



PEARL

Awareness of social care needs in people with epilepsy and intellectual disability

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Awareness of social care needs in people with epilepsy and intellectual disability



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ABSTRACT

Background: Nearly a quarter of people with intellectual disability (ID) have epilepsy with large numbers experiencing drug-resistant epilepsy, and premature mortality. To mitigate epilepsy risks the environment and social care needs, particularly in professional care settings, need to be met.

Purpose: To compare professional care groups as regards their subjective confidence and perceived responsibility when managing the need of people with ID and epilepsy.

Method: A multi-agency expert panel developed a questionnaire with embedded case vignettes with quantitative and qualitative elements to understand training and confidence in the health and social determinants of people with ID and epilepsy. The cross-sectional survey was disseminated amongst health and social care professionals working with people with ID in the UK using an exponential non-discriminative snow-balling methodology. Group comparisons were undertaken using suitable statistical tests including Fisher's exact, Kruskal-Wallis, and Mann-Whitney. Bonferroni correction was applied to significant ($p < 0.05$) results. Content analysis was conducted and relevant categories and themes were identified.

Results: Social and health professionals ($n = 54$) rated their confidence to manage the needs of people with ID and epilepsy equally. Health professionals showed better awareness ($p < 0.001$) of the findings/recommendations of the latest evidence on premature deaths and identifying and managing epilepsy-related risks, including the relevance of nocturnal monitoring. The content analysis highlighted the need for clearer roles, improved care pathways, better epilepsy-specific knowledge, increased resources, and better multi-disciplinary work.

Conclusions: A gap exists between health and social care professionals in awareness of epilepsy needs for people with ID, requiring essential training and national pathways.

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1. Introduction

1.1. Intellectual disability and social care

People with intellectual disabilities (ID) face challenges in the acquisition of new skills and understanding of complex information, causing impairment in their daily lives [1]. Difficulties in communication, frequent cooccurring physical disabilities, and deficits in interpersonal skills contribute to significant barriers in accessing healthcare, social support, and community activities for people with ID [2,3]. Poverty and related socioeconomic issues further compound the challenges faced by this vulnerable population [4]. Advancing age is also associated with increased vulnerability in people with ID [5] and 63% of people with ID die prematurely before the age of 65 [6]. A much higher proportion of people with ID die before the age of 50 compared to the general population with reported numbers of 22% and 9% respectively. This discrepancy in early mortality has been accounted for in full by causes of death which could have been avoided by good quality care. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK reported 37% of people with ID to have died of avoidable causes, compared to 13% of the general population [7].

Political initiatives in the UK have seen a shift in health and social care provisions for people with IDs away from hospitals towards more individualized and flexible care provisions in the community [8]. Social care providers work closely with people with IDs in their own homes and various care home settings to address these challenges and enable them to live safe, healthy, and fulfilling lives. In the period 2019–2020, 153,145 adults in England received long-term social care support primarily due to ID, and of these 24,635 were in residential care [9]. This likely underestimates the true utilization, as it would not cover those for whom social care is not the primary reason for their care needs. Social care should work proactively in partnership with health services to anticipate and address the holistic needs of the person they support and implement reasonable adjustments to meet the specific health and social care requirements [10].

1.2. Epilepsy and people with ID:

Epilepsy is a common neurological disorder, affecting around 1% of the general population in the UK [11]. There is a strong association between epilepsy and ID [12]. For many people, there is a shared genetic aetiology that predates both, such as a genomic rearrangement like a copy number variant or a ringed chromosome, for others it is a Mendelian gene change. Acquired causes include hypoxic-ischaemic injury or early-life meningoencephalitis. For the many however there is no objective cause and these alongside a wide range of idiopathic processes, contribute to prevalence rate estimates up to 20 times greater than the general population [13], with higher prevalence correlating with increasing severity of ID [14]. Co-occurring neurodevelopmental, physical, and psychiatric conditions are common, and impact significantly on treatment needs and quality of life [15–19]. Sudden unexpected death in epilepsy (SUDEP) is estimated to be 3 to 9-fold higher in people with ID compared to people with epilepsy in the general population [20] and contributes to making epilepsy one of the most common causes of death for people with ID [6,21].

People with ID and epilepsy experience higher rates of medication side effects and psychiatric conditions [14] and over two-thirds had poorly controlled epilepsy [22]. Polypharmacy is commonly encountered and while it may be clinically justifiable, due to antiseizure medication resistance and the high prevalence of multimorbidity in people with ID [23], there are concerns that

inappropriate prescribing is commonplace in people with ID and that specific de-prescribing guidelines should be implemented [24]. There is no fixed pathway, structure, or guidance nationally for specialist or primary care epilepsy reviews for people with ID in the UK [25]. All these factors may contribute to the higher mortality of people with ID, and co-occurring epilepsy compared to ID or epilepsy respectively [26]. Due to the complex needs associated with both intellectual disability and epilepsy, the co-occurrence of the two conditions call for robust, person-centered, day-to-day support in all aspects of daily life to mitigate the amplified epilepsy-related risks, monitor for seizure activity and support medication compliance.

