences of relationships. Some women described repeated experiences of abuse or exploitation in relationships, suggesting heightened and pervasive vulnerability.

Back then I didn't know anything about getting into a relationship, how dangerous it is (Rachel)

Notably, over half of the parents spoke of feeling betrayed by professionals, particularly where children had been removed from their care. Parents expressed feeling 'tricked' by the system and surprised by the outcomes. This not only led to a breakdown in their relationships with professionals, but more enduring difficulties with developing trust.

I thought they were gonna help us, but I think they were just doing it to take the bairn off us (Alison)

Three-quarters of parents shared difficulties finding a voice, expressing a sense of feeling victimised and identified as an 'easy target' (Marie) as a consequence of feeling unable to assert themselves.

People with learning disability, they're too frightened of speaking up. They daren't. They won't...or they can't do it on their own (Jill)

They often shared perceptions of being spoken down to and treated 'like a child' (Jill). This was particularly prominent where professionals from multiple services were involved, with parents sharing their experiences of feeling largely ignored and then patronised when spoken to

Social Services talked to them [other professionals] more than they talked to me...when they did talk, they treat us like a two-year-old, talking down to us... (Dawn)

3.2 | Theme 2: Assumptions of incompetence

They don't think I can cope, because I have got a learning disability...it always came back to that (Marie)

Parents described their experiences of others (predominantly professionals) presuming they would not be competent parents. Parents felt they were regarded differently to those without learning disabilities, resulting in particular pressures to prove competence in the face of what they felt were unreasonable expectations.

Parents shared messages they had received that their learning disability meant parenthood was an unattainable prospect for them, and sometimes actively discouraged.

The doctors didn't really want me to have the baby, with me having a learning disability (Carol)

Parents felt that professionals struggled to see beyond their learning disability, making assumptions and judgements based upon their disability rather than their capabilities and skills as a parent. Parents felt they were evaluated through a lens of incompetence and described their perception that professionals were 'just looking out for faults' (Alison).

If you've got a learning disability you get judged you can't parent (Neil)

Amongst those co-parenting with a non-learning-disabled individual, there were often suggestions of the wider system minimising the learning-disabled parent's role by automatically assuming greater competence from the non-learning-disabled parent/carer, even in cases of domestic abuse.

My relationship with their dad got bad...the social workers said if I left him, they will put all the three kids in care. I wouldn't have got no support. He used to hit me (Marie)

Parents described feeling pressure from the outset to actively demonstrate their parenting skills and commitment to professionals. Once pregnant, a number of couples proactively self-referred to social care as a means of pre-emptively acknowledging their support needs and demonstrating their commitment to working with services to develop their abilities. However, for some parents, there was a sense this backfired when they experienced professionals as prioritising assessment of current parenting capabilities over the identification and implementation of support.

She [midwife] even got social services involved to see if they'll help me...she assessed me and they decided that he couldn't come home with me (Jessica)

Parents felt they had to demonstrate a higher level of competence and commitment than might be expected from non-learning-disabled

parents, and expressed frustration around having to endure increased scrutiny and heightened expectations as a consequence of their learning disability.

There are a lot of people that don't have a learning disability that are really naff parents and they don't have to go through all the social services (Kimberly)

Over half of the parents expressed the apparent impossibility of the standards they were being held to, describing that they 'couldn't do right for doing wrong' (Linda) and were unable to win the approval of professionals no matter how hard they tried. Parents shared their experiences of feeling criticised by professionals, and like they were actively trying to 'bring me down' (Helen). From parents' perspectives, the standards they felt they were being held to were unreachable, or were perhaps elusive; that is, parents were perhaps unaware of what was expected of them and the processes by which they would be assessed, thus leaving them feeling bereft, confused and frustrated when told their efforts were not enough.

She [social worker] said 'you can't keep your son... because you didn't pass the assessment'. I didn't know an assessment had been done (Amy)

Amongst those who had undergone parenting assessments and child protection proceedings, many parents felt they had done everything asked of them and yet still faced the prospect of their children being removed from their care.

