

LISTENING FOR A CHANGE

Medical and social needs of people with epilepsy and intellectual disability:

A joint report of the International League Against
Epilepsy Task Force on Intellectual Disabilities and
the International Bureau for Epilepsy.

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Prepared by

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‘This report was written by experts selected by the International League Against Epilepsy (ILAE) and was approved for publication by the ILAE. Opinions expressed by the authors, however, do not necessarily represent the policy or position of the ILAE.’

FOREWORD

People with hidden disabilities, such as epilepsy, are among the most vulnerable in any society. All chronic diseases affect quality of life but epilepsy has the greatest impact. Having epilepsy and intellectual disability has an even more profound impact on the lives of people with these conditions and those who care for them. Professionals, paid and family caregivers highlight many concerns.

Research into epilepsy and intellectual disabilities is desperately needed in order to improve our understanding and ultimately improve patient care

Giving a voice to these concerns will, we hope, act as a stimulus to improve the quality of care and the focus of research in this area. This stimulus should be further supported by a detailed survey of individuals with epilepsy and intellectual disability themselves – also from non-English language countries – which may answer many questions that, to date, remain unanswered.

We would like to thank the chapters of the International League Against Epilepsy (ILAE) and the members of the International Bureau for Epilepsy (IBE) for their support and sharing their views.

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EXECUTIVE SUMMARY

Epilepsy has specific and profound importance in the lives of people with an intellectual disability. It is common and occurs across the lifespan, occurring in about 1 in 4 individuals with an intellectual disability as compared with 1 in 100 without an intellectual disability. It is more severe, more chronic, causes more hospitalisation and more early death in people with an intellectual disability.

Despite this it is under researched and underprovided for in health services. The International League Against Epilepsy recognized this by establishing a topic specific Task Force to address these issues. This document provides the first step in what we hope will be a process of change.

This joint International Bureau for Epilepsy (IBE)/ International League Against Epilepsy (ILAE) report is based on an international survey of the views of professionals, paid caregivers and family members who support people with an intellectual disability who have epilepsy. The report documents their views on the delivery of health care services to people with intellectual disability who have epilepsy and on the impact of these conditions not only on the individual, but also on their wider family.

The survey aimed to be both international and representative; through working with national IBE organizations and caregiver groups we conducted a web-based survey. The survey was widely distributed amongst national groups. The study, the first of its kind, provided unique information from 133 individuals in 14 countries.

Using qualitative analytic methods important areas of concern and unmet need in the care of people with intellectual disability and epilepsy have been identified, including:

- Difficulties in diagnosis and medical treatment – misdiagnosis, poor communication, concerns over side effects and treatment input

- Poor and inequitable service delivery – difficulty accessing specialists, poor understanding of the needs of people with an intellectual disability, a lack of access to specialist nursing, poor response to behavioural concerns and a lack of accessible information for families and carers
- Difficulties in education and accessing employment – epilepsy impacting on education, poor understanding of epilepsy in educational and work situations, greatly diminished work opportunities
- A negative impact on social, romantic and family life – stigmatization, negative assumptions and poor support to form friendships and relationships

People with an intellectual disability who have epilepsy comprise the most vulnerable population within epilepsy services. In order to address the multiple challenges identified by participants eighteen recommendations for future action have been developed from this consultation and are listed below. The report's authors strongly encourage the implementation of these recommendations.

Whilst our study did not involve people with an intellectual disability themselves it is clear that our first step should be to place people with an intellectual disability central to future discussions on the themes we have identified.

PROPOSED ACTIONS

1. Proposed actions relating to investigations and diagnosis in individuals with complex needs

- 1 The ILAE should establish a Working Group to develop standards for the diagnosis of epilepsy in people with an intellectual disability, both for adults and children. This should include measures to investigate aetiology, misdiagnosis and equitable access to treatment.
 - 2 The ILAE should support educational initiatives to improve clinician communication when an individual has impaired communication and should support the call for extended consultations to ensure sufficient time is afforded to patients with intellectual disability.
 - 3 A Working Group should be established identifying a pathway to investigation for those with complex needs, to include a discussion of best interest and the use of anesthesia or sedation.
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2. Proposed actions relating to medication (including rescue medication)

- 4 The ILAE should develop a Task Force to develop guidelines for the treatment of epilepsy in people with an intellectual disability
 - 5 A Position Paper should be produced establishing best practice for the identification and management of anti-epileptic drug side effects in people with an intellectual disability. Specific attention is needed to address drug interactions due to the increase in prescribing for co-morbid conditions.
 - 6 Audit templates should be developed to ensure all people with intellectual disability who have epilepsy have had an assessment of the value of rescue medication, are prescribed when appropriate, and staff and family members have had adequate training in their administration.
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3. Proposed actions relating to enhancing medical services

- 7 Guidance should be developed on standards of information exchange in clinic settings. These should identify the input from individuals, caregivers, families and professionals.
 - 8 Guidance should be developed on the role of primary care services in the management of people with intellectual disability who have epilepsy and into how these interact with specialist services.
 - 9 Accessible information on all aspects of epilepsy management should be made available in services and on the ILAE/IBE websites.
 - 10 Mechanisms for improving communicating information in clinical situations should be explored. These include the use of shared decision methodology and option grids.
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- 11 The ILAE should promote the development of epilepsy specialist nurse provision with a particular relevance to those supporting people with an intellectual disability either in specialist epilepsy services or in services providing health care to people with intellectual disability.
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- 12 Guidance, including minimum standards, should be developed on multidisciplinary team working for individuals with epilepsy and intellectual disability.
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- 13 Guidance should be developed on appropriate durations of consultations with people with complex communication problems.
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- 14 The ILAE working with the IBE should develop training manuals to support non-specialist services managing epilepsy in community settings.
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4. Proposed actions relating to education, employment, social & family life

