




'The whole thing is beyond stress': Family perspectives on the experience of hospitalisation through to discharge for individuals with severe learning disabilities and complex needs

Megan Stock¹  | Mark Mulholland² | Vivien Cooper² | Annabel Head¹ | Sam Prowse³ | David Wellsted⁴ | Silvana E. Mengoni⁴  | Louisa Rhodes⁵  | Helen Ellis-Caird⁴

¹Lewisham Mental Health Learning Disabilities Team, South London and Maudsley NHS Foundation Trust, London, UK

²The Challenging Behaviour Foundation, UK

³Adult Disability Service and Adult Care Service, Hertfordshire County Council, Hertfordshire, UK

⁴Department of Psychology, Sports Science and Geography, University of Hertfordshire, Hertfordshire, UK

⁵West Specialist Learning Disability Service, Hertfordshire Partnership University NHS Foundation Trust, Hertfordshire, UK

Correspondence Helen Ellis-Caird, Department of Psychology, Sports Science and Geography, University of Hertfordshire, Hertfordshire, UK.
Email: h.ellis-caird@herts.ac.uk

Funding information
University of Hertfordshire

Abstract

Background: People with severe learning disabilities and complex needs are more likely to experience delayed discharge from hospital; however, there is little research into their experience in hospital and as they move out as part of the Transforming Care Programme.

Methods: Six family members of people with complex needs who had moved out of hospital took part in four focus groups co-facilitated with an expert-by-experience consultant. Participants' relatives had hospital admissions that ranged from 6 weeks to 11 years. Transcripts were analysed using reflexive thematic analysis. Additional reflections are included from an expert-by-experience consultant to capture their unique perspective.

Results: Family members reported stories of abuse in hospital and parallel experiences of institutionalisation and trauma, resulting in long-lasting impacts on themselves and their relative. Family members felt let down and undervalued by professionals. They described relief when their relatives moved out of hospital, but there were on-going difficulties accessing the right support in the community and so stability felt fragile.

Conclusions: Key recommendations to support community living include respecting family members' expertise, improving partnership working and offering psychological support for family members and people with complex needs post-discharge.

KEYWORDS

complex needs, family, hospital, mental health, severe learning disability

Accessible Summaries

- We wanted to understand the experiences of families of people with complex needs living in a mental health hospital and moving out of hospital.
- Family members talked about how difficult the experience of being in hospital had been for their relative and for themselves.

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- Family members felt very unsupported and let down by professionals.
- Family members talked about feeling relieved that their relative had moved out of hospital.
- There had been lots of on-going problems accessing the right support for their relative.
- Family members and their relatives need specialist support to help the person with complex needs to live in the community and out of hospital.

1 | INTRODUCTION

1.1 | Context

Following the undercover filming of abuse of people with learning disabilities at the inpatient unit Winterbourne View (British Broadcasting Corporation, 2011), the Transforming Care report (Department of Health, 2012) called for the number of people with learning disabilities living in England in hospital to be dramatically reduced and for the provision of community support to be improved and expanded. The resulting Transforming Care Programme was designed to enable the transition of people with learning disabilities out of hospital and reduce the need for in-patient admission, yet there are still over 2000 people with learning disabilities and autistic people living in hospitals, with the average length of stay being over 5 years (NHS Digital, 2023). Inpatient admission results in a huge mental and physical health cost to the individual with learning disabilities and their families (Burrows et al., 2023; Head et al., 2018), as well as being double the cost of community living (Mencap and Housing LIN, 2018). Furthermore, deaths and abuse in inpatient settings are still being uncovered and people are still receiving unacceptably low standards of care and support (Care Quality Commission [CQC], 2022).

Ince et al. (2022) conducted a narrative analytical review which identified that people with 'complexity of needs' (referred to in this article as 'people with complex needs') including more significant learning disabilities or physical health needs, co-occurring mental health difficulties, autism and behaviours described as challenging; have an increased chance of being 'stuck in hospital' and experiencing discharge delays. We urgently need to understand more about the experience of people with complex needs to better support them to successfully transition to living in the community long-term (Ince et al., 2022).