1.3. Social care, epilepsy, and people with ID:

Here the term ‘social care’ refers to the provision of non-medical support that includes practical, personal support such as housing and personal care. As such social care providers may be a major determinant of the environment of people with ID and therefore day to day seizure-associated risks. Furthermore, social care professionals working day to day with people with ID and epilepsy have a liaison role in maintaining access to epilepsy health care professionals for the people they support [27]. A minimum standard of training for care providers may include training in the use of nocturnal monitoring to reduce SUDEP risk and the administration of anti-seizure medications, but in the UK routine care is commissioned through social care and so this training may be lacking [28,29].

Little is known about how this vulnerable population receives holistic social care-based support based on their chronic epilepsy needs. In this article, quality of life refers more specifically to health-related quality of life, which has been described as “a term referring to the health aspects of quality of life, generally considered to reflect the impact of disease and treatment on disability and daily functioning” [30].

Holistic care refers to person-centered, individualized care, created collaboratively between care professionals and patients, “based on a mutual understanding of their physical, psychological, emotional, and spiritual dimensions” [31].

1.3.1. Aims

This survey aimed to explore care professionals’ own views and experiences of caring for people with ID and epilepsy. It sought to make comparisons between different professional care groups (health care, social care, and others) as regards their subjective feelings of confidence, accountability, and responsibility when managing and addressing needs associated with supporting people with ID and epilepsy, and looked to identify how differences in training and skills might translate into differences in care priorities.

2. Methods

The STROBE Checklist for cross-sectional studies was used to guide the project (Supplementary Information 1).

2.1. Survey and vignette development summary

A vignette-based survey comprising a mix of quantitative and qualitative measures was developed using Google Forms.

A preliminary focus group of five co-authors i.e. one neurologist with a special interest in intellectual disability, two psychiatrists working with people with ID with a special interest in epilepsy, a senior representative of a national epilepsy charity, and the patient lead of a national social change organization for people with ID col-

laboratively drafted five vignettes which were felt to be representative of clinical situations commonly encountered by care professionals supporting people with ID and epilepsy, incorporating physical, mental, behavior and social health care aspects.

These 5 vignettes were shared by invitation with a panel of ten national clinical experts consisting of two social care professionals (SCPs), four epilepsy professionals, and four psychiatrists working with people with ID. Panel members were invited to rate the suitability of the scenarios on a scale from 1 to 5 (1 being 1st preference for inclusion into the survey). The panel members were asked to rate their training and confidence in managing the health and social needs of the people presented in the vignettes and to comment on any ambiguities in care responsibilities the vignettes may have raised. The panel members were asked to take the following into consideration when deciding on their individual ratings: How common and challenging the situation described in the vignette was, whether there was any ambivalence around which service could offer the best care and whether a cross-disciplinary approach encompassing both social and health care providers was felt to be needed. This was done in a semi-structured way, to allow the panel members to be guided by their professional expertise and provide comments on content and style.

Vignette scores were organized and calculated according to the profession (i.e., social care, psychiatry, and epilepsy). The three vignettes with the lowest average scores (corresponding to the highest ranking) were selected, resulting in Vignettes 2, 3, and 4 being included in the survey. The final vignettes were amended further to absorb highlighted elements from discarded vignettes according to the panel's feedback contributions. The survey was iteratively improved, following advice from academic experts in social care and psychiatry in people with ID who helped shape the presentation and final design of the chosen vignettes. The final survey is presented in Supplementary Information 2 and the selected vignettes in Supplementary Information 3. The vignettes hoped to extract the respondent's perception of their level of confidence in exploring and managing the different common scenarios of care in which all professionals working with people with epilepsy and ID (health, social care, and others alike) are expected to report a consistent level of confidence between groups.

Care professionals responding to the survey were allocated into one of three groups (health care, social care, and others), based on which professional group they have chosen to identify within the survey.

2.2. Ethics and governance

The study was reviewed by the University of Kent Tizard Ethics Committee and ethics approval was received (Application 574/2022). Completion of the survey was regarded as consent to participate in the study and was explicitly mentioned as such.

2.3. Participants and recruitment

A cover email and link to the Google Forms survey were circulated to selected key professionals with affiliations to national health and social care organizations involved with the care of people with ID and epilepsy including the Faculty of the Psychiatry of Intellectual Disability within the Royal College of Psychiatrists, the British branch of the International League Against Epilepsy (ILAE), the National Learning Disability Professional Senate (England), the Epilepsy Nurses Association (ESNA), different adult social care organizations in England via the National Development Team for inclusion (NDTi). The rationale for these professional groups is provided in [Appendix 1](#). These key professionals were encouraged to disseminate the survey further to contacts in the respective networks, thus utilizing an exponential non-discriminative

snow-balling methodology [32]. The survey ran from 02/2022 to 08/2022.

2.4. Data analysis

2.4.1. Quantitative data analysis

Survey respondents were given an opportunity to identify themselves as belonging to specific professional groups. From this, three clear groups emerged: health care professionals (HCPs), social care professionals (SCPs), and a group of "others" who did not specify a professional identity. The data analyses summarise the results for each of the three groups separately and make a statistical assessment through overall comparisons between the three groups and by pairwise comparisons between each combination of groups. As there are multiple comparisons between pairs of groups, there is an increased risk of finding a significant result due to chance. Therefore, *p*-values from the pairwise comparisons were given a Bonferroni adjustment. Where there was no ordering of the categories, categorical variables were compared the three staff groups using Fisher's exact test. The same test was used to compare between pairs of groups. The Kruskal-Wallis test was used to compare between the three groups for variables measured on an ordinal scale (i.e., an ordering to the response categories), with the Mann-Whitney test used to compare between pairs of staff groups. The Cramer's V statistic was used to quantify the effect size for differences between groups for binary outcomes. These were interpreted as: 0.1 weak effects, 0.3 medium effects, 0.5 large effects. The statistical software package used to analyze the data was Stata (Version 15.1).