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- 15 The ILAE in association with the IBE should establish a Task Force with a wide ranging remit to establish guidance on all aspects of schooling for people with an intellectual disability and epilepsy.
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- 16 The IBE should establish a Working Group that will establish links with organisations involved in providing employment, including supported employment, to advise on reducing barriers to employment for people with an intellectual disability who have epilepsy
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- 17 The ILAE in conjunction with IBE should establish a Working Group to provide guidance to family members and those working in the epilepsy and intellectual disability fields on how epilepsy related risk can be minimized in order to promote the full inclusion of this population in social and romantic relationships.
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- 18 The ILAE in conjunction with IBE should establish a Working Group to create greater awareness of the stigmatisation and burden on family members, and provide guidance to epilepsy and intellectual disability agencies on how to optimally support families using practical solutions such as respite and family social clubs.
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TABLE OF CONTENTS

Table of Contents.....	vii
1 Introduction - Epilepsy and Intellectual Disability	1
1.1 Methodology.....	3
1.1.1 Distribution	5
1.1.2 Participants	6
1.1.3 Analysing the responses	8
2. Diagnosis and medical treatment	9
2.1 Complicated medical needs	9
2.1.1 Complicated medical needs - complexity of presentation	9
2.1.2 Complicated medical needs - complexity of treatment.....	10
2.2 Communication in the consultation	12
2.2.1 Communication in the consultation - with a person with an intellectual disability	12
2.2.2 Communication in the consultation - with family or paid caregivers.....	13
2.2.3 Communication in the consultation - perceived clinician attitudes	14
2.3 Accessing investigation	15
2.3.1 Accessing investigation – lack of facilities	16
2.3.2 Accessing investigation – consent issues.....	16
2.3.3 Accessing investigation – practical concerns.....	17
2.3.4 Accessing investigation – discrimination	17
2.4 Medication.....	18
2.4.1 Medication – side effects.....	18
2.4.2 Medication – rescue medications.....	20
2.5 Monitoring treatment.....	21
2.5.1 Monitoring treatment – quality of information from caregivers	21
2.5.2 Monitoring treatment – aspects of intellectual disability that hamper monitoring	23
2.5.3 Monitoring treatment – treatment plans.....	24
2.5.4 Monitoring treatment – monitoring in primary care.....	24
2.6 Knowledge transfer.....	25
2.6.1 Knowledge transfer - availability of information	25
2.6.2 Knowledge transfer - the quality and source of information	26
2.6.3 Knowledge transfer – relevant and accessible information	27
2.6.4 Knowledge transfer - unanswered questions?	28

3. Service delivery	29
3.1 Specialist services	29
3.1.1 Specialist services – multidisciplinary working	29
3.1.2 Specialist services – specialist nurses	30
3.2 Access to local services	31
3.2.1 Access to local services – inconsistent service provision.....	31
3.2.2 Access to local services – family access to local services.....	32
3.3 Primary health care.....	33
3.4 Quality and length of consultation	34
3.5 Training – skilled care delivery.....	35
4 Education and employment.....	35
4.1 Schooling and education.....	36
4.1.1 Schooling – restricted participation in educational activities.....	36
4.1.2 Schooling – educational provision and reluctance to tailor curriculum content.....	37
4.1.3 Schooling – impact of epilepsy and intellectual disability on learning	38
4.1.4 Schooling – positive adaptations	39
4.2 Employment.....	40
4.2.1 Employment – concerns over health and safety	41
4.2.2 Employment – disability awareness	41
4.2.3 Employment – stigma, discrimination and low expectation	42
4.2.4 Employment – practical concerns.....	43
4.2.5 Employment – impact on parental employment.....	43
4.2.6 Employment – positive adjustments to the work environment	44
5. Social, romantic and family life.....	45
5.1 Social activities and friendships	45
5.1.1 Social activities and friendships – concern over health and safety	45
5.1.2 Social activities and friendships – disability issues	46
5.1.3 Social activities and friendships – facilitators	46
5.2 Romantic lives.....	47
5.2.1 Romantic lives - stigma	47
5.2.2 Romantic lives –barriers	48
5.2.3 Romantic lives – vulnerability of population	49
5.2.4 Romantic lives – facilitators.....	50

- 5.3 Public perceptions of people with epilepsy and intellectual disability 50
 - 5.3.1 Public perceptions - a negative reaction 51
 - 5.3.2 Public perceptions – social isolation and abuse 51
 - 5.3.3 Public perceptions – families as educators..... 53
 - 5.3.4 Public perceptions - facilitators 54
- 5.4 Family life and coping with complex needs 54
 - 5.4.1 Family life – practical concerns 54
 - 5.4.2 Family life – the emotional burden..... 58
 - 5.4.3 Family life – facilitators..... 61
- 6. Summary of Proposed Actions..... 63

- References 65

- Appendix A – Key Themes 68

1 INTRODUCTION - EPILEPSY AND INTELLECTUAL DISABILITY

Research has consistently identified marked disparities in health status and access to health services between people with intellectual disabilities and the general population [1, 2, 3, 4]. Amongst these, epilepsy stands out as having a substantially higher prevalence rate among people with intellectual disabilities when compared with the general population [4, 5]. Population-based data from the United States cite estimates of 1% for self-reported active epilepsy in the adult general population [6]. This can be compared with a review of children with intellectual disabilities which identified epilepsy as the most prevalent co-morbid condition, reporting a weighted prevalence of 22% [7]. This elevated prevalence is not confined to children as prevalence estimates among adults with intellectual disabilities, identified through disability services throughout Europe, are similarly high, with 30% of 19-34 year olds reporting a diagnosis of epilepsy [8]. Whilst the figure declines somewhat to 15% for those aged 65 years and over, a pattern which may reflect increased mortality among those with epilepsy and intellectual disability, it still remains ten times that of the general population [9].