1.2 | Existing literature

Sadly, this understanding appears some way off: Although there are many publications regarding being in or moving out of hospital since deinstitutionalisation began in the 1960s, only a small number sought the views of people with learning disabilities or their families, and even fewer attempted to include the experiences of people with complex needs.

Owen et al. (2008) and Hubert and Hollins (2010) followed people with severe learning disabilities and behaviours that challenge as they moved out of long-stay UK institutions, using observation and interviewing key stakeholders. These studies found that people with learning disabilities were not involved nor prepared for their move. For those that moved directly to permanent homes in the community, with a stable staff team, improved quality of life was reported, but in both studies, participants who were placed in temporary accommodation experienced more distress and disturbance. It is unclear whether these findings are relevant to a post-Transforming Care context in which clearer guidelines are in place around the moving process.

Leaning and Adderley's (2015) case study followed the experience of 'Raymond', an autistic man with severe learning disabilities moving out of hospital under Transforming care. Raymond had been hospitalised for 46 years and deemed 'too challenging' to live in the community. The researchers described building new stories about Raymond to support discharge and the importance of involving Raymond's family throughout the transition process. However, Raymond's experiences were described from the 'distant proxy' perspective of a clinical psychologist and may differ significantly from the views of Raymond himself.

Baranowski et al. (2023) explored family perspectives on the experience of people with severe learning disabilities transitioning out of long-stay institutions in Canada. The study reported generally positive experiences of the transition, although some challenges were noted in regard to unanticipated delays and inconsistent communication with professionals. This study was undertaken in Canada which limits generalisability to a UK setting.

These studies provide a limited picture of the hospital experiences of those with complex needs and their transition out of hospital, with only one case study conducted in the United Kingdom since Transforming Care. The exclusion of those with more complex needs from nearly all the research is a significant problem, particularly as this group are the most likely to be 'stuck in hospital' for longer and to experience increased barriers to moving out.

This study was co-conceived with the Challenging Behaviour Foundation (CBF), an organisation that supports people with complex needs and their families with the intention of beginning to address this exclusion of the experiences of people with complex needs from research. However, due to the time period and budget of the study, it was not possible to overcome the challenge of conducting research with people who do not use spoken language as their primary form of

communication. The CBF highlighted the rich knowledge and insight that family carers may hold about their relatives' experiences and the importance of understanding family's views and experiences. We acknowledge that family members can only provide a partial insight into their relatives' direct experience; but that this form of 'close proxy' sampling is an established method of enquiry (Yoon, 2023) and appropriate for an initial exploratory study. We intend to use this study as a starting point for a larger, funded piece of work in which more inclusive and participatory approaches can be incorporated (de Haas et al., 2022).

1.3 | Co-production

Co-production was valued throughout the research and established in line with INVOLVE principles (Hickey et al., 2018). The CBF supported us in the recruitment of an Expert-by-Experience consultant, Mark, bringing to the project his personal experience as a family carer of someone with complex needs living in hospital. Mark played a full and equal role in all stages, from contributing to the design, co-facilitating the focus groups, defining and refining themes, and contributing to the drafting of this article. Mark's additional reflections are included throughout the article, adding a unique layer to the research from his insider researcher perspective. Drawing on Mark's expertise, the terms 'people with complex needs' and 'loved ones' were used during the conduct of the focus groups to refer to participants' relatives and will be used in the write up of results below.

1.4 | Aims

The current study was a small-scale, in-depth qualitative exploration of a little-known community, considering the experiences of people with complex needs and their families:

- in hospital;
- in the transition out of hospital under the Transforming Care programme;
- in their current homes in the community.

2 | METHODS

2.1 | Design

A co-produced qualitative focus group design was used.

2.2 | Participants

Participants were family carers of adults with complex needs who had been discharged from hospital at least a month prior.

Six participants were recruited. This was considered an optimal number to allow an in-depth and individualised approach to each participant and reflects precedent set in other qualitative research involving the family members of those with learning disabilities (Williamson & Meddings, 2018) (Table 1).