2.4.2. Qualitative data analysis

The survey included free text boxes following each of the three vignettes, where respondents could describe their top three health priorities for each scenario.

We applied content analysis to quantify the presence of common concepts within the non-numerical data. Codes related to each other through meaning were grouped into categories and further developed into themes [33]. In this process, the researcher (AG) consulted with two of the co-authors (PT and AH), both experts in qualitative data analysis, and codes were read and agreed on collaboratively based on the opinions expressed in the qualitative responses.

The free text responses ranged in quality from brief one- or two-word bullet point responses to longer, more reflective answers which considered not only what the care goals were, but how these would be achieved and what the obstacles to achieving these might be. Such more in-depth responses were included in the narrative and quoted directly in the text, with the participant's professional role noted following the quote to provide further context. A mind-mapping approach was used by the research assistant to aid them in structuring high-frequency words visually, while looking to generate codes and categories [34]. The interpretation of the qualitative data has been summarised descriptively under "results".

In addition to applying content analysis to the qualitative data, we also visualized this in graph form; we collated high-frequency words and phrases from free text responses and counted these manually. The three most frequently occurring words or phrases corresponding to each free text question were converted into percentage form and presented as graphs (Supplementary information 9).

3. Results

3.1. Quantitative results

The survey received a total of 54 responses, comprised of 41% ($n = 22$) HCPs, 35% ($n = 19$) SCPs, and 24% ($n = 13$) other profession-

als from England and Wales represented. Details of the specific functions, settings, expected tasks, and numbers of each group of care professionals who responded are provided in supplementary information 10 and 11. The results suggested no significant differences in time spent working in ID/epilepsy services between the three staff groups. Overall, 54% (n = 29) of respondents across professional groups reported over fifteen years of work experience in their field. Table 1 summarised the characteristics of the professionals responding to the survey. The Bonferroni adjusted p-values and the Cramer's V statistic from these comparisons for the staff characteristics are summarised in Table 2.

SCPs (44%, n = 8) and other professionals (46%, n = 6) were more likely than HCPs (5%, n = 1) to report expertise in social care issues in general and specific to ID (p = 0.004).

The most commonly completed training was in relation to the Mental Capacity Act, completed by 95% (n = 19) of HCPs, 83% (n = 15) of SCPs, and 90% (n = 9) of other professionals. Overall, 90% (n = 43) of all professionals had received this training. Epilepsy-related training, received by 48% (n = 23) of all professionals, varied significantly between the three groups (p = 0.0003, effect size 0.61).

Of the respondents 39% (n = 21) did not have confidence in managing the needs of people with ID and epilepsy, choosing scores of 3 or less (three being "neutral", 2 "less confident" and 1 "not confident"). HCPs reported significantly higher confidence in identifying and managing epilepsy-related risks, including nocturnal monitoring and SUDEP, with 77% (n = 17) giving a score of four or five, compared to only 17% (n = 3) of SCPs and 23% (n = 3) of others, resulting in statistical significance between both HCPs and SCPs (p < 0.001) and HCPs and Others (p = 0.002). Notably, 0% (n = 0) SCPs and other professionals rated their confidence as 5 (very confident) on the question of managing epilepsy-related risks in people with ID. The majority of respondents (77%; n = 40) felt confident or very confident in managing the needs of carers. Respondents' confidence in identifying and managing different areas of work is reported in Table 3 and p-values from the pairwise comparisons are summarized in supplementary information 4.

Across groups, there were significantly varied responses on the responsibility to manage versus just having awareness of core support needs (p = 0.05) with SCPs most likely to take responsibility (79% n = 15). Views on the advocacy role varied significantly (p = 0.03) between the three groups, with HCPs (68%, n = 15) and SCPs (74%, n = 14) more likely to consider this part of their responsibility than others (31%, n = 4). HCPs (86%, n = 19) were more likely to indicate that they felt responsible to manage health liaison needs than SCPs (53%, n = 10) and others (77%, n = 10) (p = 0.05). Less than 50% of all respondents felt responsible to manage needs related to finance and housing. Social care professionals were significantly more likely (p = 0.002) to take responsibility for respite (18%, n = 4 for HCP, 68%, n = 13 for SCP and 23%, n = 3 for Others), also resulting in a statistical difference on pairwise comparison between HCPs and SCPs (p = 0.006, with an effect size 0.51). Table 4 provides the overall comparison of the perceived roles of professionals in supporting people with ID and epilepsy and the p-values from the pairwise comparisons are in supplementary information 5.

3.1.1. Vignette scenarios

Of the respondent population, 75% (n = 48) of HCPs, 62.5% (n = 35) of SCPs, and 74% (n = 29) of others reported that they could not deal with the case alone and they would require input from other professionals. These responses did not vary significantly between the three groups, nor did they reach statistical significance in the pairwise comparisons. Respondents overall felt confident in managing the situations described in the vignettes, with 70% (n = 38) choosing "confident" or "very confident". Confidence levels corresponding to a score of 4 or 5 on the survey were more common amongst HCPs (82%, n = 18) than SCPs (74%, n = 14) and others (46%, n = 6), tending to statistical significance (p = 0.08). The results are summarised in Table 5 and supplementary information 6.

