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“Epilepsy, it’s just not sexy, is it?”: A qualitative exploration into health and social care professionals’ perspectives of people with intellectual disabilities and epilepsy, in social care

Jay Price [a], Paraskevi Triantafyllopoulou [a,*], Ceridwen Evans [a], Rohit Shankar [b,c]

[a] Tizard Centre, University of Kent, Canterbury CT2 7NF, UK
[b] University of Plymouth, Plymouth PL4 8AA, UK
[c] CIDER, Cornwall Partnership NHS Foundation Trust Truro TR4 9LD, UK

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ABSTRACT

Background: Epilepsy is prevalent in 22.2% of the intellectual disability (ID) population, with complexities spanning across health and social care sectors. Minimal research has been conducted to explore the experiences of epilepsy care within social care, despite its significance.
Methodology: Qualitative methodologies, using semi-structured interviews, were used to explore the experiences of health and social care professionals within the United Kingdom and analysed using Braun and Clarke’s reflexive thematic analysis framework.
Results: Four overarching themes were constructed from 11 interviews a) “It’s just not sexy, is it?”: Barriers to good epilepsy care, b) “My mission is to make their life better”: Facilitators of good epilepsy care, c) “Sometimes they appear frightened”: Impact of epilepsy, d) “Epilepsy training as a mandatory”: Future of epilepsy care. Fear was the most prevalent emotion described by participants throughout, which was perpetuated by the lack of resources and understanding/awareness, such as training. However, facilitating better epilepsy care for people with ID, can help reduce fear, and promote better wellbeing in all. Participants made recommendations such as mandating epilepsy training, and involving all key stakeholders, including families of people with ID, to improve epilepsy care in the future.
Conclusion: Mandating epilepsy training in health and social care settings is beneficial for care delivery and reducing the impact of epilepsy upon families and caregivers. Involving key stakeholders, such as families and caregivers, in all aspects of epilepsy care for people with ID, improves communication, service delivery and quality.

1. Introduction

Intellectual disabilities (ID) are defined as deficits in a person’s adaptive and intellectual functioning, with a scored intellectual quotient below 70 and onset before adulthood [1]. People with ID are estimated to constitute 1–3 % of the world’s population, depending on the country [2] and the classification used [3]. In the United Kingdom (UK), it is approximated that the population of people with ID is 1.2 million [4] of the 67 million estimated population as of 2021 [5].

1.1. Physical care needs

The prevalence of epilepsy in people with ID is 22.2 % [6], compared to < 1 % in the general population [7]. The rate of epilepsy prevalence also increases with the severity of ID, with epilepsy occurring in 10 % of people with mild ID versus 30 %-50 % for more severe to profound ID [8]. However, rates of misdiagnosis are estimated between 28–32 % in people with ID [9]. Diagnosis of epilepsy in ID populations may be skewed due to an over/under diagnosis resulting from a range of factors, with misinterpretation of events being one of the main causes [10]. This is further complicated by the additional factors, such as stereotypical behaviours and the dependence on carers/families to reliably report events [9].

People with ID are more likely to experience multiple types of seizures, that are challenging to control and are more likely to be refractory in nature [11,12]. The management of refractory epilepsies in ID

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* Corresponding author at: Tizard Centre, University of Kent, Cornwallis North East, Canterbury, CT2 7NF Kent, England, UK.
E-mail address: p.triantafyllopoulou@kent.ac.uk (P. Triantafyllopoulou).

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requires a multi-disciplinary approach [10], which incorporates professionals and expertise in both conditions [13], such as neurologists and community learning disability teams. This ensures a more holistic approach in supporting the individual beyond their epilepsy diagnosis, and subsequent seizure management [14], whilst aiming to improve the person's quality of life [15]. Health and social care professionals need to upskill themselves in either diagnosis to a level of confidence and competence, that is expected when supporting people with epilepsy and ID [15]. Programmes, such as Step Together [13], have been established to outline a varied level of competencies both in ID and epilepsy, to ensure that professionals and commissioners are aiding the integration of ID and epilepsy services [13]. The absence of such factors being implemented within professions and services, can increase the risk of mortality and reduce a person's quality of life [13].

It has been well documented that people with ID die 25 years earlier, on average, than the general population [16], with epilepsy identified as one of the leading causes [17]. Sudden unexpected death in epilepsy (SUDEP) is one of the primary causes of epilepsy-related mortality [18]. The risk of SUDEP in people with ID is three to nine times higher than in the general population [19]. A most recent review of epilepsy deaths in people with ID in the UK, identified that one in five deaths were recorded as SUDEP [20,21]. This elevated risk of SUDEP is thought to be associated with the higher prevalence of health co-morbidities in people with ID [6]. The potential absence of overnight monitoring for people who experience nocturnal seizures, may increase the risk of SUDEP further. [22].

Increased comorbidities in people with ID and epilepsy have been well-researched over the last 20 years [6], verifying the increased health complexity within this population and increasing the risks of premature seizure-related mortality, and SUDEP [23]. Multimorbidity is higher in the ID population than the general population [24], with conditions such as gastro-intestinal disorders and mental health conditions recorded as the most common [10]. There is a higher prevalence of psychiatric conditions in the ID population overall [25], with some physical health comorbidities increasing the predisposition of psychiatric diagnoses [26], but more commonly attributed to biopsychosocial factors [27]. People with ID and epilepsy are at an increased risk of developing comorbid psychiatric conditions [28], with evidence highlighting the seven-fold increase compared to the ID population without epilepsy [29]. Even though this is a small sample size study, research into this niche cohort can be challenging due to the difficulties in obtaining and recruiting a control group and utilising standardised instruments to assess mental health [30].

Behaviours of concern [31], are defined as behaviour of such intensity, frequency, and duration that can threaten or impact the quality of life and the physical safety of the individual or others, which can lead to practices that can be deemed restrictive, aversive, or excluding in nature [32]. The presence of behaviours of concern in the ID population is estimated to be 50 % [33]· Evidence into the prevalence of behaviours of concern in the ID and epilepsy population is difficult to interpret, and the relationship between the two is considered complex [10]. However, it is more likely that people with ID and epilepsy will experience behaviours of concern, and this can impact upon the diagnosis and management of epilepsy [15]. This is due to the presence of repetitive stereotypical behaviours within the ID population [34], and the likelihood that this presentation is used as a communicative method to express distress or need [10]. It is likely that these behaviours can be misinterpreted and associated with epileptic diagnostics [10]. On the other hand, caution must be exercised when exploring the causation behind the behaviour and not dismissed or diagnosed as "challenging behaviour", as some presentations can be atypical presentations of epileptic seizures and activity [9] People with ID are more likely to be prescribed multiple medications for the management of physical and mental health comorbidities [16], a practice often referred to as polypharmacy [16]. The introduction of anti-seizure medications (ASMs) and their subsequent side effects can increase the rate of psychiatric comorbidities [10], behaviours of concern [35], and physical health comorbidities, such as constipation [36]. Thus, highlighting the complexities associated with the management of epilepsy in the ID population [15,37].