2.3 | Recruitment procedure

Purposive sampling was used; CBF advertised the study via email and directly approached families they support. The study was also advertised using a flyer on the research team's social media account. Participants contacted the research team to express interest, and a member of the team met with each participant beforehand to discuss the study in detail and gain informed consent.

2.3.1 | Focus groups

Focus groups were used to elicit in-depth information while also offering a potential therapeutic benefit to participants of sharing similar experiences (Powell & Single, 1996). Participants were split into two groups of three depending on availability, to allow each participant enough time to share their experiences in depth. Each group met for a virtual focus group that lasted an hour and a half. Participants were invited to attend an additional focus group a week later to reflect on areas covered in the first group and deepen discussion. Four out of the six participants chose to attend the

TABLE 1 Demographic characteristics of participants and their loved ones.

| Participant pseudonym | Relationship to loved one | Ethnicity of loved one | Gender of loved one | Age of loved one | Length of hospital admission |
|-----------------------|---------------------------|------------------------|---------------------|------------------|------------------------------|
| Madeleine | Mother | White British | Male | 20–30 | 22 months |
| Laura | Mother | White British | Male | 30–40 | 2.5 years |
| Victoria | Mother | White British | Male | 20–30 | 6 weeks |
| Farida | Mother | West and South Asian | Male | 30–40 | 11 years |
| Alison | Sister | White British | Female | 40–50 | 8 weeks |
| Howard | Father | White British | Male | 20–30 | 14 months |

additional focus groups. The focus groups were facilitated by the Expert-by-Experience consultant and two researchers and were semi-structured to cover the main aims of the study while also remaining responsive to the needs of participants. Questions included: 'What factors were important to you in the transition out of hospital?' and 'What is life like for your loved one now?' Focus groups were audio recorded and then transcribed.

2.4 | Ethics

The current study was granted full ethical approval by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (Protocol number: LMS/SF/UH/04823(2)). Participants reported experiences of abuse during the

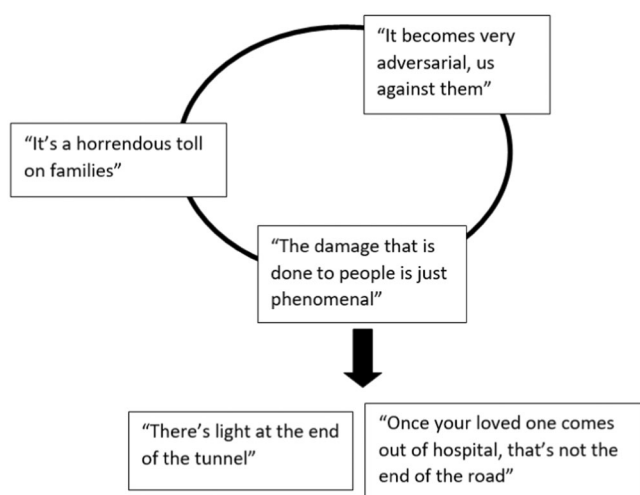


FIGURE 1 The on-going impacts of an inpatient admission on family members and their loved ones.

TABLE 2 Main themes and subthemes.

| Overarching theme | Subthemes |
|---|--|
| (1) 'The damage that is done to people is just phenomenal' | 'They set him up to fail' 'They're just in completely the wrong environment' 'Every single day [he was] abused physically and mentally' 'He still exists with his trauma' |
| (2) 'It's a horrendous toll on families' | 'It's taken a huge toll on my health' 'There's so much to do' |
| (3) 'It becomes very adversarial, us against them' | 'I feel I was lied to' 'They did nothing that I asked them to do' |
| (4) 'There's light at the end of the tunnel' | |
| (5) 'Once your loved one comes out of hospital, that's not the end of the road' | 'I just don't like it! But I have to put up with it!' 'God knows what's happening next, I really don't know' |

focus group; it was confirmed with participants that these had been reported to the relevant agencies at the time.