No respondent across professional groups recorded a score lower than three for the importance of the different aspects of epilepsy care, with a majority of responses recorded as either four or

Table 1
Staff characteristics – Overall comparison.

Variable	Category	All professionals (n = 54)	Health Care (n = 22)	Social Care (n = 19)	Other (n = 13)	p-value (*)
UK area	England	36 (67%)	18 (82%)	7 (37%)	11 (85%)	(+)
	Wales	17 (31%)	4 (18%)	12 (63%)	1 (8%)	
	National	1 (2%)	0 (0%)	0 (0%)	1 (8%)	
Time working ID/epilepsy	0 – 5 years	9 (17%)	2 (9%)	5 (26%)	2 (15%)	0.54
	5 – 10 years	12 (22%)	7 (32%)	4 (21%)	1 (8%)	
	10 – 15 years	4 (7%)	1 (5%)	1 (5%)	2 (15%)	
	>15 years	29 (54%)	12 (55%)	9 (47%)	8 (62%)	
Expertise (#) (**)	Epilepsy general	13 (25%)	6 (29%)	4 (22%)	3 (23%)	0.92
	Epilepsy in ID	19 (37%)	10 (48%)	5 (28%)	4 (31%)	0.44
	Health issues	18 (35%)	7 (33%)	5 (28%)	6 (46%)	0.58
	Social care (general)	15 (29%)	1 (5%)	8 (44%)	6 (46%)	0.004
	Social care in ID	15 (29%)	1 (5%)	8 (44%)	6 (46%)	0.004
Training (#) (***)	Autism	27 (56%)	11 (55%)	11 (61%)	5 (50%)	0.87
	ID	14 (29%)	6 (30%)	4 (22%)	4 (40%)	0.60
	Epilepsy-related	23 (48%)	15 (75%)	7 (39%)	1 (10%)	0.002
	Mental Capacity Act	43 (90%)	19 (95%)	15 (83%)	9 (90%)	0.61
	Other	14 (29%)	4 (20%)	4 (22%)	6 (60%)	0.09

(*) Expertise data reported for 52 staff (21 health care, 18 social care, 13 other).

(**) Training data reported for 48 staff (20 health care, 18 social care, 10 other).

(#) Staff could indicate in more than one category. Percentages may not add up to 100%.

(+) No formal comparison between staff groups made due to small numbers in some categories.

Table 2
Staff characteristics – Pairwise comparison.

Variable	Health Care vs. Social Care		Health Care vs. Other		Social Care vs. Other	
	V	p-value	V	p-value	V	p-value
UK area		(+)		(+)		(+)
Ethnicity		(+)		(+)		(+)
Time working ID/epilepsy		1.00		1.00		0.97
Expertise – Epilepsy general	0.07	1.00	0.06	1.00	0.01	1.00
– Epilepsy in ID	0.20	0.97	0.17	1.00	0.03	1.00
– Health issues	0.06	1.00	0.13	1.00	0.19	1.00
– Social care (general)	0.47	0.02	0.50	0.02	0.02	1.00
– Social care in ID	0.47	0.02	0.50	0.02	0.02	1.00
Training – Autism	0.06	1.00	0.05	1.00	0.11	1.00
– ID	0.09	1.00	0.10	1.00	0.19	1.00
– Epilepsy-related	0.37	0.14	0.61	0.003	0.31	0.58
– Mental Capacity	0.19	0.98	0.09	1.00	0.09	1.00
Act						
– Other	0.03	1.00	0.40	0.14	0.38	0.29

Figures are Cramer’s V statistic (binary outcomes only) and Bonferroni-adjusted p-values (+) No formal comparison between staff groups was made due to small numbers in some categories.

Table 3
Confidence in identifying and managing areas of work – Overall comparison.

Variable	Category	All professionals (n = 54)	Health Care (n = 22)	Social Care (n = 19)	Other (n = 13)	p-value (^)
Needs in People with ID and epilepsy	1 (not confident)	1 (2%)	0 (0%)	0 (0%)	1 (8%)	0.63
	2	2 (4%)	0 (0%)	2 (11%)	0 (0%)	
	3	18 (33%)	8 (36%)	5 (26%)	5 (38%)	
	4	26 (48%)	10 (45%)	10 (53%)	6 (46%)	
	5 (very confident)	7 (13%)	4 (18%)	2 (11%)	1 (8%)	
Risk concerns (^)	1 (not confident)	7 (13%)	1 (5%)	4 (22%)	2 (15%)	<0.001
	2	10 (19%)	0 (0%)	6 (33%)	4 (31%)	
	3	13 (25%)	4 (18%)	5 (28%)	4 (31%)	
	4	17 (32%)	11 (50%)	3 (17%)	3 (23%)	
	5 (very confident)	6 (11%)	6 (27%)	0 (0%)	0 (0%)	
Carers	1 (not confident)	2 (4%)	0 (0%)	1 (5%)	1 (8%)	0.12
	2	3 (6%)	1 (5%)	1 (5%)	1 (8%)	
	3	16 (30%)	4 (18%)	7 (37%)	5 (38%)	
	4	24 (44%)	12 (55%)	7 (37%)	5 (38%)	
	5 (very confident)	9 (17%)	5 (23%)	3 (16%)	1 (8%)	

(*) Data reported for 53 staff (22 health care, 18 social care, 13 other).