The population of people with an intellectual disability is defined in general by an IQ under 70, deficits in adaptive behaviour and onset in childhood years. There is considerable variation within this population with severity of the intellectual impairment influencing the prevalence of epilepsy. Population-based studies across all age groups for those with intellectual disability have reported rates of 20% for active epilepsy, ranging from 11% among those with mild intellectual disability and rising to 59% among those with profound levels of intellectual disability [10].

Epilepsy is associated with high health care usage. Attendance rates for those with intellectual disability at inpatient, outpatient and emergency services, for example, are elevated for those who have epilepsy [9]. In addition, epilepsy is the most commonly presenting health condition for people with intellectual disability in primary care settings [5]. This high usage of primary care services is likely to increase as those with intellectual disabilities transfer from institutionalised facilities to community-based living [11]. Anticonvulsant medication is among the most commonly prescribed

medication for patients with intellectual disability by primary care physicians, even when excluding prescriptions for the control of behaviours that challenge [5, 12].

The complex presentation of epilepsy among this population is challenging. Those with intellectual disability and epilepsy are more likely to present with more severe epilepsy that is often resistant to treatment, [10, 13, 14, 15]. They experience an increased risk of prolonged seizures and status epilepticus [16] and experience higher mortality rates than their age-related peers with an intellectual disability who do not have epilepsy [17].

Included in the treatment challenge for professionals are issues of: (1) multiple medications for co-morbidities [16]; (2) a lack of expertise among neurologists of the specific needs of those with intellectual disability, such as behaviour disorder [12, 18]; and (3) the need to manage through caregivers, as often those with intellectual disability and epilepsy will have limited capacity to manage their condition [19, 20].

Despite these powerful factors little attention has been paid to the specific needs of people with intellectual disability and epilepsy [11, 12, 21]. The lack of recognition of the substantial needs of this population can result in a tendency to underestimate, and moreover, underfund the needs of those with intellectual disability and epilepsy [22]. Most recently, a substantive review of public health issues in epilepsy has noted the diminished quality of life experienced by this group, and has called for greater collaboration between disability and epilepsy organisations to promote optimal management of the condition [23].

The research presented in this report has sought, through surveying professionals, paid caregivers and family members, to examine the impact of epilepsy on individuals with intellectual disability and their caregivers, and to garner views on the adequacy and quality of available treatment for this population.

This survey is a first step in addressing some of the deficits in accessing high quality services for this population. The survey was undertaken under the auspices for the Intellectual Disability Task Force of the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The aim was to conduct an international consultation that would identify challenges in providing appropriate supports to people with intellectual disabilities who have epilepsy with a view to recommending key areas for reform.

1.1 METHODOLOGY

The aim of the survey was to explore the views of family members, paid caregivers and health care professionals from a wide a range of countries. Individuals were accessed through branches of, and organisations affiliated with IBE. IBE provides an umbrella organisation for non-professional epilepsy support groups internationally. A number of IBE members were approached and asked if they would assist in promoting awareness of the survey to support groups in their own countries.

In order to facilitate international participants an online qualitative survey was deemed the most appropriate methodology, and a survey was subsequently developed using Bristol Online Survey Software [24]. The full survey is outlined in Box 1. Participants were invited to describe, in their own words, their perception of health services for people with intellectual disability who have epilepsy. They were also asked how they thought epilepsy and intellectual disability impacted upon the health, employment, educational, social, family life, and relationship status of individuals affected by these conditions. The survey and full study design were then submitted to, and approved by, the Research Ethics Committee of the School of Medicine at Cardiff University.

Box 1. Survey Questions

1. What are your views on the diagnosis and medical treatment of people with epilepsy and intellectual disability? What are the problems? What helps?
2. What are your views on anti-epilepsy medications (including rescue medications)? What are the problems? What helps?
3. What are your views on services provided to support the care of people with epilepsy and intellectual disability? What are the problems? What helps?
4. Do you think there is enough information available about treatment, management and support for people with epilepsy and intellectual disability? Where do you look for this kind of information? Is it easily available?
5. In your experience how does having epilepsy and intellectual disability impact on getting and keeping employment? What are the problems? What helps?
6. In your experience how does having epilepsy and intellectual disability affect schooling or other forms of education? What are the problems? What helps?
7. In your experience how does having epilepsy and intellectual disability affect engaging in social activities and developing friendship groups? What are the problems? What helps?
8. In your experience how does having epilepsy and intellectual disability affect romantic relationships? What are the problems? What helps?
9. How do you think people with epilepsy and intellectual disability are seen by other people? Can this cause problems? Can this cause good things?
10. In your experience how does having epilepsy and intellectual disability affect family life? What are the problems? What helps?
11. In your contact with people with intellectual disability and epilepsy, have they expressed any particular views that are relevant to this consultation?
12. Is there anything you would like to tell us that you think is relevant to this consultation that is not covered by the questions above?

1.1.1 DISTRIBUTION

The survey was distributed through a number of membership organisations of IBE, as well as a number of professional networks, charity organisations and support groups which were identified as supporting people with an intellectual disability and epilepsy.

A definite limitation of the survey was that it restricted to those countries with IBE associations which were either English speaking, or had English as a common second language. This restriction was imposed due to the limited resources of the research team. The intention is, however, that the study may be extended in due course to non-English speaking countries.

In total, 15 organisations including national epilepsy associations, support groups and professional networks, located in seven countries, promoted the survey either on their website and/or by distributing documentation to their members. Box 2 presents a list of participating organisations.