2.5 | Data analysis

Little is known about the experiences of people with complex needs; therefore, an inductive approach to analysis was undertaken. Data were analysed using NVIVO (2020) following Braun & Clarke's (2021) 6-stage reflexive thematic analysis framework. The first author coded and generated the initial themes while attending regular supervision with an experienced qualitative researcher (Author 3) and completing a reflective log. In a reiterative, on-going process, the themes were developed, reviewed and refined in collaboration with Mark. Emphasis was placed on using quotes taken from the data as theme headings to better ground the themes in participant experience (Byrne, 2022). Relationships between and within themes were modelled, and a thematic map produced.

2.6 | Reflexivity

As clinicians, experts-by-experience and researchers, it was challenging to hear the stories of abuse and how let down family carers felt by services. Researchers debriefed after each focus group and reflections were documented to keep awareness of our own subjective view to centre the family carers' experiences in the analysis.

3 | RESULTS

From the four focus groups, five overarching themes and subthemes were identified (Table 2). The first three themes cluster around the impact of hospitalisation and the process of moving out of hospital and highlight the parallels between the experiences of participants and their loved

ones. The latter two themes cluster around the hopes and challenges of living in the community.

3.1 | 'The damage that is done to people is just phenomenal'

All participants shared harrowing stories of their loved ones' time in hospital and their resulting experiences of trauma and long-lasting physical and psychological injuries:

My son was so traumatised when he was in the ATU [Assessment and Treatment Unit] unit, at least ten times a day for the whole 14 months, he had shredded his clothes. (Howard)

On a broader level, participants reflected on the systemic failures and lack of appropriate support that results in the injustice of people with complex needs being placed in hospitals:

I don't know why at this day and age we're still at this stage of locking people unnecessarily. (Madeleine)

The damages caused in the lead up and resulting hospital admission are detailed in four subthemes:

3.1.1 | 'They set him up to fail'

Participants had similar experiences of inappropriate placements that were not equipped to meet their loved ones needs leading to placement breakdown:

The environment is everything. If you place a severely autistic person in a flat on the sixth floor of a tower block with noisy, drunken neighbours or drug-dealer neighbours, they're going to fail. They will have a meltdown, and it's not their fault. (Howard)

Participants felt their loved ones had been let down by community provisions, including challenges accessing appropriate support from social care and NHS services, which resulted in the admission:

If I'd have had the help and the support from the start, it was pointless, and we could have all done that together. (Victoria)

3.1.2 | 'They're just in completely the wrong environment'

Once admitted to hospital, all participants reflected that the hospital environment exacerbated their loved one's difficulties, resulting in an increase in aggression and self-injurious behaviour:

He was so violent in there, like constantly having incidents, constantly attacking the staff, and that doesn't happen anymore. (Howard)

Hospital staff were described as lacking appropriate communication training (e.g. Signalong, Makaton) and described a mismatch between the ward environments and the sensory needs of their loved ones:

The phone outside the door, just things like that constantly ringing. And, again, [loved one]'s noise-sensitive. (Alison)

3.1.3 | 'Every single day [he was] abused physically and mentally'

All participants reported that their loved ones had experienced abusive practice, including physical abuse that resulted in multiple broken bones for one participant's loved one. Examples were provided of loved ones being subjected to disproportionate levels of chemical and physical restraint including unethical physical restraint positions:

So whenever I went there, I saw six, seven people from his window, I could see in the lounge he was restrained with huge, huge people, six, seven people, and they with haloperidol injection. (Farida)

Loved ones were often heavily sedated and were unable to recognise their family members at times:

He was just so drugged up he didn't even know who I was. (Victoria)

Some participants witnessed abusive practise first-hand, and all had noticed injuries:

One evening, he was assaulted by the night staff... they said that he could have done it to himself, but his eyes were blackened, and his back was all scratched up. (Howard)

Some participants described the poor conditions and limited access to family as a deprivation of their loved ones' human rights:

Where is his equality? What about his diversity? He's a human being, and you're not treated like human beings. (Laura)

3.1.4 | 'He still exists with his trauma'

As a result of their loved ones' admission, participants described persistent physical injuries and psychological difficulties that remained:

[After discharge] for over 2 years, he was having nightmares and jumping out of bed in the morning and attacking the staff, screaming. (Howard)