(^*) p-value for the significance of the overall difference between the three groups.

five (epilepsy/SUDEP training: 96%, n = 52, Physical health training 91%, n = 47, Mental health training 98%, n = 52, Holistic care 100%, n = 53 and Accessing care 96%, n = 52). As to confidence managing the same aspects, there was a noticeable variation between groups with HCPs (82%, n = 18) more likely to report confidence scores of four or five compared to SCPs (58%, n = 11) or others (46%, n = 6), resulting in borderline significant results (p = 0.06) between the three groups and significance on pairwise comparison between HCPs and others (p = 0.04). Full results are provided in Table 6 and supplementary information 7.

Overall, 53% (n = 28) of all respondents agreed or strongly agreed with the statement that sufficient resources were available in their organization, and the three subgroups did not vary significantly in this respect (50%, n = 11 for HCP, 53%, n = 10 for SCP and 58%, n = 7 for others). From the HCP subgroup, 82% (n = 18) were aware of and had read the Learning Disability Mortality Review (LeDeR) [6], a national service improvement program that aims to improve the lives of people with ID, compared to 16% (n = 3) in the SCP group and 50% (n = 6) in the other group. Statistical dif-

ference was noted between HCPs and SCPs (p < 0.001). full results in supplementary information 8.

3.2. Qualitative results: (Supplementary information 9)

Following the coding of the brief answers provided in the vignettes, the following categories and themes were identified across all 3 vignettes used in the current study:

3.2.1. Wellbeing and safety

Amongst physical health considerations, epilepsy care was the most frequently expressed priority amongst both SCPs, HCPs, and others alike. Needs around risk assessments and relevant staff training were also highlighted as important and were identified as initial codes. However, many felt that such expertise is widely missing in the social care world, especially in the context of working with people with ID. Social care professionals and the other group saw their role in epilepsy and SUDEP as more limited to “referring on” and “signposting,” rather than actively supporting and managing, which

Table 4
Role in supporting People with ID and epilepsy – Overall comparison.

Variable	Category	All professionals (n = 54)	Health Care (n = 22)	Social Care (n = 19)	Other (n = 13)	p-value ^(^)
Activities	Awareness	23 (43%)	11 (50%)	4 (21%)	8 (62%)	0.05
	Responsible	31 (57%)	11 (50%)	15 (79%)	5 (38%)	
Advocacy	Awareness	21 (39%)	7 (32%)	5 (26%)	9 (69%)	0.03
	Responsible	33 (61%)	15 (68%)	14 (74%)	4 (31%)	
Finance	Awareness	41 (77%)	19 (86%)	11 (61%)	11 (85%)	0.13
	Responsible	12 (23%)	3 (14%)	7 (39%)	2 (15%)	
Health liaison	Awareness	15 (28%)	3 (14%)	9 (47%)	3 (23%)	0.05
	Responsible	39 (72%)	19 (86%)	10 (53%)	10 (77%)	
Housing	Awareness	37 (68%)	17 (77%)	10 (53%)	10 (77%)	0.18
	Responsible	17 (31%)	5 (23%)	9 (47%)	3 (23%)	
Respite	Awareness	34 (63%)	18 (82%)	6 (32%)	10 (77%)	0.002
	Responsible	20 (37%)	4 (18%)	13 (68%)	3 (23%)	

(^) p-value for the significance of the overall difference between the three groups.

Table 5
Health-related care needs outside the remit of professional role & confidence managing situations – Overall comparison.

Variable	Category	All professionals (n = 54)	Health Care (n = 22)	Social Care (n = 19)	Other (n = 13)	p-value ^(^)
Outside remit - Vignette 1	No	17 (31%)	7 (32%)	7 (37%)	3 (23%)	0.71
	Yes	37 (69%)	15 (68%)	12 (63%)	10 (77%)	
Outside remit - Vignette 2 ^(*)	No	12 (23%)	3 (14%)	5 (28%)	4 (31%)	0.41
	Yes	41 (77%)	19 (86%)	13 (72%)	9 (69%)	
Outside remit - Vignette 3 ^(**)	No	18 (35%)	6 (30%)	9 (47%)	3 (23%)	0.31
	Yes	34 (65%)	14 (70%)	10 (53%)	10 (77%)	
Confidence managing situations	1 (not confident)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.08
	2	4 (7%)	0 (0%)	1 (5%)	3 (23%)	
	3	12 (22%)	4 (18%)	4 (21%)	4 (31%)	
	4	24 (44%)	9 (41%)	12 (63%)	3 (23%)	
	5 (very confident)	14 (26%)	9 (41%)	2 (11%)	3 (23%)	

(*) Data reported for 53 staff (22 health care, 18 social care, 13 other).

(**) Data reported for 52 staff (20 health care, 19 social care, 13 other).

(^) p-value for the significance of the overall difference between the three groups.

was demonstrated by comments such as “the epilepsy team to manage epilepsy” (Participant: social care worker) and “specific teams manage different aspects of care my team concentrates on social care” (Participant: social care worker) suggesting they did not consider themselves to be part of this team. HCPs were more likely to feel “responsible and accountable” for the management of epilepsy and were far more likely to refer to the management of epilepsy-related risks to “avoid tragic consequences e.g., status, SUDEP, head trauma, fractures, etc” (Participant: Psychiatrist in Intellectual disability).