Box 2 – Distributing Organisations

Epilepsy Ireland (IRE)	Epilepsy Society (UK)
Epilepsy Connections (UK)	Learning Disability Forum (UK)
Learning Disability Wales (UK)	Epilepsy New Zealand
Epilepsy Action (UK)	Epilepsy South Africa
Epilepsy Research UK	Canadian Epilepsy Alliance
Rett UK	Caritas Malta Epilepsy Association
Matthew's Friend (UK)	JECA Australia
Down Syndrome Association (UK)	

1.1.2 PARTICIPANTS

Participants were invited to complete the survey if they were health professionals working in the epilepsy and/or intellectual disability fields, were paid caregivers similarly working in the fields of epilepsy and/or intellectual disability, or if they were a family member of someone with epilepsy and intellectual disability.

In total, 144 people responded from a total of 13 countries. Responses from eleven individuals, however, were excluded at this stage of the analysis on the basis that the content of their responses indicated that these individuals had epilepsy, and it was not possible to determine whether they also had an intellectual disability. Their exclusion was based on the fact that ethical approval to include those with intellectual disabilities in the survey would have required an assessment of capacity to consent, a process which was not possible given the anonymised nature of the online survey.

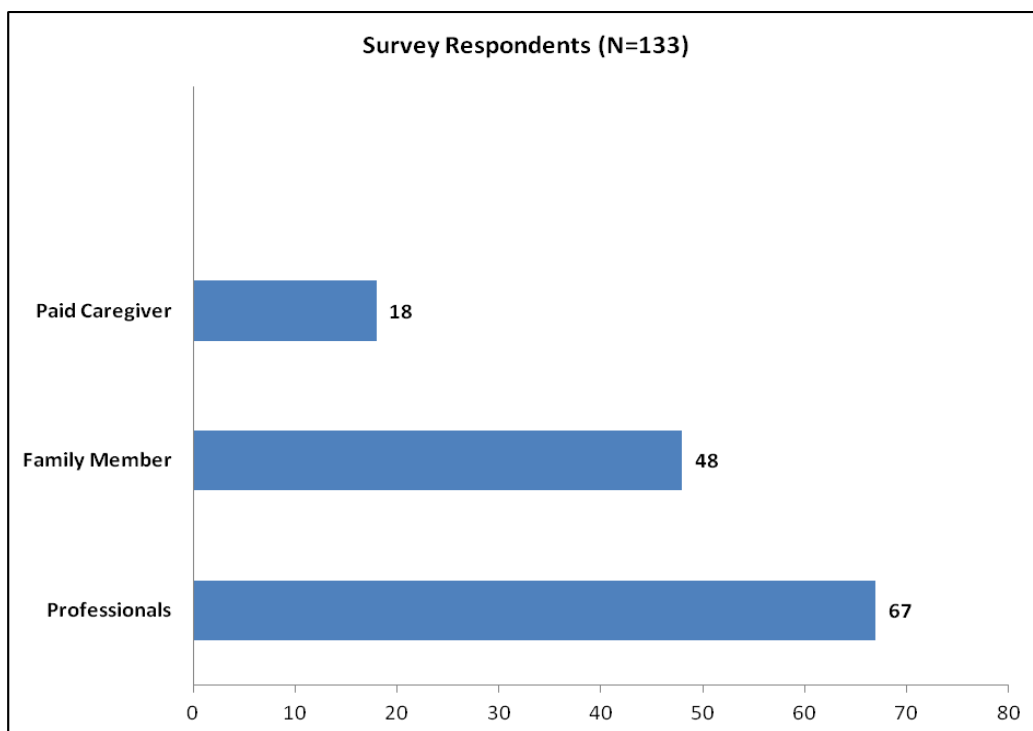


Figure 1 – Breakdown of Respondents to the Survey

Of the eligible responses returned (n = 133), half (n = 67; 50%) identified themselves as professional staff working in either the epilepsy or intellectual disability fields. This group comprised clinicians, specialist nurses, epilepsy key workers, care managers and individuals who worked for charitable organisations. Over one third of respondents (n = 48; 36%) stated they were family members who cared for a person with epilepsy and intellectual disability. Finally, a third group of respondents comprised paid caregivers to people with epilepsy and intellectual disabilities (n = 18; 14%).

A breakdown of the nationality of respondents is presented in Figure 2. It is notable that two-thirds of all respondents (n = 96) stated that they were located in the UK. Given the small sample size generally, and most particularly from non-UK jurisdictions, findings should be treated with caution.