So they've done lots of damage to [loved one], and still his arm is so fragile it's not healed, because of their poor treatment. (Farida)

One participant felt that because of the admission, their loved one had lost trust in them and their relationships with family members had been impacted. Some participants and their loved ones' carers had accessed trauma-informed care training, however, there was an unmet desire for direct psychological support:

I wanted psychology support for [loved one] with his trauma, and no matter how many times I made a referral and followed up referrals, that still never happened for him. (Laura)

3.2 | 'It's a horrendous toll on families'

The second major theme describes the impact on participants of their loved one's hospital experiences. Participants described feeling anxious about the safety of their loved one and being in a state of on-going hypervigilance. Participants described the far-reaching impact of the admission on their own mental and physical health, as well as how time-intensive the admission was:

After all these years of stress, 11 years, myself, I'm not... Now I have become really ill. (Farida)

Further details of these impacts are outlined in the related subthemes below.

3.2.1 | 'It's taken a huge toll on my health'

All participants described the impact of the admission on their mental health and most participants had sought psychological support for their own mental health:

I also went through a lot of psychological problems when my son was in the ATU unit, and I had to approach professional counselling for help. (Howard)

Changes in participants' emotional wellbeing were noted, including feelings of guilt, bitterness, anger and a loss of confidence in their caring abilities. One participant described suicidal ideation during their loved ones' admission:

I just thought, I can't cope with this, I can't—I don't think I could go back there. I was really thinking of killing myself. (Madeleine)

Participants also described changes in their physical health such as increase in blood pressure because of the stress.

It's taken a huge toll on my health this year, with high blood pressure and back into pre-diabetes. (Alison)

3.2.2 | 'There's so much to do'

Participants described working hard independently to access appropriate support for their loved ones in hospital. This involved compiling detailed documentation for the transition, bringing in food, creating timetables and liaising with external agencies:

You're supporting the hospital visits, the transition and all the other stuff that goes with that, getting her home ready as quickly as possible and talking to all the various agencies. (Alison)

They described the high levels of demands and the difficulties juggling these with other responsibilities, including childcare. Some participants were travelling long distances to visit their loved ones in hospital which also increased the demands on their time:

In his hospital stay, I feel I worked hugely... I worked harder at that than my full-time job that I get paid for. I'm surprised I've actually still got employment, because the amount of effort I put into [loved one] was huge. (Laura)

Participants shared a mutual understanding of the challenges they faced and described feeling frustrated and isolated when their friends or members of the public do not recognise or understand their experiences:

I don't think they realise what he was like, and what I went through. (Madeleine)

3.3 | 'It becomes very adversarial, us against them'

The third major theme describes the battle participants described with professionals to access appropriate support for their loved ones in response to the poor care they described witnessing:

You have to jump up and down on a daily basis, and I just, I became a pain in the arse, because I had to. (Alison)

Participants felt under attack from professionals and described having poor relationships with the multi-disciplinary team. Participants wanted to protect their loved ones from the hospital team, by spending as much time on the ward as possible, and through advocating for them in meetings:

Some of those relationships are really awful. There were some, and it's mainly the higher management one, that I used to go through that door and think, I hope she's not there today, please don't let her be on shift today. (Laura)

Feelings of being let down, dissatisfied and powerless were discussed in two subthemes:

3.3.1 | 'I feel I was lied to'

Most participants described feeling hopeful at the start of the admission, as they were desperate for support for their loved one, and had been informed that an admission would provide specialist intervention:

I took him over to A&E like the last time, and I just got on my hands and knees, and I begged them to admit him...And they finally looked at him and said, yeah, we need to get him in. And I was like, thank goodness! (Victoria)

However, many participants then described feeling let down by the reality of the inpatient experience and frustrated by the minimal input and long waits for treatment that their loved ones experienced:

The ATU units is just like prisons; they're holding, they're just holding cells. There's no input. The whole thing was a scam. (Howard)

3.3.2 | 'They did nothing that I asked them to do'

All participants expressed dissatisfaction with the level of communication and care from professionals:

There was no one that could do BSL, so he couldn't communicate, for starters. I even made, at home, a communication board... for the staff...Each time I went to visit him that had not been touched. (Victoria)

Participants also described feeling undervalued by professionals and that their expertise was not taken seriously, escalating their loved one's difficulties:

His situation escalated and he was very constipated, and then they tried to do suppositories. I mean, that's just horrendous and none of that is actually needed, if they'd listened to what I'd said. (Laura)

All participants described on-going difficulties throughout the admission in enacting change for their loved one and feeling powerless. Participants found the appeal process unhelpful and many sought solicitor advice due to desperation:

I went to so many solicitors and I was begging them, my son is going to die! Do something! (Farida)

The three major themes described above provide the context within which participants experienced their loved ones' eventual discharge, and it could be argued, informed both their level of relief and subsequent unease described in the next two major themes.

3.4 | 'There's light at the end of the tunnel'

The fourth theme details the huge sense of relief that all participants shared when their loved one was discharged from hospital:

And, to me, it was like winning the 100 million Euro lotteries; it was priceless. It was absolutely priceless. (Howard)

All participants expressed that living in the community was preferred over their loved one being in hospital. Loved ones had more access to choice, were nearer to their families, and their quality of life was improving since discharge:

He's very, very happy and he's talking now. He becomes social. He's coming home every Wednesday, and he goes to the busiest shop, to the street, high street, everywhere. (Farida)

Participants shared examples of their loved ones engaging in activities, seeing family regularly and being well-supported by care teams, with two participants described being able to successfully reduce their loved one's medication as fewer incidents were occurring:

Now that my son is coming off some of these dreadful medications that he doesn't have a diagnosis for, we're beginning to see him. (Laura)

Participants discussed the positive impact that a consistent staff team of good carers has on the well-being of their loved ones and expressed gratitude for their support, as well as for the support they have received from the CBF while trying to get their loved ones discharged:

You have to find people who believe in your son.
(Madeline)

everything, but I just thought, hmm, I need to stay
nice. (Madeleine)

3.5 | 'Once your loved one comes out of hospital, that's not the end of the road'

The last major theme describes participants' on-going challenges in the community, including experiences of poor care staff teams and high levels of medication:

it did get to a very, very low, low place where [loved one] actually said he wanted to go back to hospital ... and that nearly broke me, the fact that life was better in hospital. (Laura)

Loved ones were frequently described as living in isolated, clinical home environments with limited opportunities to enable them to develop:

Sometimes I walk into [loved one]'s house, and the carers are doing the washing up, and it frustrates me because, like I say, I think independence is very important. (Howard)

The extensive challenges and the uncertainty of living in the community were explored in two subthemes:

3.5.1 | 'I just don't like it! But I have to put up with it!'

Participants described accepting homes that were not wholly appropriate for their loved one so that they could move out of hospital as soon as possible, such as moving out of area or a home on a busy road:

It's near a busy road, so that's not ideal, because she's got no road safety. She'll just see Morrison's over the other side, and never mind about lorries and cars and that's where the Coke is and off I go! (Alison)

Participants also described needing to keep a balance between raising issues with the care provider and 'keeping the peace' and described their fear that if they upset staff they might resign and put the placement in jeopardy. As such, there was a sense of resignation to accept less-than-ideal care:

The key to success, is being supported with the same team, because that's what he couldn't cope with in the past, the change of staff. So that's why I'm not falling out with the people, and obviously I don't like

3.5.2 | 'God knows what's happening next, I really don't know'

Participants described the future feeling uncertain and daunting. One participant reflected on how the risk feels greater now as their loved one was under greater scrutiny since their inpatient admission:

I keep calling and referring to him as Mr Three-to-One, because it seems now that once you've been in an inpatient unit, all his references now are that he's more complex than he was before he went in. (Laura)

Many participants' loved ones were in a state of flux; one participant was in the process of trying to move their loved one into supported living, and another's care provider had given notice. For another, funding was being questioned:

Because I said he was doing all right at the moment, and they're now up in arms on whether he should still be Continuing Health funded or go back to social care funding. (Victoria)

There was recognition from all participants that their loved ones have complex needs meaning adaptations will always be required by others to support them. As such, participants were continually assessing potential risk and proactively reducing behaviour that challenges:

I do find it quite intensive, yeah, and I am on edge for 5 hours, non-stop, because he can switch mood and you have to be ready for what he wants. (Madeleine)

4 | DISCUSSION

Key findings from the study are explored below.