1.2. Social care needs

Social care is defined as a service delivering non-medical care, including practical and personal support [38]. People with ID often face challenges associated with the functional impact of their disability, making them more likely to require care packages based on assessed needs [39] ranging from domiciliary to residential care, funded by health and social care budgets [40]. Service provision for ID and epilepsy care across the UK is variable [41]. Evidence highlights the prevalence of people with ID in professional care settings rather than in the community (such as a family home) [42]. In 2019/20, 18 % of adults were identified as requiring long-term support from adult social care, as a result of their ID [43], long-term care is defined as a long-term health or social care need that does not have a time limit and can be provided for as long as the need is identified [44]. Although these figures are likely to underrepresent the population of people with ID requiring long-term support not relating to their social care needs [38].

Managing health conditions is a statutory component of social care packages [45]). As a result, there is a greater need upon social care to provide appropriate provisions and support for families, carers, and professional care settings [46]. The circles of support for people with ID play a vital role in managing a person's epilepsy, but they often report receiving inadequate information regarding the condition [47], insufficient training (especially families and unpaid carers) [38] and feeling unheard [45]. These challenges add significant stressors for families and carers [48].

Accessing social activities poses significant challenges for people with ID and epilepsy, often due to a lack of appropriate provisions or accessibility [49]. Moreover, a lack of sufficient epilepsy training can result in people with ID being excluded from services [13], which can further exacerbate the stress and burnout experienced by their support networks [50]. Families and carers may also unintentionally add to these challenges due to concerns regarding the standard of care [51], or the need to be present in emergencies [28], and impact of seizures which may prevent the attendance/engagement from people with ID [48].

The stigma associated with epilepsy can significantly affect the quality of life for people with ID, impacting their acceptance within society and access to necessary provisions [28].

Despite the high prevalence of epilepsy within the ID population, limited research has been conducted to examine the social care factors influencing this population [38,48]. Without a deeper understanding of these experiences in social care, policy and practice are likely to remain stagnant, exacerbating risks such as carer burnout [52] and the social exclusion of people with ID and epilepsy [23,48]. These challenges can negatively affect individuals' wellbeing [42], reducing health outcomes [35] and contributing to persistent health inequalities [16].

This research aimed to explore and better understand the experiences of health and social care professionals on epilepsy care within social care through qualitative interviews with health and social care professionals working in the field.

2. Methods

2.1. Participants and settings

Purposive and opportunistic sampling methods were employed to recruit health and social care professionals working with children and/or adults with ID and epilepsy in the UK. The study was advertised through social media forums, with recruitment taking place from July 2023 until October 2023. The majority of participants (81 %) had lived experience of caring for people with ID and epilepsy, either through their current role or previous experience.

2.2. Interview Design

Interview questions were derived by the authors, and collaboratively refined, reflecting the multidisciplinary expertise of the team, which includes specialisations in nursing, psychology, and psychiatry. The questions were also influenced by existing research into social care and people with ID and epilepsy [28,38]. The interview began with basic demographic questions before introducing the main topics of discussion. The finalised interview schedule comprised of 10 questions (supplementary information 1), with follow up and prompt questions for the interviewer to further explore the topic with participants. The schedule was applied flexibly to allow for deeper exploration of participants' experiences as needed.

2.3. Procedure

Participants expressed their interest in the study, by contacting the research team via email, and provided informed consent prior to their interview. All interviews were conducted online by the first author, a registered nurse with extensive experience working with people with ID and epilepsy. The interviews were conducted via Microsoft Teams, recorded for transcription purposes, and lasted approximately one hour. Verbatim transcriptions were produced immediately following each interview to facilitate analysis. Although participants were offered the opportunity to review their transcripts, none chose to do so. Upon completion of the study, a summary of the findings was shared with all participants.

2.4. Ethical approval

The Tizard Centre Ethics Committee, University of Kent reviewed this research and granted ethical approval (Application 0778/2023).

Written informed consent was obtained from all participants, supplemented by verbal confirmation. Participation was entirely voluntary, and all participants provided consent for their interviews to be audio/visually recorded and transcribed.

2.5. Analysis

The semi-structured interviews were uploaded to NVivo 14 and analysed using reflexive thematic analysis [53]. Thematic analysis was conducted by the first and second authors of the research. Codes were generated inductively, discussed collaboratively, and grouped into broader categories to identify and refine themes. While an inter-coder reliability percentage was not calculated, the level of agreement between the coders was high.

2.6. Reflexivity

Professionals caring for people with ID and epilepsy in the UK are diverse. However, this study had limited access to that diversity. Four of the 11 participants were known to the authors prior to the study. To maintain rigour, reflexive diaries were kept throughout the analysis process and data were analysed from two researchers (JP & PT).

Initially, the analysis focused more on the medical aspect of epilepsy care and how this coincides with social care. Peer-debriefing and further analysis of the data was undertaken and provided a more holistic perspective of the research, which helped reconstruct the codes and themes. This further reduced the element of bias from the medical perspective within the research. The authors' epistemological and ontological approaches are grounded in social constructionist and interpretivism assumptions. This dual framework enhances the understanding and facilitates contextual applications, such as the social care needs of people with ID and epilepsy.

3. Results

A total of 11 health and social care professionals participated, representing a diverse group that included two registered managers from supported living settings, seven nurses, one specialist ID physiotherapist, and one deputy manager in supported living. Participants had varied job roles as seen in supplementary information 2. Nine out of 11 of the participants had responsibilities relating to the direct care of people with ID and epilepsy, ranging from providing personal care and support to creating and implementing care plans with circles of support. Table 1 provides a detailed breakdown of participant demographic and employment characteristics.

Thematic analysis generated four overarching themes: a) "It's just not sexy, is it?": Barriers to good epilepsy care, b) "My mission is to make their life better": Facilitators of good epilepsy care, c) "Sometimes they appear frightened": Impact of epilepsy, d) "Epilepsy training as a mandatory": Future of epilepsy care. The connections between the overarching themes and their associated subthemes are presented in Fig. 1. Supporting participant quotes in relation to the themes and subthemes are also presented in Table 2 below.

3.1. Theme 1: "It's just not sexy, is it?": Barriers to good epilepsy care

There are numerous barriers reported for people with ID attempting to access epilepsy services. These include a lack of reasonable adjustments, diagnostic overshadowing, and unequal access to healthcare, with epilepsy not being a priority for commissioners (those who procure services at local level based on individual need). Nevertheless, the shortage of resources and lack of understanding of epilepsy and ID emerged as the most prominent barriers identified by participants.

3.1.1. Lack of resources

Participants reflected on the inadequate allocation of funding for epilepsy care, highlighting that the government's budget cuts can result in commissioners prioritising the reduction of care packages for people with ID. This approach may increase risks for people with ID and epilepsy (see quote 1.1.1 in Table 2). In addition, commissioners often dispute increased expenditure, as funding requests may arise from either health or social care needs. The lack of prioritisation for epilepsy funding also negatively impacts service delivery. Specialist teams are often unable to provide essential epilepsy training, despite its importance for patient safety.

> *"…they [commissioners] mainly focus on the funding side of it so instead of like discussing the needs of the individual, they purely focus on the funding …[it] become[s] like a business 'how we can do more cuts? How can we cut there? How can we cut that?" (Participant 9, Interview 11).*

The lack of epilepsy training can lead to an overreliance on emergency services or family members, who typically do not receive formal training and are often excluded from accessing this resource due to insurance or funding restrictions (1.1.2). Training for health and social care professionals is often driven by legislation and incident prevalence rather than individual needs or proposed service outcomes (1.1.3). However, some professionals question the relevance of available training to their roles (1.1.4), while others noted that current training programmes are too generic and fail to address the complexities associated with epilepsy in the ID population (1.1.5).