Times of transition between care settings and/or care teams were recognized as particularly stressful for patients, which necessitate additional support, but care priorities varied. HCPs were wary of the need to ensure good epilepsy management throughout the transition and beyond. Social care professional and other respondents focused more on providing emotional support for anxiety and distress caused by the transition and maintaining family contact.

3.2.2. Multidisciplinary teamwork

All professional groups widely recognized that close collaboration between patients, family members, and the multidisciplinary

team was desirable to achieve good outcomes and these were identified as initial codes. As well as supporting physical and mental health aspects, professionals envisaged that meaningful activities, promotion of independence, and supporting decision-making were key.

Many described an uncertainty in the multidisciplinary team (MDT) around the relative responsibilities of constituent professional groups, which could lead to confusion, duplication, or omissions of tasks related to the management of epilepsy-risks. In some cases, this was attributed to the service provision model in a particular area, which meant the professionals’ role would be “limited due to service provision and model” (Participant: Psychiatrist in intellectual disability,) and services were described as being “spread across organisations and work in a fractured way” (Participant: Psychiatrist in intellectual disability). In other cases, input into the MDT by different professional groups was felt to be “variable with “no formal links” between learning disability services and neurology” (Participant: Psychiatrist in intellectual disability).

Often MDT work appeared challenging to coordinate, with “different teams managing different aspects of care,” (Participant: social worker), and many called for collaborative work to improve. It

Table 6
Ratings of importance and self-confidence – Overall comparison.

Variable	Category	All professionals (n = 54)	Health care (n = 22)	Social care (n = 19)	Other (n = 13)	P-value (^)
Epilepsy/SUDEP training - Importance	1 (not important)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.34
	2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
	3	2 (4%)	1 (5%)	0 (0%)	1 (7%)	
	4	12 (22%)	3 (14%)	4 (21%)	5 (38%)	
	5 (v. important)	40 (74%)	18 (82%)	15 (79%)	7 (54%)	
Epilepsy/SUDEP training - Confidence	1 (not confident)	4 (7%)	0 (0%)	3 (16%)	1 (8%)	0.06
	2	3 (6%)	1 (5%)	2 (11%)	0 (0%)	
	3	12 (22%)	3 (14%)	3 (16%)	6 (46%)	
	4	14 (26%)	6 (27%)	4 (21%)	4 (31%)	
	5 (v. confident)	21 (39%)	12 (55%)	7 (37%)	2 (15%)	
Physical health training - Importance (*)	1 (not important)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.56
	2	0 (0%)	0 (7%)	0 (0%)	0 (0%)	
	3	5 (10%)	1 (5%)	2 (21%)	2 (15%)	
	4	10 (19%)	3 (14%)	4 (22%)	3 (23%)	
	5 (v. important)	37 (72%)	17 (81%)	12 (67%)	8 (62%)	
Physical health training - Confidence	1 (not confident)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.53
	2	4 (7%)	0 (0%)	3 (16%)	1 (8%)	
	3	12 (22%)	4 (18%)	4 (21%)	4 (31%)	
	4	24 (44%)	12 (55%)	7 (37%)	5 (38%)	
	5 (v. confident)	14 (26%)	6 (27%)	5 (26%)	3 (23%)	
Mental health training - Importance (**)	1 (not important)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.73
	2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
	3	1 (2%)	1 (5%)	0 (0%)	0 (0%)	
	4	8 (15%)	2 (9%)	3 (16%)	3 (25%)	
	5 (v. important)	44 (83%)	19 (86%)	16 (84%)	9 (75%)	
Mental health training - Confidence	1 (not confident)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.32
	2	2 (4%)	1 (5%)	1 (5%)	0 (0%)	
	3	9 (17%)	3 (14%)	4 (21%)	2 (15%)	
	4	22 (41%)	6 (27%)	8 (42%)	8 (62%)	
	5 (v. confident)	21 (39%)	12 (55%)	6 (32%)	3 (23%)	
Holistic care - Importance (+)	1 (not important)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.76
	2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
	3	0 (0%)	0 (5%)	0 (0%)	0 (0%)	
	4	7 (13%)	2 (9%)	3 (17%)	2 (15%)	
	5 (v. important)	46 (87%)	20 (91%)	15 (83%)	11 (85%)	
Holistic care - Confidence	1 (not confident)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.87
	2	2 (4%)	0 (0%)	2 (11%)	0 (0%)	
	3	5 (9%)	2 (9%)	2 (11%)	1 (8%)	
	4	23 (43%)	12 (55%)	5 (26%)	6 (46%)	
	5 (v. confident)	24 (44%)	8 (36%)	10 (53%)	6 (46%)	
Accessing holistic person-centered care services - Importance	1 (not important)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.81
	2	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
	3	2 (4%)	1 (5%)	1 (5%)	0 (0%)	
	4	8 (15%)	4 (18%)	2 (11%)	2 (15%)	
	5 (v. important)	44 (81%)	17 (77%)	16 (84%)	11 (85%)	
Accessing holistic person-centered care services - Confidence (**)	1 (not confident)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.17
	2	1 (2%)	0 (0%)	1 (5%)	0 (0%)	
	3	13 (25%)	7 (33%)	4 (21%)	2 (15%)	
	4	19 (36%)	10 (48%)	4 (21%)	5 (38%)	
	5 (v. confident)	20 (38%)	4 (19%)	10 (53%)	6 (46%)	