I thought I was going to get my children back 'cause I was doing all the right things' (Rachel)

Some parents expressed difficulties comprehending the complexity of the factors that ultimately led to the decision to remove children from their care. Sometimes parents shifted the 'blame' and responsibility onto others when reasons for the judgement remained unclear to them.

I paid my solicitor to help me get my children back, but she didn't...[she should] do her job better (Rachel)

Over half of the parents felt they had been 'set up to fail' (Kimberly) and shared experiences of being denied services or not receiving the support that had been agreed. Where support was offered, some parents spoke of it not appropriately meeting their needs, yet feeling 'dictated to' (Helen), and being penalised for not engaging with what was provided. Parents reflected on how support was often too slow to arrive. There was a sense that support is only offered in a 'crisis' (Neil), with authorities missing crucial opportunities to implement support at an earlier stage.

For months there was no support there. Then I got ill and like the support came, but it were too late for me and my son (Jessica)

Parents felt this was rooted in prejudice and stigma towards those with learning disabilities.

We want to be parents like everybody else, but we're not having opportunities because of their attitudes (Amy)

3.3 | Theme 3: Challenging assumptions and proving competence

Parents shared defiant rejections of the stigmatising messages that their learning disability rendered them incapable of parenting. Central to all assertions was the idea that a learning disability does not define or limit a parent, despite societal attitudes.

You don't have to listen to the negative stuff...you're just as good as anybody else (Carol)

Parents spoke of their pride where they maintained care of their children in the face of adversities and social care involvement, although this was felt to represent the exception and not the rule.

Being a mum with a learning disability I just, I beat the system (Carol)

Almost all parents made some reference to recognising their own support needs; they spoke of the importance of proactively seeking support, and strongly encouraged others to do so. In being open about the challenges they faced, they sought to lessen the shame of acknowledging difficulties and accepting help, conceptualising this as a sign of strength.

Go to a social worker and say that you need help with learning difficulties...there's nothing wrong with that (Kelly)

However, in order to seek and engage with support, it was crucial that professionals expressed recognition of parents' efforts, and their capabilities and strengths as a parent.

[She] was the best social worker ever...she was the only ever children's social worker that believed we could keep our children (Amy)

Many parents spoke of how crucial informal social support had been, encouraging others to reach out to those around them.

Don't be scared to ask your family and friends to help out, they will be there with you to guide you (Rick)

However, not all of the parents in the sample had a readily available support network. Some were very socially isolated, whilst others described remaining within previously neglectful or abusive family systems. It was noticeable that the four parents within the sample who reported no formal

parenting assessment, had all benefitted from the involvement of a secure, supportive family network. Arguably, those most in need of support, with the highest vulnerability associated with persistent experiences of powerlessness, were the same parents who had no ready support network or advocacy involvement available to them.

I begged everybody that I knew [to help]...and no one would, no one cared enough (Jessica)

3.4 | Theme 4: Claiming power

I feel like I've took the power back...I've got confidence now (Neil)

Parents spoke of their experiences of making themselves heard, standing up for themselves and asserting their rights as a parent and as a person with a disability, having previously felt victimised or ignored when unable to speak up.

I speak up more for myself now than I used to...if you keep quiet that's when you get picked on (Marie)

Some parents used their voice to call out professionals for what they believed to be unrealistic expectations or dispute claims they regarded as untrue. Others spoke of asserting themselves with family by affirming their independence and right to make their own decisions.

I said who do you expect me to be, Mother Theresa? (Amy)

Some parents spoke of the inner strength they developed as a consequence of the adversities, challenges and losses they faced on their parenting journey. In instances where the valued role of being a parent had been negated by children being removed from their care, parents appeared to strongly align with and value their identity as a 'strong person'.

It's made us stronger. I can speak out more, and I encourage the other mums to do the same (Dawn)

Over three quarters of the parents also spoke of feeling empowered by being with others with similar experiences, emphasising the benefits of peer support. Sharing experiences appeared to help parents to feel less isolated, enabling them to develop trust in a safe space, as an initial step towards personal recovery. For those with complex histories of abuse, this often represented their first experiences of feeling cared for and held in mind by people they trust.