The lack of appropriate training and funding adds further pressure to services. Participants described staff shortages, feelings of burnout, and gaps in service provision (1.1.6——1.1.8).

3.1.2. Understanding and awareness

A lack of understanding and awareness of people with ID and epilepsy was attributed to the stigma associated with these diagnoses (1.2.1) and limited practical experience among health and social care professionals, including gaps in training and education (1.2.2).

Table 1
Demographics of Participants.

Participant	Age	Gender	Ethnicity	Job Role	Length of experience	Highest level of qualification	Region of UK	Age of client group	Amount of Epilepsy Training
1	35	F	White British	LD & Behaviour Clinical Nurse Specialist	20 years	First Class Honours Degree	South East	Children (3–19)	Paediatric Epilepsy Training 1, Epilepsy Awareness and Buccal Midazolam Administration
2	36	M	White British	Registered Manager – Supported Living	20 years	NVQ Level 5	South West	Adults	Epilepsy Awareness and Buccal Midazolam Administration
3	35	F	White British	Clinical Specialist LD Physio & Senior Clinical Lead CLDT	14 years	Master's degree	South West	Adults	Epilepsy Awareness and Rescue Medication Administration
4	45	F	White British	Community Learning Disability Nurse	20 years	BSc Honours	North Wales	Adults	Diploma in Epilepsy, Epilepsy Awareness, Buccal Midazolam Administration, Train the Trainer course
5	51	F	White Irish	Epilepsy Specialist Nurse / Acting Service Manager	34 years	Degree & Post-Graduate Certification	Northern Ireland	Adults	Post-graduate certificate in Epilepsy Studies
6	67	M	Mixed Race	Interim Managing Director – Learning Disability Nurse	49 years	Master's degree	Nationwide	Adults	Epilepsy Awareness and Buccal Midazolam Administration
7	52	F	White British	Clinical Lead – IST – Community Learning Disability Nurse	36 years	Master's degree	South West	Adults	Epilepsy Awareness and Rescue Medication Administration
8	59	F	White British	Senior Clinical Lead – IST – Community Learning Disability Nurse	42 years	Degree	South West	Adults	ENB N45 at Chalfont
9	32	M	Romanian	Registered Manager – Supported Living	9 years	NVQ Level 5	South West	Adults	Generic Epilepsy & Emergency Rescue Medication Administration
10	25	F	White British	Deputy Manager – Supported Living	3 years	NVQ Level 3	South West	Adults	Online Epilepsy and Buccal Midazolam Administration
11	35	M	White British	Manager of LeDER – ICB − Nurse	10 years	Bachelor's degree	East	Adults	Epilepsy Awareness and Buccal Midazolam Administration

Note. LD = Learning disability; CLDT = Community Learning Disability Team; IST = Intensive Support Team; ICB = Integrated Care Board; NVQ = National Vocational Qualifications; BSc = Bachelor of Science.

Participants perceived this lack of understanding, within themselves and the circles of support for people with ID and epilepsy, as detrimental to the care delivery, leading to unsafe decisions being made and restrictive measures being implemented under the guise of safeguarding this vulnerable population.

> *"Uhm… people [care provider] were like 'we're scared we'll take him out for a drive you know, but we don't want him to get out the car'cause… what do we do if he's had a seizure and broken something, out in the middle of the forest, how do we get him help?" (Participant 7, Interview 7)*

Furthermore, this lack of understanding can also contribute to interpersonal conflicts between professionals, hindering communication and, thus, limiting future access to or support from specialised services (1.2.3).

3.2. Theme 2: "My mission is to make their life better": Facilitators of good epilepsy care

Promoting and advocating for good epilepsy care in the ID population usually encompasses much more than building relationships with individuals. It also ensures that professionals demonstrate leadership qualities and are proactive in care delivery.

3.2.1. Care relationships

All the participants exhibited overwhelming compassion for people with ID and epilepsy (2.1.1). This quality enabled professionals to advocate better, promote independence, empower, and build trusting therapeutic relationships with people with ID and epilepsy (2.1.2——2.1.3). Participants reflected upon their own inclusive and positive practices in providing epilepsy care for people with ID while acknowledging that service improvements are still needed (2.1.4). Strong care relationships within the MDT supporting the person with epilepsy and ID were seen as facilitating better outcomes due to improved communication, trust, and support (2.1.5).

> *"…I think he knew that we were doing everything in our power to keep him safe." (Participant 2, Interview 1)*

3.2.2. Leadership

Leadership qualities were described as involving a hands-on approach to care delivery while motivating and guiding other professionals towards a shared goal of supporting people with ID and epilepsy (2.2.1). Good leaders often set high expectations for themselves and their teams; however, participants noted that these expectations are not always sustainable, potentially creating a sense of "setting others and themselves up to fail" (2.2.2). Despite these challenges, strong leadership was seen as essential in promoting the team's wellbeing, particularly during crises, to ensure resilience and better team recovery (2.2.3). These leadership qualities were viewed as contributing to help to improved care of people with ID and epilepsy, as the team around the person feel more involved and respected in their care.

> *"…I remember, … being on shift at seven AM the next morning to tell each member of staff what had happened and making sure because the last thing I wanted for them to come in to wake one of them up and then not be there … we did huge reflections within the team and we made sure that the whole team is able to go to his funeral and actually then we did a few fundraisers we planted a tree, and in the garden where he loved being." (Participant 2, Interview 1)*