(*) Data reported for 52 staff (21 health care, 18 social care, 13 other).
 (**) Data reported for 53 staff (22 health care, 19 social care, 12 other).
 (+) Data reported for 53 staff (22 health care, 18 social care, 13 other).
 (++) Data reported for 53 staff (21 health care, 19 social care, 13 other).
 (^) p-value for the significance of the overall difference between the three groups.

was recognized that the MDT possessed a wealth of knowledge but due to work pressures this is not always shared and SCPs at times found it difficult to access support around epilepsy-related issues from HCPs.

Resources could also be lacking for training for identifying and signposting certain physical health issues from the social care aspects, that was described as a “contentious” issue. Overall, a picture of a service which was fragmented and challenging to navigate

emerged and many acknowledged that holistic care goals were difficult to achieve.

3.2.3. Resources and care pathways

Respondents described facing significant challenges in achieving holistic care goals for people with ID and epilepsy. Initial codes around staffing issues, funding, and workload were identified under this category. All professionals expressed frustration around underfunding and staff shortages, adding to the strain on the team. One SCP described a “*desperate shortage of healthcare professionals*” in their area. Fragmented and poorly defined care pathways without clear links between ID services and Neurology adds to the complexity, and some found that they spent a considerable amount of time liaising; “*I should not have to liaise for everything, but find that I have to. As I am very busy this is a strain and makes me grumpy*” (Participant: *Epileptologist*).

4. Discussion

Health and social care influences on people with ID and epilepsy is an area already highlighted in the literature as lacking in research, particularly around care provisions, social care environment, and staff training needs for this vulnerable cohort [35]. Two surveys undertaken by the International League Against Epilepsy (ILAE) indicated that paid carers and family members alike experience a lack of support and communication from services [36,37].

Our study describes the different attitudes, perceived levels of responsibility, and levels of confidence of the professionals who care for people with ID and epilepsy. We show that most respondents (>90%) across professional groups uniformly highly rated the importance of epilepsy and SUDEP training but less than 60% of non-HCPs felt confident in managing these care aspects, compared to over 80% of HCPs. *Critically SCPs were more likely to have their training lapsed (>2 years)*. This mismatch between knowing what is important and being confident in implementing impactful care indicates a significant training deficiency. Some of this may be related to chronic under-resourcing in this area and all people who care for people with ID should be empowered to demand the correct training.

Most respondents irrespective of group felt that they would need additional support with the scenarios described in the vignettes, due to aspects of care falling outside of their professional remit. Not everyone in the MDT is interchangeable and there was a consensus about individual roles. HCPs were more likely to consider health liaison as their responsibility. In contrast, SCPs were more likely to take responsibility for respite care, daily activity provision, and advocacy. This raises questions about how care roles and responsibilities are defined and shared within teams. If the duty to liaise with other professionals is perceived to be limited to a few, such perceived divisions of responsibility and roles could contribute to care fragmentation.

Two in five respondents rated themselves as not having the confidence to manage the holistic needs of people with ID and epilepsy – this confidence was higher in HCPs. This uncertainty around managing epilepsy care was further reflected in respondents’ rated self-confidence in managing epilepsy risk (including SUDEP). This stands in stark contrast to professionals’ views on the importance of epilepsy care and risk management, where respondents indicated that these were important in supporting people with ID and epilepsy. This could point to challenges in accessing relevant training in non-HCP staff groups and might contribute to an over-reliance on HCPs in leading on and liaising around epilepsy and physical health issues. The HCP role comes with an inherently higher degree of responsibility for health care

issues (such as epilepsy) than social care roles, which in practice may translate into easier access to training for HCPs, in turn leading to higher levels of confidence, better self-esteem in relation to these issues and greater disparity between confidence in HCPs and SCPs. Only a quarter of SCPs were aware of LeDeR compared to most HCPs. The LeDeR [6], a national service improvement program that aims to improve the lives of people with ID, highlights areas of both health and social care that require improvement. As such it is a valuable resource for anyone working with people with ID and epilepsy.

Qualitative data highlighted concerns about patient safety which shows that staff is aware of the increased needs of people with intellectual disability and epilepsy. There were also statements about understaffing, under-resourcing and disjointed care. There appeared to be a lack of joint responsibility with comments such as “*epilepsy team to manage the epilepsy*”, suggesting the respondent does not see themselves as part of providing this care. It also questions who the “*epilepsy team*” is. The constellation of the local epilepsy team and the level of care the person with ID and epilepsy will receive varies considerably between geographical areas, contributing further to confusion and variability in care provisions nationally [38].