I didn't think there was no one else going through it... till I came to the group (Jessica)

Parents spoke of their involvement with self-advocacy groups, parenting projects and peer mentoring. There was a strong sense of parents

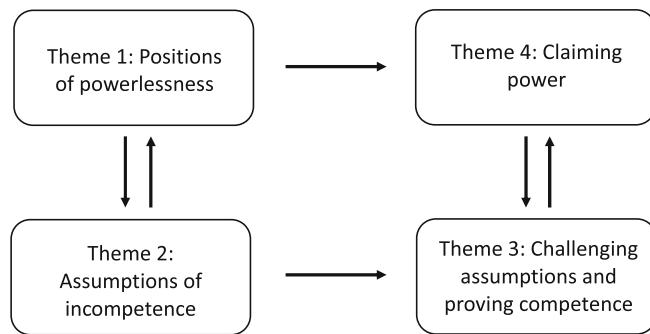


FIGURE 1 Thematic map

wanting to improve the experiences of other learning-disabled parents, even when outcomes for their children had already been determined. Parents spoke of sharing their own experiences with professionals as a way of influencing change and fostering understanding towards learning-disabled parents.

We go out...telling them our story...so they can get the right services (Dawn)

Their efforts demonstrated a commitment to addressing wider systemic issues associated with the imbalance of power between learning-disabled parents and others.

3.5 | Thematic map

The themes were incorporated into a thematic map (Figure 1), which provides a summary of the themes generated, and represents an interpretation of how these themes may relate to one another. There appeared to be reciprocal relationships between parents' experiences of being in positions of powerlessness (Theme 1) and the assumptions of incompetence they faced from others (Theme 2). Equally, reciprocal relationships appeared between parents' experiences of challenging these assumptions (Theme 3) and claiming back power (Theme 4). Parents' efforts to empower themselves and others (Theme 4) were born out of their experiences of subjugation into powerless positions (Theme 1), just as their rejection of stigmatising labels and desire to prove their competence (Theme 3) stemmed from the presumptions and prejudice they had faced (Theme 2).

4 | DISCUSSION

The findings from this study contribute to the growing evidence base depicting substantial power differentials between parents with learning disabilities and 'powerful others' in their social and professional networks (Gould & Dodd, 2014). Parents were left feeling pressure to prove a level of competence exceeding that expected from non-learning-disabled parents (Gould & Dodd, 2014), and felt professionals struggled to see beyond their

learning disability (Booth, 2000). These assumptions frequently served as a continuation of earlier experiences of abuse and stigma for parents, having been exposed to narratives defined by their limitations throughout their lives (Scior & Lynggaard, 2006).

Despite best efforts, parents were often left feeling they could never do enough to prove themselves and felt they were being held to impossible standards. It seemed parents faced 'elusive expectations'; they were aware of the costs of getting it wrong yet were not aware of what was expected of them or the processes by which they were being assessed, consistent with other research (Malouf et al., 2017). It is perhaps best described by Booth and Booth (2005) as "like playing a game without being told of the rules" (p. 113). Despite the existence of good practice guidance (WTPN, 2016) emphasising the need for transparent communication, it seemed parents were still being disadvantaged by a clear lack of understanding. Parents shared experiences of feeling betrayed by professionals, particularly where children had been removed from their care; parents struggled to comprehend the complexity of factors that led to this decision and lost trust in and disengaged from services more broadly. Given non-compliance with support is commonly regarded by professionals as an indication parenting will not improve (Booth & Booth, 2004), this has potential implications for further perpetuating professionals' concerns about parenting ability (Traustadottir & Sigurjonsdottir, 2008).

Contrasting with previous research (Baum & Burns, 2007), parents often acknowledged the need for support and reflected on the challenges they faced as parents in the context of their learning disability. However, parents emphasised the need for professional support to be provided in a sensitive and empowering way, motivated by an underlying belief in the parents' capabilities. This is in line with Tucker and Johnson's (1989) model of competence-promoting (vs. competence-inhibiting) support for parents with learning disabilities, which proposes that it is not the provision of support alone, but the quality of the support, which promotes parenting competence.