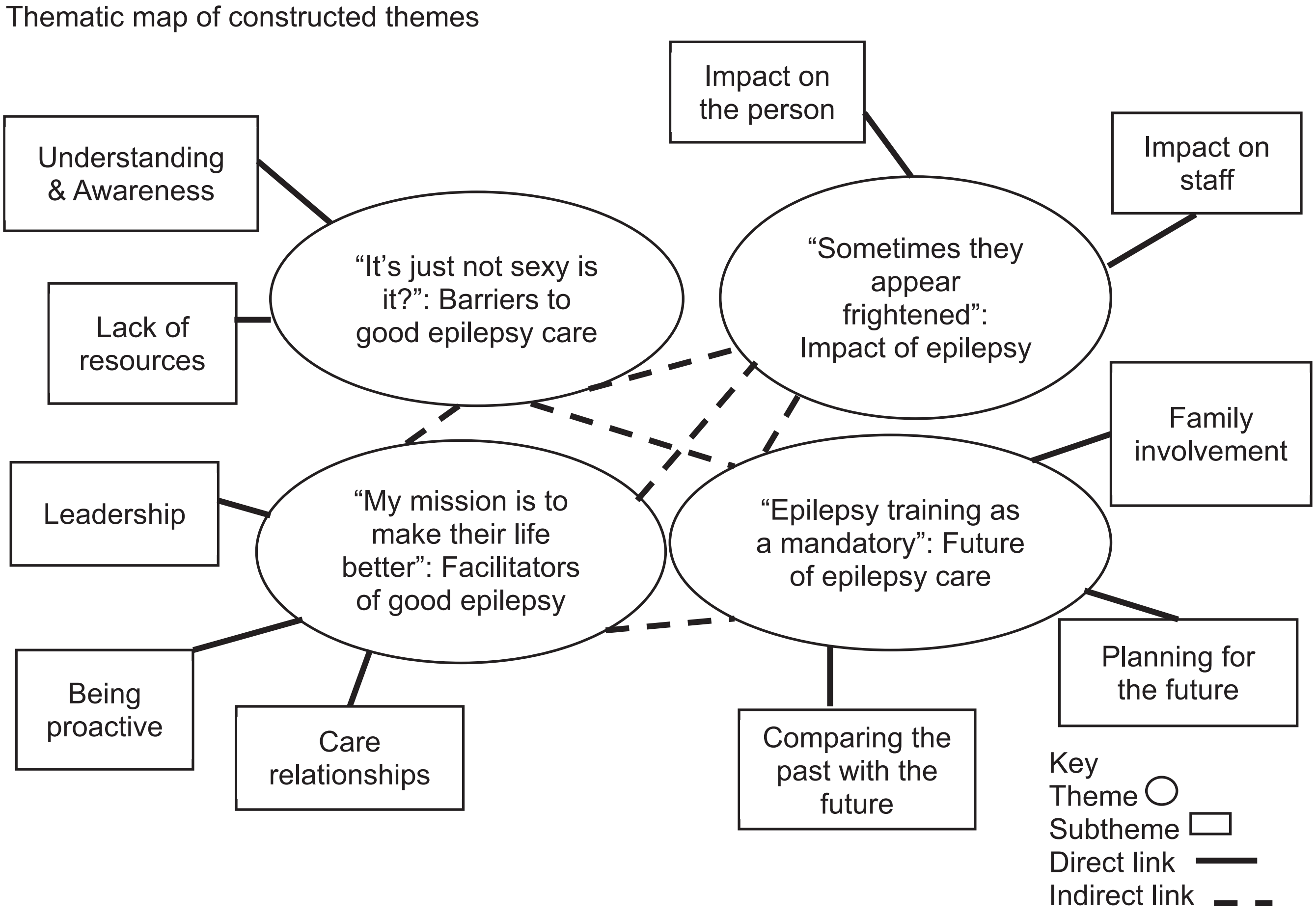

Fig. 1. Thematic map of constructed themes.

3.2.3. Being proactive

Another trait that was identified to facilitate better care for people with ID and epilepsy is being proactive. This includes ensuring that training is executed (2.3.1), care relationships are improved (2.3.2), and relevant documentation is routinely reviewed (2.3.3).

To ensure documents reflect the most up-to-date information, professionals should engage in health-related training, including epilepsy care, which can be adapted to more specific and individualised needs (2.3.4). Some participants reflected on their experiences of informing care plans by consulting health and social care professionals (2.3.3), whereas others explained the process of co-development of risk management strategies with people with ID and epilepsy (2.3.5).

Some professionals also emphasised the importance of further specialised training within the epilepsy or ID field for continuous professional development. Improving the knowledge and understanding of epilepsy was seen as enabling the implementation of additional proactive measures, such as safer staffing levels, comprehensive risk assessments and detailed care plans (2.3.6—–2.3.7).

> *"…so, mum who was like really switched on she'd done things like put three quarter length baths, in the bathroom so that he could never lie down in the bath which was sad because he really wanted to lie down in the bath but it meant if he had a seizure in the bath which he did on a regular basis, there wasn't a problem." (Participant 7, Interview 7)*

Participants also acknowledged their positive experiences working collaboratively with other professionals to enhance their knowledge and understanding, facilitating better care relationships and, thus, care delivery (2.3.8).

3.3. Theme 3: "Sometimes they appear frightened": Impact of epilepsy

Epilepsy affects not only individuals diagnosed with the condition but also their support networks. Participants described their emotional responses, particularly fear, and how these feelings influenced the care provided to people with epilepsy and ID.

3.3.1. Impact on staff

Most participants expressed fears about managing epilepsy, often stemming from negative experiences throughout their careers, some of which originated during their training (3.1.1).

> *"It's scary for me and from one of my past experiences so when I was a deputy manager, I had a twenty-five year old chap die on shift with me and so again he was epileptic he had a seizure in the back of the car." (Participant 2, Interview 1)*

Participants noted that post-incident measures can help mitigate the negative impact of these experiences and provide a safe space for debriefing (3.1.2). However, not all professionals have access to such measures, which can lead to diminished compassion and fixation on "worst-case scenarios" (3.1.3), ultimately compromising care delivery for people with ID and epilepsy. The availability of support during incidents was highlighted as a key factor affecting outcomes. Positive assistance from management and emergency services not only benefitted people with ID and epilepsy but also the staff members involved (3.1.4). Conversely, a lack of support undermined resilience, leading to high staff turnover or perpetuation of fear (3.1.5).

Table 2
Supporting participant quotes in relation to themes and subthemes.

Theme	Subtheme	Quote
Barriers to good epilepsy care	Lack of resources	*1.1.1 “I think it’s a lack of recognition of the importance of it isn’t it if you think about how even just epilepsy services are funded then it’s not on the top of the agenda.” (Participant 8, Interview 10)*
		1.1.2 “So that can be a real big barrier and transport for our children, children on transport having not trained professionals but trained people on their bus that would know how to give buccalam in the event of emergency… they all are call an ambulance…Just because no one is commissioned to provide the service and no one can continue the needed monitoring.” (Participant 1, Interview 5)
		1.1.3 “…trying to think what makes our training mandatory…most of the time it’s just it’s what the trust sees as, being important for our service to do, as a lot of our mandatory training is the stuff that’s either directed from NHS England or has come up from kind of legislation in different places, or if it’s come from a serious case review or something like a very significant incident that’s affected the trust and so the trust suddenly think ‘ooh this is very important and we’ll make this mandatory’, whereas yeah that’s what I said like epilepsy seems to fall in that gap where it’s not mandatory from a trust perspective.” (Participant 3, Interview 4)
		1.1.4 “…and I don’t think they see that they need to know that kind of information anymore they don’t see it as a social care thing but they need to know and said at work ‘that’s a health thing so why do we need to know about that?’” (Participant 8, Interview 10)
		1.1.5 “…it’s interesting like when people do the training they go ‘well, that says five minutes, and this is three minutes’ well yes cause it’s not the same for everyone.” (Participant 2, Interview 1)
		1.1.6 “Yeah, I think it’s basically how few epilepsy specialists there are… there are very far and few between, and how incredibly busy they are.” (Participant 7, Interview 7)
		1.1.7 “Because lots of times you’re just completely exasperated and you’re holding onto stuff you surely shouldn’t be holding on to as a nurse and that it eats away.” (Participant 5, Interview 2)
		1.1.8 “If you’ve got a learning disability and epilepsy you’ve automatically got two diagnosis so therefore you’ve got comorbidities and ‘oh you don’t fit under the remit of our service because our service is just for this one specific diagnosis over here so yes you’ve got that one but you’ve also got these so therefore now you don’t you don’t meet our criteria’” (Participant 3, Interview 4)
	Understanding and Awareness	*1.2.1 “Yeah, I think people still misunderstand what it is don’t they still think it’s contagious and mental illness or you know some cultures it’s still that the person’s possessed and that kind of thing.” (Participant 8, Interview 10)*
		1.2.2 “…so lack of experience lack of exposure to ever meeting anyone with a learning disability and, learning disabilities not being covered on, most Uni courses… you end up working in an LD sector at the end but there isn’t a separate course for it there isn’t even a separate module most of the time, and you can easily qualify as an Allied Health Professional like a physio or an OT without ever having met someone with a learning disability or heard the term learning disabilities… so you then add in epilepsy on top of that and people are automatically thinking well these are kind of there’s an unknown element.” (Participant 3, Interview 4)
		1.2.3 “… there’s certain departments that will see a diagnosis and go ‘oh but you’re a specialist learning disability team you’re used to supporting people with epilepsy they can go to you’ so examples would be like GP’s instead of them, taking people seriously and listening to the care provider concerns about these new symptoms that are presenting … They’re just saying, ‘oh it’s probably just a seizure go and speak to your LD nurse and they’ll sort it out’” (Participant 3, Interview 4)
Facilitators of good epilepsy care	Care relationships	*2.1.1 “I think it can be very disabling I think it’s another label and it’s a very distressing label for some people with a learning disability definitely the people who are, maybe over diagnosed you know I would’ve had a few people maybe who were diagnosed eighteen nineteen and I remember parents saying to me ‘you know I can get my head around the learning disability and the ASD I could cope with this this this this is killing me’ so, massively debilitating.” (Participant 5, Interview 2)*
		2.1.2 “So what I do is I go to the appointment on his behalf, or with his parents and I’ll then when he comes back from his day service I’ll sit down and I’ll make a really clear so today I spoke to ((redacted)) about your epilepsy we talked about your seizures and she’s really happy or we’re gonna try a new medicine or are you OK with that sort of thing and can break it down for him, and he knows obviously he knows that he’s got an epilepsy doctor and a nurse he’s seen them on teams and he’s been obviously into clinics with them.” (Participant 2, Interview 1)
		2.1.3 “I have to be respectful and all I can do is give them the information in a format that they understand and say ‘right you know what, this is your information and this is what you told me and I respect that however these are the risks’, and I write them out and I do whatever to share it with them … it’s not until I get the answer I want until I’m confident that they know the absolute risks because well none of us want anything bad to happen to anybody but I’m respectful of people that will make decisions, that I don’t agree with.” (Participant 5, Interview 2)
		2.1.4 “…whereas now I run clinics in school, where I will do bloods and we will do lots of distraction lots of different