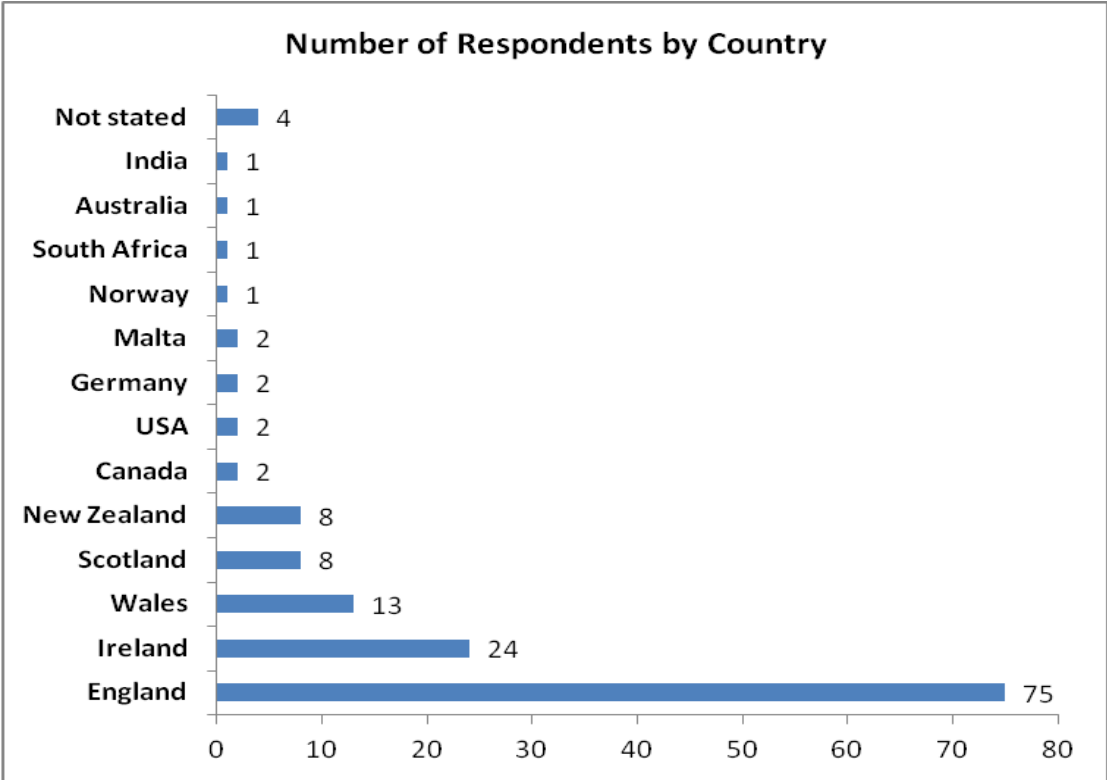


Figure 2 – Breakdown of Respondents by Country

1.1.3 ANALYSING THE RESPONSES

All survey responses were analysed using Thematic Analysis [25]. Themes were identified in the data that related both to individual questions and to the data set as a whole. The data is presented in four sections following the structure of the survey instrument. These sections comprise:

Diagnosis and medical treatment (Section 2)

Service delivery (Section 3)

Education and Employment (Section 4)

Social, romantic and family life (Section 5)

Within these broad areas relevant themes were identified. Themes were noted as being either relevant to one broad area, or across two or more areas. Within each theme, different strands or sub themes that emerged from within each theme were explored. A full overview of the themes and sub themes identified for this analysis are presented in Appendix A.

In an attempt to ensure that survey respondents had the strongest voice in this report, the commentary on findings is extensively supported by quotations from survey respondents, in part or in full, to illustrate these points. In a small number of cases two minor adjustments were made to the original quotations. These adjustments included (1) spelling errors, as presented in the original quotes, which were corrected for presentation in this report (e.g. 'varies considerable' to 'varies considerably' (2) a small number of inserts appearing as [-] were placed in notational type quotes to improve the comprehension of the quotation (e.g. Patchy [-] some areas have epilepsy liaison support some don't).

2. DIAGNOSIS AND MEDICAL TREATMENT

Both the process of gaining a diagnosis and achieving effective treatment were generally considered to be challenging by all three respondent groups; family members, paid caregivers and professionals. The quotation below illustrates some of the challenges facing those seeking diagnostic and medical treatment.

“It can be hard to get unequivocal seizure descriptions from carers/patients, very profoundly disabled patients may be experiencing seizures that are not ‘text book’ in their presentations and may be misinterpreted as behavioural or vice versa. If a patient has behavioural difficulties, it can be difficult for them to access generic services/investigations/treatments. Consent to treatment is not always necessarily sought and to assess capacity of each individual with regards to their epilepsy treatment could actually lead to delays. Generic services are not geared up to provide support to certain groups of people with learning disabilities¹.” (Professional Q1)

2.1 COMPLICATED MEDICAL NEEDS

Respondents reflected considerably on how the complexity of an individual’s disability impacted on care delivery. Approaches that reflected this complexity and responded to it were identified as important.

2.1.1 COMPLICATED MEDICAL NEEDS - COMPLEXITY OF PRESENTATION

The diagnosis of epilepsy was generally felt to be more challenging for people with an intellectual disability than for people without an intellectual disability. The complex presentation of many

¹ ‘Learning disability’ is the common term for intellectual disability used throughout the UK.

patients, including communication difficulties, the possibility of many different types of seizures, and the presence of other co-morbidities impacted both on diagnosis and treatment options.

“People with ID and epilepsy are extremely complex in their presentation and as such require professionals who are experienced in both fields to adequately assess them and ensure their needs are not dismissed through disinterest or professional inexperience.” (Professional Q1)

“There are endless problems caring for people with epilepsy and intellectual disability, my daughter cannot speak so unless she has a seizure we do not know there is a problem.” (Family Q3)

PROPOSED ACTION 1

The ILAE should establish a Working Group to develop standards for the diagnosis of epilepsy in people with an intellectual disability, both for adults and children. This should include measures to investigate aetiology, misdiagnosis and equitable access to treatment.

2.1.2 COMPLICATED MEDICAL NEEDS - COMPLEXITY OF TREATMENT

Because of the complicated and sometimes uncertain nature of epilepsy in people with intellectual disabilities, establishing an effective treatment regimen was deemed challenging. Respondents highlighted the time consuming nature of finding the right AED combination for patients. In particular, respondents spoke of the process of weaning patients on and off different formulations, and of compiling complex medication protocols.

“We have tried two so far – [AED brand name] and [AED brand name] and neither has proved successful yet in controlling the seizures but we are still waiting to get to the right dosage. I find it frustrating we have to start on such low dosages, and I have also found both types make my daughter very hyperactive and naughty making life quite difficult.” (Family Member Q2)

“Anti-epilepsy medication can help, but it can take a while to discover the correct dosage/mix of medications.” (Paid Caregiver Q1)

Respondents also spoke of their confusion regarding whether presenting symptoms or behaviours were a consequence of epilepsy, intellectual disability or medication effects. The inability of some people with an intellectual disability to communicate the difficulties they were experiencing added to this confusion.