In the face of the prejudice parents perceived in their lives, they highly valued their identity as a parent. Where parents face threats to this identity through scrutiny of parenting competence or possible separation from their children, it has been suggested this may negate the valued 'parent' status and reinforce the stigmatised identity of being 'learning disabled' (Gould & Dodd, 2014); this may help explain why parents in this study were so motivated to challenge the stigma levelled against them as parents and to redress the imbalances of power at a more systemic level. Broader literature on the exploration of stigma and identity in people with learning disabilities contests the degree to which individuals show awareness of their stigmatised status (Beart et al., 2005; Jahoda & Markova, 2004). Whilst arguably the value attached to their parental status facilitated a degree of shift in their social identity, the parents in this study remained very much aware of the stigma attached to being 'a parent with a learning disability'. Although some of the parents spoke of apprehensions around being 'good enough' to be a parent, indicative of some possible internalised stigma prior to having children (Kaspar & Stenfert Kroese, 2017), the majority of parents perceived the stigma as unjust

and expressly rejected the stigmatic messages they had received, without endorsing and applying the negative stereotypes to themselves (Sheehan & Ali, 2016), or seeking to distance themselves from the stigmatised 'in-group' (Tajfel & Turner, 1979). Similar to Roth et al.'s (2016) study of self-advocates' experiences of stigma in the wider learning-disabled population, it appears the parents 'swallowed the insult, but did not accept it' (p. 53).

It is possible, however, that it was involvement with self-advocacy organisations, and the sense of social belonging this offered, that afforded parents the opportunity to challenge the stigmatised notions of incompetence, incapacity and dependency previously attached to their social identity as a learning-disabled parent (Anderson & Bigby, 2017). In line with Branscombe et al.'s (1999) Rejection-Identification Model of Group Identification and Self-Evaluation, it is possible that identifying as a member of the stigmatised group of 'learning disabled parents' afforded protection for parents' self-evaluations through the provision of social support and resources to reject the prejudice and discrimination experienced by the group. Whilst further research into the application of these ideas to a learning-disabled population is warranted (Crabtree et al., 2016), these findings nonetheless appear to advance understanding of the central role of self-advocacy, and its potential to offer self-protective value against the stigmatised status of being a learning-disabled parent.

The finding that parents not only rejected stigmatising messages, but described feeling empowered to support others and mobilise wider societal change, represented a two-fold redressal to the power imbalances parents had experienced; both externally, through explicit attempts to influence service/policy change, and internally, through the shift away from a stigmatised self-identity to that of an 'expert' position. The reference group were clear to emphasise, however, that many parents only come into contact with self-advocacy organisations after they encounter a significant challenge to their parenting (e.g., separation from a child), and not all parents in similar positions have access to such organisations. This is especially pertinent to consider given the continued cuts to funding in the United Kingdom threatening the sustainability of this much-valued resource (Anderson & Bigby, 2017). The current findings highlight the crucial role self-advocacy organisations play in offering parents an opportunity to redress the power imbalances in their lives. This emphasises the need to both protect such organisations from further funding cuts, and to expand the availability of this support to help parents at an earlier stage of their parenting journey.

It must also be recognised that the current study represents the experiences of parents who had largely negative experiences of services, given that the majority had experienced enforced separation from their children. Such accounts are more prominent in the literature, perhaps unsurprisingly given that learning-disabled parents are disproportionately subject to child protection interventions; however, there is a small but growing body of research explicitly focusing on 'successful' practice with parents with learning disabilities (Tarleton & Turney, 2020). In a small but in-depth research project which took place in local authorities recommended as demonstrating 'successful practice', professionals specifically described deliberately choosing

not to start from the recognised stigmatised presumption that learning-disabled parents are incapable (Tarleton & Turney, 2020). 'Successful' professional practice can be described to follow Tarleton et al.'s (2018) '6Ts' approach; namely ensuring sufficient 'time' to get to know parents, to build 'trust' between parents and professionals through relationships-based support, ensuring 'tenacity' and persistence to work with parents over the longer term if required, 'truthfulness' and 'transparency' with parents about what is happening, and ensuring an individualised 'tailored response'. If implemented, these '6Ts' would combat stigmatised experiences described by parents in the current study, and this positive approach to supporting learning-disabled parents is already supported by current UK legislation and policy (Tarleton & Turney, 2020). However, 'austerity politics' in the United Kingdom has triggered reduced funding and tighter eligibility criteria for services, and a predominant focus on crisis management rather than the proactive, positive support advocated for in good practice guidance (WTPN, 2016) and by learning-disabled parents themselves.