(continued on next page)

Table 2 (*continued*)

Theme	Subtheme	Quote
		techniques social stories pictures breathing, nice calm environments sometimes parents come in and sit on them because that's parental choice, but you know there are so many more children now that are being able to access having their bloods done more regularly to monitor their epilepsy medications." (Participant 1, Interview 5)
		2.1.5 "he would be stooped over constantly because it's closer to fall to the floor isn't it and less sort of damage and things like that, and then they would like they've made- he loves pool so they made like a pool table on the floor for him rather than up there" (Participant 4, Interview 6)
	Leadership	*2.2.1 "… from the manager right the way down, you can all do the same job" (Participant 2, Interview 1)*
		2.2.2 I feel that I go in there with all sorts of recordings and they're like 'oh you're prepared then' so I go in with their height and weight and I go in with seizure recordings, and I end up just telling the GP this because I see them making notes and they'll go 'okay we're done now as long as you know what you're doing' but every provider won't necessarily be like me. (Participant 2, Interview 1)
		2.2.3 "I think they feel supported from what I've heard, urn and knowledgeable, we make sure that there's a good induction process and shadowing when they start off, so that they don't feel like they're on their own supporting somebody, and don't know what to do, and then we almost always- I say almost always have a senior uhm on shift, they are as well always available for questions to help them" (Participant 10, Interview 9)
	Being Proactive	*2.3.1 "I mean we prioritise the training cause you know even before allocating someone, to work with them we need to make our approach is to make sure they are first epilepsy trained and they're trained to administer their rescue medication." (Participant 9, Interview 11)*
		2.3.2 "And our consultants really like that because they will get in touch with us prior to reviewing students and they'll say 'is there anything you need to tell us how many seizures have they had in school' because our students spend thirty-seven and a half hours a week in school don't they and the rest of the time they're at home or at a respite centre or they're asleep so parents sometimes miss a big picture with seizures so the consultants will contact us and say 'what's their presentation been like at school have they had seizures what they've been like', and they find it really useful." (Participant 1, Interview 5)
		2.3.3 "Yeah, so we do have uhm an epilepsy nurse uh community epilepsy nurse which is involved quite regular with us, uhm she comes in the service to-to complete the protocols uh for the rescue medication too, we're sending her monthly reports of the epilepsy records where she's reviewing them" (Participant 9, Interview 11)
		2.3.4 "So uhm we provide them general awareness training so general awareness about epilepsy and then buccalam administration, uhm specifically for each child and young person who has an individual protocol" (Participant 1, Interview 5)
		2.3.5 "So we talked to him [person with ID and epilepsy] about the cameras, we sat down and we looked on Amazon together and we were like 'well this this one has two cameras and you can talk to us and we can talk to you through it' erm and as part of his evening routine we will switch the monitors on and we'll talk, we'll talk to him and he will talk back to us erm we've got a voice monitor above his bed so we can hear any changes in his breathing we've also got an epilepsy erm alarm underneath his mattress which we purposely set off in front of him so he can see that we're doing all of our evening checks." (Participant 2, Interview 1)
		2.3.6 "I had to learn about refractory epilepsy and she had focal and refractory epilepsy, so it was working out and then I realised…that part of the focal epilepsy is depending on what part of the brain was being activated at the time … and that was a real learning curve for me because I hadn't realised that epilepsy could work like that, and then obviously I was able to pass that onto the staff team who had no idea either so…you stop the placement from breaking down you help the staff make more resilient through education and knowledge sharing". (Participant 7, Interview 7)
		2.3.7"I attend uhm a specialist epilepsy nurse group and I've gone to master classes and attended online master classes … I kind of uhm seen it as my, responsibility to keep up to date so … I will then update my training so if things if- you know if uhm things have changed or there's new bits of research so, a lot of the SUDEP research" (Participant 8, Interview 10)
		2.3.9 "I'd like to think I improved their practice as much as they improved my practice because I was able to say well a learning disability you know say like somebodies fragile X or whatever and I was able to talk to them about what fragile X is or you know like a person with down syndrome and talk about the deterioration that they experience or why they might have seizures and you know so it was as much me giving back as me receiving." (Participant 5, Interview 2)
Impact of epilepsy	Impact on staff	*3.1.1 "…experience of seeing a seizure that's the most important most valuable experience for all of them, as all of them have said once they've experienced one, they feel fine but it's the fear of the unknown… yeah just the fear of the unknown of what they're gonna be presented with how they're gonna manage it." (Participant 1, Interview 5)*
		3.1.2 "…before one year and a half ago we used to like debriefs after, every one

(*continued on next page*)

Table 2 (*continued*)