“I find that when the medication has changed my son's personality it is not always expected that it is the medication and doctors think it is because of developmental problems when clearly the problem started when medication has changed.” (Family Q1)

Indeed, the complexity involved in caring for someone with epilepsy and intellectual disability, as outlined by respondents, appears to lead to a myriad of complications, some of which will be explored more fully in the following sections.

2.2 COMMUNICATION IN THE CONSULTATION

Communication was a central theme. Respondents commented on the challenges which arose from communication difficulties arising from a triad of interactions occurring at moments of contact with epilepsy services. This triad comprises a three way process involving the individual, the professional and the caregiver or family member.

2.2.1 COMMUNICATION IN THE CONSULTATION - WITH A PERSON WITH AN INTELLECTUAL DISABILITY

Paid caregivers and family members commented that they preferred clinicians to attempt to talk directly to the person with an intellectual disability during clinical consultations and not ‘talk directly over their heads’ to the caregiver or family members. Where clinicians did talk directly to the patient, some family members commented that they did not adjust their language to an appropriate level when talking to the person with an intellectual disability. Clinicians who were deemed good communicators, and who knew the person well, were highly praised by family members.

“Medics do not make allowances for my son's slow processing of information. Because he looks OK there is an assumption by them that he fully understands sometimes complex sentence structures.” (Family Q1)

Time was also cited as a factor of contention during consultations with respondents reporting that professionals did not spend enough time with the person during the consultation. Caregivers and family members commented that short consultation times could result in issues being overlooked and snowballing to later appointments.

“Not enough help with epilepsy, no explanations given to person with LD [learning disability], to try and help them understand. What helps - time - not a five minute appointment.” (Family Q3)

2.2.2 COMMUNICATION IN THE CONSULTATION - WITH FAMILY OR PAID CAREGIVERS

Caregivers and family members reported communication difficulties in their interaction with health care professionals. Some commented on the lack of 'take away' accessible information about epilepsy, medications and treatments. Others reported a reluctance by medical staff to take initial concerns seriously, a reluctance to give separate consideration to symptoms of illness or problematic behaviour in favour of treating them as part of the syndrome (including where families believe behaviour change is related to medication), and a failure to answer questions about the nature of the intellectual disability and its association with epilepsy.

"I think an area that really needs to be worked on is having information on epilepsy and treatment available in an accessible format for the individual with an ID, at the consultants' clinics." (Paid caregiver Q1)

"I asked the epilepsy nurse if there was any groups where I could talk to other parents going through the same as us that we could talk to and I was told there was no groups. I have since been on the internet and discovered Purple Day for epilepsy who do have a forum so you can chat to others going through the same as you and other children can discuss how they feel and the problems they face in school and life in general with others their own age. I think epilepsy nurses and doctors should know about these sites and should be educated about support groups." (Family Q4)

2.2.3 COMMUNICATION IN THE CONSULTATION - PERCEIVED CLINICIAN ATTITUDES

The attitude or interest of mainstream clinicians was raised by a number of professionals as having a direct impact on the quality of care a person with an intellectual disability received. Professionals and family members expressed concern that some clinicians may 'give up' earlier when attempting to control seizures among this population when compared with patients who did not have intellectual disabilities. Professionals described this approach to treating patients with intellectual disability as discriminatory.

"It appears at times that medical practitioners 'give up' on treating people with learning disability and epilepsy and the individual has to accept that 'this is their lot'. I wonder whether this would be the same for someone without a learning disability." (Professional Q1)

"I don't think problems are taken seriously enough, sometimes have found an attitude of 'oh well they have LD².'" (Family Q1)

Some family members reported having to be quite aggressive with clinicians in pursuing diagnosis or treatment for epilepsy.

"We were on holiday at the time of the first few seizures and although seen by the local hospital they were reluctant to take things further and kept referring us back to our GP. It was only by eventually ending up in our local A and E and me breaking down to the doctors that we got taken seriously." (Family Q1)

² LD refers to 'learning disability' the common term for intellectual disability used throughout the UK.

“I had a really bad experience with my daughter when she was put on [AED brand name], it really made her sleepy and she could not function as a normal child at all. It took too long to get the specialists to take her off it and in the end we had to change her specialist.” (Family Q2)

In contrast, some respondents spoke of how motivated clinicians with an interest in this field facilitated good quality care for the person with an intellectual disability. Clinicians who were considered to be kind, caring and competent were also highly valued.

“Having a good consultant is crucial. Someone you can get in touch with easily when going through bad times. Someone who understands the person very well from both a medical and clinical point of view and who understands how the condition affects the person's life.” (Family Q1)

PROPOSED ACTION 2

The ILAE should support educational initiatives to improve clinician communication when an individual has impaired communication and should support the call for extended consultations to ensure sufficient time is afforded to patients with intellectual disability.

2.3 ACCESSING INVESTIGATION

Barriers to accessing epilepsy investigation were identified. These included equity of access and the need to adapt to the specific needs of people with an intellectual disability.

2.3.1 ACCESSING INVESTIGATION – LACK OF FACILITIES

Difficulties in accessing investigations were highlighted as a barrier for effective diagnosis and treatment of epilepsy in people with intellectual disability.

“Lack of access to MRI, EEG and other facilities is an issue...” (Professional Q1)

Families commented on their frustrations resulting from delays in receiving a diagnosis, arranging investigations, and securing appointments with specialists.