4.1 | Stories of trauma

Mark's perspective: 'The stories and experiences put forward by participants in this study were often harrowing and set out the trauma caused to them and their loved ones by extended placements in unsuitable environments. The fortitude and resilience of each participant was remarkable in how they shared their experiences with authenticity and a clarity which clearly showed the experience of having a loved one in hospital for such a long time has such a deep

impact that it would be almost impossible to express these experiences unless one has lived them'.

As Mark describes, a prominent feature of participants' narratives was the harrowing experiences of abuse which their loved ones endured in hospital. Participants accounts were of a similar level of severity to that uncovered in undercover investigations of learning disability inpatient settings (e.g., British Broadcasting Corporation, 2011), considered at the time to be 'one-off' abuses of power, but which were reported here by participants in a wide range of hospital settings nationally. Participants also reported excessive restrictive practises consistent with charity analyses (Mencap, 2021) which found that there have been at least 102,010 recorded reports of restrictive practices in inpatient learning disability settings since October 2018, with the figure likely to be much higher as only a minority of hospitals contributed data (Figure 1).

Although previous research has reported people with learning disabilities experiencing restrictive hospital practise (e.g., Head et al., 2018), there appears to be a stark difference in the level and severity of experiences described in the current article. This difference may be due to the current study exploring the experiences of people with complex needs, who, possibly due to communication difficulties and higher levels of support needs, may be more vulnerable to abuse (Hewitt, 2014).

4.2 | Parallel experiences of family members and loved ones

Mark's perspective: 'Participants were honest and clear in the focus groups as to how the stay of their loved ones in a hospital had dramatic and negative consequences on them. However, it was clear that each participant's primary focus in terms of telling their story was first and foremost on their loved ones, and their stress and pain as family members and carers was considered incidental and secondary to the dire impacts their loved ones endured. The pain they felt was often an extension of a proxy of the pain and distress they felt their loved one was enduring daily'.

As Mark describes, a novel feature of this study's findings was the parallels in the experiences of family members and their loved ones. Descriptions of loved ones feeling institutionalised, powerless, and having challenging relationships with professionals were reflected in stories of how family members themselves had felt. Similarly, enduring changes in their physical and mental health because of the hospital admission were reported as impacting both family members and their loved ones. This parallel process gives some indication of the wide-reaching impact a hospital admission has on the system around the person with complex needs and of the level of distress that families are managing at the same time as attempting to advocate for their loved ones' needs. This indicates the importance of providing support to families as a key part of any treatment planning. This finding supports a previous survey of family carers which found that over 85% of participants had experienced depression and 89% anxiety due to the trauma their loved ones with learning disabilities had experienced

(Challenging Behaviour Foundation, 2020). The CBF survey was not exclusive to individuals who have experienced a hospital admission therefore the impact on wellbeing may be even higher in this population. On-going fears of their loved one being re-admitted replicate similar fears expressed by people with learning disabilities after discharge from a hospital setting (Head et al., 2018) and indicate the long-lasting impact of an admission on both the person with learning disabilities and their family carers. These findings fit with wider research looking at the strong interplay between carer and 'patient' quality of life and the need to consider both together (Al-Janabi et al., 2022).

4.3 | Difficult relationships with professionals

Mark's perspective: 'I'm struck by the power imbalance clearly expressed during the interviews. Due to the failings of professionals and the health and social care system in providing for their loved ones with complex needs, it is of course going to be extremely difficult for loved ones and family to then seek support from the system they believe has failed their family members'.