Theme	Subtheme	Quote
		of like much more risky incidents that took place but what we introduced in the last year we introduced our weekly debriefs, where we kind of capture the whole week incidents seizures and everything and we give the chance to the team to feedback how they felt if there's anything that's been learned, if there's anything that's worked while dealing with a stressful situation and, you know just giving them the opportunity to discuss and you know if there's any lesson learned from them, capturing the lessons learned and sharing with the team in the next lengthy meeting, for that specific person." (Participant 9, Interview 11)
		3.1.3 "I remember being devastated he passed away in his sleep with SUDEP and like he'd gone I mean he must have been late fifties… So it had an impact on me but the carer called me up because she needed to get his equipment collected and I was the first person that she kind of properly spoken to, and just broke down on the phone and she said 'what else could we have done' whatever because I knew SUDEP was a risk because we'd spoken about it because we had the right care plans in place I could confidently say 'there is nothing else you could have done', and you can give that reassurance… And you know it affects how compassionate you can be towards other people." (Participant 3, Interview 4)
		3.1.4 "I had an occasion probably a few years ago where the advice the person going through the tonic clonic seizure stopped breathing, and, they were advised by the person on the emergency service to start CPR and the person then started breathing and they still advised to continue with the CPR where the person was still going through the seizure which I found a bit not giving them the right advice personally especially you know… felt a little bit like conflictual direction from you know emergency service should be a professional, you know body part that gives the right guidance to the staff." (Participant 9, Interview 11)
		3.1.5 "…so we managed to get a defib on him, we had off duty police officers turning up we had police officers turn up, we had ambulance crews we had response cars we had everything and more, but when you were phoning the on-call phone for help they weren't answering ((shakes head once)) so I had to make the phone call to the parents saying 'your sons had a really nasty seizure, he's on his way to hospital I need you to leave and come down now' which was tough." (Participant 2, Interview 1)
	Impact on person	*3.2.1 "Well I think it's kind of like the longer-term impact isn't it so if someone is having quite severe generalised seizures then you've got the kind of longer-term effects so injuries that kind of thing then missed moments in time, depending on how they are after a seizure as well it's having to take the medication you know and how that medication makes you feel, if they have partial epilepsy that people don't actually recognise again it's them missing out on things aren't they." (Participant 8, Interview 10)*
		3.2.2 "…in terms of like accessing community services I think there's a lot of people who miss out because their care providers are scared so because the individual carers and support workers are afraid, and instead of wanting to do the risk assessment or thinking about it or asking for extra funding for more staffing to enable people to access certain activities, it's just easier for them to just 'oh just stay home and put the telly on'" (Participant 3, Interview 4)
		3.2.3 "Yeah, and for one lady because of her frequency of her seizures so she has seizures almost every day, her support she always has to have somebody with her, at all times, so that would impact you as well if you if you never get a chance to actually be alone that's not very nice." (Participant 10, Interview 9)
		3.2.4 "I took a young lady with really severe epilepsy to her aunties wedding… drove her to ((redacted)) so she could be part of her auntie's wedding as a bridesmaid, she had really severe drop seizures tonic clonic seizures I mean she'd probably have ten or twelve a day… and a lot of people shied away from wanting to take her I was like 'no we're all good we got her meds we've got a plan I know where the hospital is we'll all be good." (Participant 1, Interview 5)
	Family involvement	*3.3.1 "…you look at the chap that we're talking about and he's got every sign that he won't live long, and you know he used to have one hundred seizures a day. …and I think for me the parent well his dad certainly…he is completely obsessed with his son and I completely understand why…he still wants him home every weekend and every waking minute he wants to know that he's okay and, and I think he almost dreads the time that I call." (Participant 2, Interview 1)*
		3.3.2 "…it's really tricky especially when you know like some families, everything's kind of exhausted at a local level being referred to a tertiary centre and actually they're going they're like 'it was awful I don't want to go back there' …a lot of families feel very got at then… yes we need more support so we've been referred up…yeah which families some families are fine with some families are happy to tell their story over and over again there are some that are like 'are you absolutely kidding me why have you sent me there?'" (Participant 1, Interview 5)
		3.3.3 "…the risk of his placement breaking down versus death in SUDEP as hard as it was she was like and being a nurse she obviously had a lot of insight, … but she was like 'I'm making a decision about watching him going into hospital long-term hospital because we can't maintain his place in the community or him having a seizure and risking SUDEP if I go this way the risk is

(*continued on next page*)

Table 2 (*continued*)

Theme	Subtheme	Quote
		less and let him have the seizure but I know his placement won't break down I know he won't spend years and years in hospital, he might die but his quality of life" (Participant 7, Interview 7) *3.3.4 "I phone the parents and go 'by the way I've been to this appointment today' and they're like 'you don't need to phone me, you record it all on Nourish we have access' Nourish is our care planner and I've given the parents access so they can write notes and actually they're like 'you don't need to phone and tell us anymore because I can see it all. Your recording is wonderful like you actually do a better job than us' and I'm like 'yeah but you are the parent at the end of the day I'm just the manager I could go tomorrow'" (Participant 1, Interview 2)* *3.3.5 "It's not as thoroughly recorded as ours are, so it's difficult to kind of see and to understand why, but it I guess it might as well be as she does sleep in the same bed as her sometimes so she reports, that she will have very short seizures for a couple of seconds where her body will just stiffen, and that's something that we wouldn't be able to record, because we've talked to the epilepsy nurse about mats before to go on the bed and it wouldn't pick that up, and the epilepsy nurse said that it's 'a short seizure for two seconds of just stiffening the body is unlikely to realistically harm her' and we still do visual observations and we listen to her through the audio monitor." (Participant 10, Interview 9)*
Future of epilepsy care	Comparing the past with the future	*4.1.1 "I mean for him his life changed overnight it literally the introduction so they started off they didn't know how to deal with it and you gotta remember, that we're going back a long time so the meds weren't as good as they are now… So, he didn't have the right rescue meds they didn't exist, so he had a safe room where he could take his clothes off and hopefully the police wouldn't get called and stuff like that, and then it came out about using clobazam as a proactive PRN." (Participant 7, Interview 7)*
	Planning for the future	*4.2.5 "It would be a case of 'you either change your policy, or you move out of ((redacted)) and ((redacted)) because we don't commission that sort of care here' and that's I guess where I'm talking about you know the care environment for me that is not a reasonable opt out… you know you wouldn't opt out of you know 'we're gonna take people that have epilepsy but we're opting out of giving buccal midazolam'… No that's not something that you can do I guess as an example that's what I'm talking about you know we need to take the power back in our commissioning and say, 'this is what you have to do to deliver services here' not 'this is what we will let you do'" (Participant 11, Interview 8)* *4.2.1 "Probably quicker and easier access to neurology services… because as I said it works really well for myself and ((redacted)) the epilepsy specialist but if you we could, improve that access as in like time wise if we could reduce the time that the person's waiting to see the neurologist but that could be the same it's not just neurology isn't it it's the same that you know people who are waiting for any consultants with learning disabilities and not epilepsy, you know they're waiting a long time as well." (Participant 4, Interview 6)* *4.2.2 "I mean two or three things I'd like to change really I mean as I said you know we talk a little bit about you know the family members you know have helping them to acquire the right training to help the individual we support… a bit more understanding for the community as well I mean to a lot of people out there in the community they don't really understand the learning disability and they just seem to like 'oh wow look at that person oh God they're staring' and this kind of stuff and you can see that because of the lack of understanding." (Participant 9, Interview 11)* *4.2.3 "I know that that's a big what if and it's a big jump but if we don't have the research out there to explore that and to kind of measure that and underpin that we're never gonna be able to overcome these barriers with accessing services and change that legislation that we mentioned before, to make things mandatory because we don't have the statistics or the evidence base to then be able to take it forward so yeah more research and then once we've got more evidence we want more money more resources and lots of things for everyone." (Participant 3, Interview 4)* *4.2.4 "I hate the alarm systems that we have to use the thing the mattresses the alarm under the bed, that sort of thing I think it's really ineffective there doesn't seem to be enough money put into those sort of things you hear in the non-disabled world, that there are people wear watches and things like that our guys aren't even given that as an option they're really not, and there's just access to different meds I know there's some really groundbreaking meds and stuff going on out there" (Participant 7, Interview 7)*

3.3.2. Impact on person

The impact of epilepsy on people with ID is significantly variable, with participants reporting additional health comorbidities secondary to medication, seizures, and the diagnosis itself (3.2.1) whilst also facing restrictions in their daily lives due to the fear their support networks have regarding their epilepsy (3.2.2). People with ID may also experience fear of their epilepsy, which may be communicated through behavioural changes, task avoidance, or even verbal communication.