“I am still waiting for a cause to my son's epilepsy after it being over 2 years since his first seizure so I feel diagnosis is slow.” (Family Q1)

2.3.2 ACCESSING INVESTIGATION – CONSENT ISSUES

Both clinicians and family members alike acknowledged that communication, behavioural and comprehension difficulties make some investigations difficult to complete. Difficulties in assessing how well people with an intellectual disability who have epilepsy understood information, and whether they had the capacity to consent to investigations meant that this patient group is less likely to undergo investigations for their epilepsy such as MRI or video EEG.

“Detailed recording of events and use of video recording can be helpful but may be challenging [-] consent issues need careful consideration. Investigations are often difficult to complete and clinical decisions may be the only way for diagnosis depending on the experience” (Professional Q1)

2.3.3 ACCESSING INVESTIGATION – PRACTICAL CONCERNS

A number of respondents also highlighted the practical difficulties in addressing the needs of patients with behaviours that challenge. Respondents commented on the lack of adjustments afforded to this population, such as desensitisation or the use of medication or anaesthesia.

"Some people with ID [-] very afraid of needles [-] hampers investigation as does difficulties with scans, sometimes need to weigh risk of sedating/anaesthetising patient against risk of not scanning." (Professional Q1)

"... patients have difficulty accessing investigations because they are less able to comply - need anaesthetic for MRI, and may need melatonin to get an EEG which is not available to us without referral to tertiary service. I have concerns they do not have equitable services compared with people who do not have intellectual disability, because system less accessible for them." (Professional Q1)

2.3.4 ACCESSING INVESTIGATION – DISCRIMINATION

The inability or refusal of mainstream services to make adjustments to facilitate people with intellectual disability, and the unsuitability of some mainstream environments were deemed discriminatory by some respondents.

"Although there are some isolated individual clinicians who are interested in ID the majority are not, so people with ID continue to receive a substandard service. I have direct experience of discrimination, of clinicians ignoring SIGN guidelines and of diagnostic overshadowing." (Professional Q1)

PROPOSED ACTION 3

A Working Group should be established identifying a pathway to investigation for those with complex needs to include a discussion of best interest and the use of anesthesia or sedation.

2.4 MEDICATION

Respondents' views on medication reflected a balancing exercise; on one side there is an overwhelming concern about side effects, and on the other a recognition of the potential positive impact of treatment and the need to access the best possible treatment.

2.4.1 MEDICATION – SIDE EFFECTS

Concerns about side effects were a prominent issue. Nausea and vomiting, shaking, and effects on mood, concentration, cognitive ability and weight were all highlighted as problematic. Families also expressed concern about the sedating effects of AEDs, especially in the early phases of treatment.

“He has shaky hands (thought to be a side effect of his medication) which has taken away any confidence to do tasks like shaving himself or using sharp knives when preparing food so it has taken away some of his independence. He is acutely aware how vulnerable he is having epilepsy. It always helps to have someone with him who is understanding and reassuring.” (Family Q2)

“The problems for my son on [AED brand name] to date has been significant weight gain, i.e. 20kg in less than 18 months (a 50% increase in body weight from 43kg to 63kg). Eating healthily & fitness program has helped recently & now he is going on to [AED brand name] instead, to halt the weight gain. [AED brand name] also dulled his cognition, so too can the new drug but we are open to trying it out.” (Family Q2)

Some family members seemed conflicted as to the 'trade off' between a reduction in seizure frequency which was attained at the price of debilitating side effects. Sedation effects were deemed particularly distressing as they contributed to a loss of the individual's personality.

"Lots of issues regarding side effects and how we monitor these. Difficulty in making changes as a result. I also find carers and family are reluctant for change." (Professional Q2)

"It is a shame how much they affect my son - when starting new medications he is very drowsy and we 'lose' the real him. He becomes a shell. We had to rapidly increase his dose of [AED brand name] to try and get his seizures under control and he was so heavily sedated as a result it was heart breaking to see him. He was lifeless almost. It is sad to think that in order to control the seizures, you have to use a medication that takes a piece of them away almost." (Family Q2)

Some respondents also expressed concern that clinicians were reluctant to change medications when side effects were causing difficulties. In addition clinicians were deemed to be reluctant to continue trialing new AEDs in patients with intellectual disabilities where this was not thought to be the case for the general population. It was suggested by some respondents that low therapeutic expectations for people with intellectual disabilities may be a contributory factor to this attitude.

PROPOSED ACTION 4

The ILAE should develop a Task Force to develop guidelines for the treatment of epilepsy in people with an intellectual disability.

PROPOSED ACTION 5

A Position Paper should be produced establishing best practice for the identification and management of anti-epileptic drug side effects in people with an intellectual disability. Specific attention is needed to address drug interactions due to the increase in prescribing for co-morbid conditions.

2.4.2 MEDICATION – RESCUE MEDICATIONS

Rescue medications were mentioned by all three respondent groups as being useful for preventing unnecessary hospital admissions, and for increasing the confidence of families to live a more normal life. Buccal preparations, in particular, were singled out as an importance advance in treatment as their administration was deemed less invasive than more traditional rescue medications.

“I also use rescue medications on a regular basis as she suffers from non-convulsive status every couple of weeks. I think without these medications my daughter would not be alive today.”
(Family Q2)

“[AED brand name] has been great for us as a family as it has given us confidence that we have meds for an emergency.” (Family – Q2)

Some concerns were, however, expressed regarding the use of buccal medications. These concerns included the prescribing of buccal preparations by primary care physicians, the potential overuse of these medications, the lack of clear protocols for their usage, and training issues for care staff. Where respondents were aware of policies regarding training, their commentary on the policies was largely positive.