4.1 | Strengths and limitations

In line with calls for more inclusive participation in research (Beail & Williams, 2014), this study demonstrates how co-researchers can significantly contribute to all stages of the research process, refuting the 'often-implicit assumptions that those with intellectual disabilities cannot meaningfully participate' (Ditchman et al., 2016, p. 42). Furthermore, the overall collaboration between university academic researchers and a learning disability theatre company, has allowed the project to progress its broader aims to reduce societal stigma and increase progressive attitudes towards the parenting rights of people with learning disabilities, through creative outputs sharing parents' experiences. The research findings have directly fed into the public-facing outputs delivered by theatre company Mind the Gap: 'Anna', a forum theatre interactive workshop aimed at both professionals and people with learning disabilities; 'Mia', touring theatre production; 'Zara', large-scale outdoor theatre production; and 'Paige', including Photobook and a series of training films for professionals, aimed at prompting conversation and reflection on best practice (Mind the Gap, 2020; available at <http://pc.rhul.ac.uk/staff/K.Theodore/index.html>).

This research is not without its limitations, most notably in relation to the limited representativeness of the sample. Whilst the decision to recruit on the basis of parents' involvement with self-advocacy services and self-identification as learning disabled arguably supported the researchers to capture a broader range of individuals who may present with mild or borderline difficulties, this nevertheless limited the degree to which findings can be generalised. It is possible, for example, that the group included parents with a relatively higher level of functioning than if recruited through formal services. Furthermore, in their journey towards contact with self-advocacy groups, it is possible that these parents had encountered a higher degree of adversity and challenges, both in their parenting role and in other aspects of their lives (e.g., the high prevalence of childhood abuse within the sample).

This increased degree of marginalisation arguably enhances the need for these parents' experiences to be heard and understood, but it must nevertheless be acknowledged that as self-advocates these parents may be more experienced in talking about painful issues (Roth et al., 2016), and thus there may still exist other parents who have gone through similar adversities whose voices remain unheard. Furthermore, it should be noted that the sample consisted largely of parents who did not have current full-time care of their children, and who had experienced either temporary or longer term separation from their children. Whilst parents with learning disabilities are disproportionately subject to child removal (Tarleton & Turney, 2020), the experiences of this particular group of parents, and as a result their perception of their experience of stigmatisation, may be very different to parents who feel they have developed positive working relationships with professionals (Tarleton et al., 2018). The small sample of fathers further limits the generalisability of the findings. Further research is needed to expand upon the limited understanding of how experiences of parenting with a learning disability intersects with gender, but also other marginalised identities, such as those from ethnic minorities.

5 | CONCLUSION

Throughout their lives, parents reported experiencing stigmatisation in the form of feeling disempowered by non-learning-disabled others within their social and professional networks. In particular, parents faced assumptions of parenting incompetence, threatening their parental identity and placing them under pressure to demonstrate a level of competence they felt exceeded that expected of non-learning-disabled parents. Parents demonstrated a strong determination to reject their stigmatised status and prove themselves as parents, but were often left confused and frustrated by the elusiveness of the standards they were being held to. However, despite the stigma, adversities and losses faced by parents in the sample, they continued to embrace their highly valued identity as a parent, and appeared to draw strength, belonging and social affirmation from their involvement with self-advocacy services. Self-advocacy appeared to provide a platform to redress the imbalance of power in their lives through the unique opportunities involvement afforded parents to collectively reject stigma, empower oneself and others, fight injustice and mobilise wider societal change.

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CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

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