> *"In a way epilepsy can be quite confusing for them because it's something that they don't have control over it and it just happens and sometimes they appear frightened…" (Participant 9, Interview 11)*

As a result, this fear can evoke changes within the person's life that can negatively impact their quality of life, such as the imposition of continuous supervision deemed necessary for safety (3.2.3). However, some participants emphasised positive approaches, highlighting their efforts to avoid letting epilepsy unnecessarily restrict the lives of people with ID (3.2.4).

3.3.3. Family involvement

Family members of people with ID play a crucial role in epilepsy care. They are significantly affected by the diagnosis of epilepsy and the care of their loved ones, with fear being the predominant emotion reported (3.3.1). Family members often take on dual roles, acting as both relatives and as historians, advocates, and everything in between (3.3.2——3.3.3). Professionals noted that families experience a wide range of emotions in this caregiving role, from gratitude to burnout (3.3.4).

> *"And with the increase in epilepsy you're seeing a loss of function, and sort of a regression in that person's ability, and you know you're seeing, a sort of a parent lose a child sort of before their eyes really." (Participant 11, Interview 8)*

These emotional responses are likely to influence the care provided to people with ID and epilepsy. Families may adopt measures they believe to be protective, which may be considered restrictive by external agencies (3.3.5).

3.4. Theme 4: "Epilepsy training as a mandatory": Future of epilepsy care

Services should be able to reflect on the past to plan the future of epilepsy care. Without assessing previous and current epilepsy practices, proposals on how to enhance epilepsy care for the ID population may be limited. All participants were asked to share their thoughts on potential improvements within the epilepsy sector to improve the care of people with ID.

3.4.1. Comparing the past with the future

Reflecting on current and past practices within the field is necessary to identify areas of epilepsy care that require improvement. Participants acknowledged progress in practices such as seizure treatment and understanding of epilepsy (4.1.1).

> *"…there were people who didn't have an intellectual disability who were in the institutions because they were an epileptic in those days and when you used to get taught as a student nurse about the epileptic personality." (Participant 6, Interview 3)*

3.4.2. Planning for the future

Participants proposed several strategies for future improvements, including expanding the current evidence base, fostering good leadership qualities within services, improving access to and the quality epilepsy training, strengthening safety precautions, and evaluating staff recruitment and retention initiatives. For these suggestions to be considered and actioned, commissioning priorities must be reviewed to better incorporate and promote epilepsy care (4.2.1——4.2.5).

> *"That everyone that came into the caring field whether it be health or social care, has to attend epilepsy awareness training as mandatory and it has to be a certain standard not just, stick them in front of a computer for half an hour." (Participant 8, Interview 10)*

4. Discussion

This research explores health and social care professionals' perspectives on the role of social care in supporting people with ID and epilepsy. It is the first in-depth qualitative study on this topic, offering insights relevant to current service delivery in the UK. The analysis identified four interwoven themes, revealing both barriers and facilitators in epilepsy care. Additionally, the study highlighted the broader impact on support networks and individuals, assessing how these factors contribute to the evolution of epilepsy care.

Previous studies on social care and epilepsy management for people with ID have typically used mixed methods, via the use of questionnaires [28,38]. In contrast, this study relies solely on qualitative interviews, providing deeper insights into professional perspectives. The current findings complement existing literature by identifying key areas, such as, training [47,54], awareness and understanding of epilepsy [28,55,56], and access to services [13,38].

It is essential to consider how this research contributes to existing literature regarding people with ID without epilepsy. Our findings align caregiver and professional experiences in supporting people with ID who do not have epilepsy, which highlighted gaps in training and the negative impact on support networks, as key issues [57]. Consequently, a focus on improvements in these areas would have benefits to people with ID, including those who also have epilepsy.

Extensive research exists on epilepsy in people without ID [58], whereas studies on its impact with people who have ID and epilepsy as participants remain limited, due to recruitment challenges and communication barriers related to the severity of ID [59,60]. However, research on the experiences and perspectives of people with ID is growing, with an increased push for their inclusion in studies [61]. To better evaluate care for this population, further research needs to focus on engaging with the ID and epilepsy population, rather than their proxy contacts (families/care providers), to obtain their views and perspectives, with tools such as Wordless Interventions [59,60], to facilitate discussions.

Participants noted a national lack of funding for epilepsy services, affecting local care. Epilepsy remains an underfunded health need [13] yet research on expenditures in this area is limited [40], making it difficult to assess the full impact of inadequate funding. A longitudinal economic evaluation of epilepsy care within the UK, would be beneficial to comprehensively understand the expenditures and deficits within this field more.

Participants reported a perceived lack of understanding of epilepsy for people with ID by other social care staff (i.e., front line staff, social workers, commissioners etc.), and a perception that their role may not be vital in supporting people with ID and epilepsy [38]. Future research needs to include a wider range of stakeholders involved in epilepsy and ID care to broaden our understanding.

Although this study aimed to recruit both health and social care professionals, most participants were from the health sector despite efforts to ensure balance. This raises questions about whether recruitment reflects social care professionals' views on their role in epilepsy care for people with ID; and whether the recruitment strategies utilised were appropriate for social care professionals. One possible explanation is that social care professionals may not see themselves as part of the MDT supporting people with ID and epilepsy [38]. Further analysis and evaluations are required to ensure better recruitment of social care professionals in future research pertaining to their perspectives on the care of people with ID and epilepsy.

4.1. Training and education

Training as a barrier is well-documented in research [38], with various strategies proposed to address it [28]. However, since epilepsy care lacks funding priority [62], implementing these strategies remains difficult without government support and regulatory changes in health and social care [13].

Literature also critiques the quality of epilepsy awareness training due to differences in access, content, and delivery [55,63,64]. This study supports those concerns showing that lack of training affects care delivery and emphasises the need for accessible training for effective care planning. The demand on specialists to deliver training is significant [28,65], and without adequate resources [13], access to training remains limited. While some social care services are offered training, attendance is reported to be inconsistent [38], further hindering knowledge transfer and care quality.

Participants noted a need for more accessible literature. Limited access to training restricts professionals from providing accurate, up-to-date information. On the other hand, for direct care workers to provide health facilitation and promotion, they are likely to require adaptable health literacy themselves [66]. Further to this, funding is also limited to provide ongoing training to a workforce with a high staff turnover, whilst funding is provided for direct care and support, and not for the training needs associated with supporting people with ID and epilepsy [67]. Existing research echoes these concerns, showing that support networks often rely on inaccurate information [47], which can lead to restrictive practices for people with ID and epilepsy [68]. Although improving access to epilepsy information for circles of support for people with ID is widely recommended [28], the availability of this information can be limited, and research has critiqued the inconsistencies in the provision and accessibility of this information. This further adds to the continued scrutiny of the accessibility and availability of generic health literature for people with ID, without epilepsy [69,70].