The current study found that family carers felt undervalued by professionals and powerless during their loved ones' admission. Similarly, previous literature reported family carers of people with learning disabilities experiencing poor information sharing from staff, challenging meetings with professionals and feeling uncertain in their expertise in the face of a hierarchical health and social care system (James, 2016; Williamson & Meddings, 2018). As Mark suggests above, these experiences may impact family carers' relationships with professionals, leading to mistrust and dissatisfaction with services and the wider health and social care systems.

4.4 | Positives and challenges of community care

Participants described relief that their loved ones were living in the community and the positive impact this had on their loved ones' quality of life. Increased opportunities for choice, participation and relationship building were noted, in line with the aims of the Transforming Care agenda (Department of Health, 2012) and national drive for people with learning disabilities to access the right support to live in the community (Department of Health and Social Care, 2022). This demonstrates the clear benefits of community living for a group of individuals who, due to their complex care needs, often face exclusion from society and previously would have remained living in long-stay institutions (Collins, 2015).

However, on-going difficulties regarding funding appropriate care teams and lack of opportunities post-discharge were raised by all participants. For many, the challenges were so significant that life in the community was only viewed as positive in comparison to hospital as an alternative. Difficulties accessing suitable community placements, as described by participants, have been recognised as a concern across England where a review found 60% of discharges were delayed due to lack of suitable provision (CQC, 2020).

Participants described in-patient services as a 'revolving door' due to systemic failures, which Duffy (2019) explains as stemming from a lack of tailored support for families and people with learning disabilities by a struggling social care system. Despite CQC guidance (2021) for community support to be bespoke and specially adapted to meet people's needs, there were mixed experiences on whether this had been achieved for participants' loved one. The systemic barriers described by participants are consistent with challenges documented in the literature (Ince et al., 2022).

4.5 | Limitations

Generalisability is not an aim of qualitative research, however, the transferability of the work may be limited by the relatively small sample size. Nonetheless, the sample size allowed in-depth and emotive discussions to emerge, resulting in a rich and detailed data set, which heightened resonance (Tracy, 2010).

The recruitment strategy may have led to potential bias towards those who have had significant difficulties during their loved ones' admission resulting in them accessing support from CBF. However, high levels of recorded restrictive practise suggest that the experiences of family carers in the current study are not unusual (Mencap, 2021). Despite beginning to explore the experiences of people with complex needs, the current study did not directly involve people with complex needs and therefore research, using creative and innovative methodology, is needed to include people with complex needs directly and better understand their experiences.

4.6 | Implications

Family members highlighted the high levels of knowledge and expertise they hold in the care of their relative with complex needs. This finding is likely to have transferability. By fully respecting and incorporating family members' perspectives before, during and after hospital admission, professionals could improve care-planning and decision-making.

The traumatic effects of hospital admission on both people with complex needs and their family members were evident in this study. A trauma-informed care approach is indicated to better understand and support all parties during and after hospital admission (Baker et al., 2021).

This study further cements the importance of person-centred services to prevent placement breakdown and readmission. As well as having a significant financial implication, this study illustrates the human cost of this breakdown and the resulting erosion of trust and faith.

5 | CONCLUSION

This qualitative study aimed to explore family perspectives of the experience of hospitalisation through to discharge for their relative with complex needs. Despite the Transforming Care agenda, this

study suggests people with complex needs continue to experience institutional abuse in hospital and poor care in the community. Furthermore, the study highlights the parallel traumatisation of family members during these experiences. The results indicate the need for significant improvements in both hospital and community support for people with complex needs and for professionals to support meaningful partnership working with families.

Mark's final reflections: 'It is remarkable that given the negative experiences participants and their loved ones have endured, these participants signed up to this study and gave so generously their time and experiences. They are clearly motivated by wanting people to hear and understand the experiences of their loved ones, and despite all the setbacks they have faced, there is still this undimmed hope that things can be better. This is a true testament of the love and dedication which these participants had for their loved ones, and this is something which should be harnessed and promoted by professionals, not dismissed and ignored'.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Megan Stock  <http://orcid.org/0009-0003-5107-3576>

Silvana E. Mengoni  <https://orcid.org/0000-0002-9431-9762>

Louisa Rhodes  <https://orcid.org/0000-0001-8137-9734>

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