The qualitative aspect of the study identifies key priorities for the professional groups, including well-being and safety, MDT work, and resources and care pathways. These priorities aligned well with results from other research in this area [36,37,39], as professionals emphasized the need for holistic care and staff training delivered through a collaborative approach between the MDT, patients, and their families. This shows that clinicians know what is needed but they are not being supported to make necessary changes by the chronically underfunded system. A clearer division of roles and well-defined care pathways defined sharing of responsibilities between services and an increase in resources were actions recommended to achieve these care priorities. Clearly, there is a maximum that is possible without sufficient resources and that maximum may not be safe for all people with ID. Other research in this field has highlighted the impact of blended support networks and the impact of rotating care staff, which can contribute to challenges in obtaining accurate clinical information [40]. Frequent rotation of care staff is also likely to result in considerable variability in the level of expertise, contributing to inconsistencies in care received by the person with ID and epilepsy.

It is well recognised that people with ID and epilepsy require more robust care which is not situational but longitudinal across a range of stakeholding agencies [27], and which addresses not only those epilepsy-related care needs shared with the general epilepsy population but those that are unique to people with ID [41]. Interventions such as annual physical health checks have been found to be a protective factor [42]. While it can be considered immanent to the different job profiles that HCPs and SCPs focus on different aspects of care, professionals should be mindful that they do have a responsibility to advocate, and this should extend beyond those aspects of care which they are responsible for managing. For example, epilepsy and SUDEP advocacy does not equate to epilepsy and SUDEP care responsibility, but for many, it may not be clear where advocacy ends and responsibility begins. This may lead to anxiety around advocating, driven by fear of being held accountable for areas of care that are not within the remit of the professional role. There may also be professional repercussions for those who advocate [43]. Moreover, advocating may challenge the status quo in a workplace where diffusion of responsibility is commonplace. Lack of clear job and role descriptions, workplace cultures and role diffusion may all contribute further to this. In the process, professionals might forget that advocacy should be seen as a professional responsibility in its own right [44] and should be integral to daily practice. Two advocacy activities into

agency (which involves signposting, referring, providing information, and generally supporting the person on an individual level) and activism, which are actions that extend to the organization and wider community have been described and need establishing in holistic care for people with ID and epilepsy [45].

4.1. Limitations

Whereas 54 participants are generous for a qualitative study, it is modest for a quantitative study – particularly when it comes to looking at subgroups. However, even with the returns received there was statistical significance for various important areas (post-Bonferroni correction), and large effect sizes were noted. We cannot rule out that a larger sample might have increased the statistical confidence for certain other questionnaire items, and we accept it as a limitation of the study that a sample size calculation was not completed a priori. Clearer knowledge of the background of the other group might have helped incorporate their responses into either the HCPs or SCP group. It is possible that respondents to the survey may have been individuals with a greater interest in these issues, and therefore the views gathered may not be representative of the target population.

The questionnaire was not validated psychometrically and any feedback from replies are subjective responses of the individual responders relating to their perceived expertise and abilities. This exposes the survey to potential bias due to a lack of construct validity.

Two co-authors (AH and PT) are qualitative experts who were consulted regularly throughout. During discussions, it was acknowledged that the data available was restricted in terms of depth and quality, and we accept this as a limitation of the paper.

5. Conclusion

The study captures the recognition of health and social care professionals of the importance of holistic care provision for people with ID and epilepsy but highlights the practical challenges in its delivery. It outlines the gaps in attitudes, knowledge, confidence, and expectations between the major support groups.

5.1. Implications for clinical practice

There is a need for better connection, communication, clarification, and collaboration between currently fragmented services of the epilepsy-related roles of the different professional groups, to meet the needs of this vulnerable population. The focus must be on creating “capable communities” where there is a good understanding of the acute and chronic holistic needs of this vulnerable group. There are developing concerns of “missed opportunities” in protecting this population where epilepsy in this population is the bellwether for preventable mortality [46,47].

5.2. Implications for policy

The identified inter-agency gap in the fabric of delivery of holistic care for people with ID must be recognized at a systems level. The current failings to do so could be increasing the risk of harm and death of a vulnerable population. There is a need to support an integrated health and social approach with suitable policy and legislation with a focus on clarity of the different role expectations, resource allocation, training, etc. This then would allow for a sustainable and resilient workforce with different services competent

in delivering person-centered care working intersectional with each other.

5.3. Implication for research

To date, there has been a dearth in recognition of the need for research for people with ID and epilepsy possibly due to a lack of ownership of the complexity of the problem by either researchers in ID or epilepsy [48,49]. There is now increasing recognition that the issues of epilepsy and ID are significantly intertwined, in fact, the overall care burden being greater than the individual sum of the two conditions per se. Such complex areas require more not less research focus to understand and improve care. If successful, the dividends of which can be had across all populations of people with epilepsy or ID.

Statements and Declarations including competing interests

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Ethics Statement

We confirm that we have read the journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Author Contributions

All authors satisfy the ICMJE guidance by substantially contributing to the design, analysis, and interpretation of the work, drafting of the manuscript, and final approval of the manuscript, and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Data statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Ms. Juliet Solomon ILAE British Chapter Chief Executive.

Appendix 1:

Professional group	Rationale for involvement
Social care professionals: · Care home managers · Support workers · Social care professionals/social care worker	Invited to take part to explore understanding of physical/social health and epilepsy-related needs for people with ID from a social care perspective.
Epilepsy nurse: · With ID background · With physical health background	Clinical stakeholders invited to take part as comparators, to gauge awareness of social care requirements and responsibilities from a healthcare professional perspective.
Epileptologist Neurologist Psychiatrists working with people with ID Psychiatrist, other Occupational therapist Speech and language therapist OTHER	

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2023.109296>.

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