4.2. Attitudes and experiences

Participants shared experiences of professional attitudes towards epilepsy and ID, which impacted service access and care delivery. While they didn't identify specific challenges related to ID, they noted that health and social care professionals often misunderstand its complexities. Research indicates some services fail to meet ID needs [16,71] often due to inadequate training [72] or over-reliance on specialists [73]. Consequently, circles of support of people with ID, including families, unpaid andpaid carers, frequently feel unheard [31]. This study supports these findings, with participants describing inconsistent involvement in epilepsy management and barriers to communication between professionals and caregivers limiting access to specialised services – heightening risks of poor outcomes [37] and health inequalities [16].

Epilepsy stigma contributes to negative professional attitudes, impacting the quality of life for people with ID [74]. This study shows that both indirect stigma and inadequate understanding of epilepsy impair care delivery. Despite some progress in reducing stigma, historical perceptions continue to hinder these efforts [75]. These influences extend beyond epilepsy and are well-documented in the ID population [76], illustrating how stigma continues to shape policy and practice – placing people with ID and epilepsy at a disadvantage.

4.3. Impact of epilepsy

Participants identified fear as the primary emotion related to epilepsy, impacting care delivery and the wellbeing of those with ID and epilepsy and their support networks. This aligns with existing research, where circles of support of people both with and without ID report similar fears [77]. Health and social care professionals report a lack of confidence when supporting people with ID and epilepsy, both in epilepsy management and risk identification/management [36]. Although, this level of confidence can increase [36], this is dependent on the training completed. In contrast, there may be an over-reliance upon health care professionals to manage epilepsy in people with ID, especially in context of day-to-day and risk management [36].

In the ID and epilepsy population, these fears are intensified by inconsistent support [77], premature mortality [16], and complex comorbidities [49]. Although training and inclusive communication can alleviate some of these concerns [28], families and carers are often excluded from such initiatives, perpetuating the cycle of fear [47]. It is imperative to also explore the wider impacts of epilepsy, beyond the health need [54] and highlight the level of support that paid carers and families of people with ID and epilepsy require over time [54]. With tools such as the Step Together toolkit, these needs can become more coordinated and visible within health and social care services [13].

4.4. Limitations

There was an element of sampling bias within this study, as a result of non-respondence and specific recruitment of health and social care professionals working in ID and epilepsy. Non-respondence has impacted the diversity of the sample group, as the forums used to advertise the study were nationwide and encompassed ethnicities and nationalities within the UK. However, the sample was predominantly White British and located mainly in the South West of England with the majority of participants working with adults. As such, it does not fully represent the wider range of professionals in epilepsy and ID care across the UK. Future research should aim to include a more demographically and regionally diverse sample.

The inclusion criteria specifying health and social care professionals was deliberate to obtain the rich and in-depth data from this cohort. However, the criteria does reflect a sampling bias, as this does not include the wealth of information that could have been obtained from people with ID and their families. Secondary to this, saturation was achieved from this specific population, but saturation of the influences of social care for people with ID and epilepsy has not been obtained due to the exclusion of people with ID and their families.

Participants within this study were less involved in the day-to-day care of people with ID and epilepsy. Although, they provided important perspectives on issues such as training, funding, and commissioning issues, there is a lack of detail on the complexities with supporting people with ID and epilepsy both during and after a seizure.

As the majority of the participants were health care professionals, specifically with nursing degrees, they are more likely to have received formal and an increased availability to epilepsy training compared to the social care professionals.

Given the qualitative nature of this study, findings reflect the experiences of the participants and are not intended to be generalised. While findings align with the existing literature, they may not capture the perspectives of all professional subgroups.

5. Conclusion

This study underscored the critical need for mandatory epilepsy training across all health and social care services. Given the complex needs of people with ID and epilepsy, such training is vital for improving care quality, building professional knowledge, facilitating multidisciplinary communication and fostering more inclusive, person-centred care delivery. Participants consistently reported that inadequate training limited confidence, contributed to unsafe practices and perpetuated misunderstandings about epilepsy.

Involving families in epilepsy care was also identified as essential. Families and caregivers' roles are multifactorial, yet they are frequently excluded from decision making and training opportunities. Their inclusion would ensure more consistent care, support wellbeing and could reduce the wider impact of epilepsy. Fear, often stemming from lack of training or traumatic past experiences, was a dominant theme in the data. Addressing this fear through training, improved awareness and support systems, and is necessary to improve care outcomes for people with ID and epilepsy. Improving communication and collaboration between health and social care professionals also emerged as a key recommendation. Participants highlighted the need for accountability, shared responsibilities and more effective multidisciplinary communication to promote integrated care.

5.1. Implications for research

Further investigation into epilepsy care funding is needed due to perceptions of significant underfunding [62]. Future research should assess current expenditures, through a longitudinal evaluation, and identify more cost-effective strategies to support service delivery.

Further efforts and changes to recruitment strategies should be made to ensure that social care professionals are recruited as participants to ensure a more holistic view and understand this phenomenon in further depth.

Additionally, epilepsy's impact on people with ID highlights the importance of including them and their caregivers, who may have more direct care experience and include family members, in future research. Their perspectives are essential for developing a holistic understanding of epilepsy care and improving service quality/delivery.

6. Disclosures

RS developed the non-commercial and free to use SUDEP and Seizure Safety Checklist and the EpSMon app to reduce the risk of SUDEP and enhance seizure safety. RS is the chief Investigator of the NIHR adopted national Ep-ID register. The Register is supported and monitored by the National Institute of Health Research UK. The funding for each molecule examined by the Register is via an Investigator Initiated Support grant from each of the molecule's parent company. The funding is to RS's NHS institution and goes towards the salary of the research co-ordinator and the institution's project oversight costs. The contributing companies till date include Eisai, UCB, Bial, Jazz pharma (previously GW pharma) and Angelini. This work sits outside the submitted work. In addition to the above RS has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Neuraxpharm, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities all outside this work.

CRediT authorship contribution statement

Jay Price: Writing – review & editing, Writing – original draft, Visualization, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Paraskevi Triantafyllopoulou:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Resources, Methodology, Formal analysis, Conceptualization. **Ceridwen Evans:** Writing – review & editing, Writing – original draft, Supervision, Methodology. **Rohit Shankar:** Writing – review & editing, Methodology.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr Rohit Shankar reports a relationship with LivaNova UK Ltd that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with UCB that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with Eisai Europe Ltd that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with NEURAXPHARM UK Ltd that includes: funding grants, non-financial support, and travel reimbursement. Dr Rohit Shankar reports a relationship with Veriton Pharma Limited that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with Bial that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with Angelini that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with UnEEG that includes: funding grants, speaking and lecture fees, and travel reimbursement. Dr Rohit Shankar reports a relationship with Jazz Pharmaceuticals Inc that includes: funding grants, speaking and lecture fees, and travel reimbursement. RS developed the non-commercial and free to use SUDEP and Seizure Safety Checklist and the EpSMon app to reduce the risk of SUDEP and enhance seizure safety. RS is the chief Investigator of the NIHR adopted national Ep-ID register. The Register is supported and monitored by the National Institute of Health Research UK. The funding for each molecule examined by the Register is via an Investigator Initiated Support grant from each of the molecule's parent company. The funding is to RS's NHS institution and goes towards the salary of the research co-ordinator and the institution's project oversight costs. The contributing companies till date include Eisai, UCB, Bial, Jazz pharma (previously GW pharma) and Angelini. This work sits outside the submitted work. In addition to the above RS has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Neuraxpharm, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities all outside this work. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2025.110697.

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