“A significant personal difficulty for me is that it has taken me nearly 7 years to push a protocol for Buccal [Rescue med brand name] as a rescue medication to the highest level of my employing organisation. This has been frustrating particularly because of the number of people confined to wheelchairs currently prescribed rectal diazepam, not to mention the privacy and dignity aspect of intervention.” (Professional Q6)

“The development of a joint policy around rescue medication has helped by ensuring all organisations have clear guidance around what training is needed, who can deliver the training, what should be contained within it and how often refreshers are needed.” (Professional Q2)

PROPOSED ACTION 6

Audit templates should be developed to ensure all people with intellectual disability who have epilepsy have had an assessment of the value of rescue medication, are prescribed when appropriate, and should ensure that staff and family members have had adequate training in their administration.

2.5 MONITORING TREATMENT

Achieving good seizure control with minimal side effects is the main aim of treatment strategies for epilepsy. Many people with intellectual disability have epilepsy that is difficult to treat and as such many of these individuals have complicated treatment plans that require careful monitoring. A number of issues were identified as barriers impeding this process.

2.5.1 MONITORING TREATMENT – QUALITY OF INFORMATION FROM CAREGIVERS

Respondents commented that many people with an intellectual disability who have epilepsy may lack the communication skills to give a clear medical history. As a consequence clinicians are dependent on caregivers to provide the information they require. At issue is the adequacy of the information from caregivers, whether paid support workers or family members.

“Very dependent on the feedback from others not the person themselves if there is communication and comprehension difficulties.” (Professional Q1)

“It can be hard to get unequivocal seizure descriptions from carers/patients, very profoundly disabled patients may be experiencing seizures that are not ‘text book’ in their presentations and may be misinterpreted as behavioural or vice versa.” (Professional – Q1)

Both professionals and families acknowledged that people with intellectual disability require appropriate support during their clinical consultation to facilitate diagnosis and treatment. Professionals placed a particular emphasis on the role of third party information in making a diagnosis. In particular, they were critical of staff turnover, commenting that a myriad of caregivers may support the same individual to different appointments.

Effective support was characterised by professionals as involving caregivers who knew the person with an intellectual disability, who were knowledgeable about epilepsy, and who knew what type of information was relevant to the consultation e.g. accurate monitoring seizure frequency, behavioural changes etc.

“Due to the fact that most people with LD who have intractable epilepsy also have severe LD professionals will be reliant on information from carers. Many of these carers (especially paid services) have little knowledge around epilepsy and therefore do not monitor seizure activity accurately. This will therefore present problems with adequate treatment/management.” (Professional Q1)

“The major issues are the difficulty in obtaining information from carers whose knowledge of the person with epilepsy and intellectual disability varies considerably e.g. seizure types [-] often have no idea what types their person with epilepsy has or what drugs they are taking etc. Rarely the same person accompanies the person with epilepsy to the clinic.” (Professional Q1)

2.5.2 MONITORING TREATMENT – ASPECTS OF INTELLECTUAL DISABILITY THAT HAMPER MONITORING

On occasion, all categories of respondent, whether professionals, paid caregivers or family members, expressed concerns that communication difficulties, and confusion about what behaviours may or may not be seizure activity, restricted their ability to monitor possible side effects of AEDs. The respondents stated that they were reliant on more subtle cues of side effects such as behavioural change in the absence of verbal feedback from the individual.

Some respondents reported being confused about distinguishing behaviours that may be due to epilepsy or intellectual disability from behaviours that may be due to side effects. This situation was thought to be more complicated where individuals were on multiple anti-epileptic medications.

“Lack of communication is a major problem, our inability to understand how the individual is feeling with medication changes, our lack of understanding of how the individual feels with the seizures” (Professional Q1)

“I find it quite difficult to monitor and assess the individual for the many side effects of meds, often due to communication difficulties. It can be a bit hit and miss.” (Paid Caregiver Q2)

PROPOSED ACTION 7

Guidance should be developed on standards of information exchange in clinic settings. These should identify the input from individuals, caregivers, families and professionals.

2.5.3 MONITORING TREATMENT – TREATMENT PLANS

Some concern was expressed that protocols were not followed correctly and that medication regimens were not reviewed regularly enough by epilepsy specialists. Respondents were concerned that there were inconsistencies in clinicians' approaches to conducting reviews resulting in some people being regularly reviewed by specialists while others were seen by primary care physicians.

“In the LD [intellectual disability] population, I feel many people are over prescribed and do not receive the same levels of medication reviews. Some of this is due to some people having their reviews carried out by the consultant psychiatrist, where others are managed through the GP or neurology department.” (Professional Q2)

2.5.4 MONITORING TREATMENT – MONITORING IN PRIMARY CARE

Respondents also reported that they considered many primary care physicians did not have the appropriate specialist knowledge to carry out the role of monitoring anti-epileptic medication. They commented that where primary care provided the only input on medication for people with intellectual disability problems could occur.

“We only received specialist services by chance when we spoke to a social worker who knew of this. Since then we have had excellent support and been given good information to enable us to make choices in trying to control our daughter's epilepsy. Prior to this we were reliant on our GP, who saw her once a year to ask if medication was ok and as we did not know enough about epilepsy and treatment, believed he knew enough, despite him never seeing [child's name] have a seizure. Our daughter's seizures have reduced from over 50 per month to single figures per month.” (Family Q3)

*“Problems - GPs expectations and understanding of the client group (diagnostic overshadowing). Medication being changed or withdrawn by GPs at too swift a pace.”
(Professional Q1)*

PROPOSED ACTION 8

Guidance should be developed on the role of primary care services in the management of people with intellectual disability who have epilepsy and into how these interact with specialist services.

2.6 KNOWLEDGE TRANSFER

Ensuring that families and caregivers had enough information to effectively manage epilepsy for the people they support was a concern for all three categories of respondents.

2.6.1 KNOWLEDGE TRANSFER - AVAILABILITY OF INFORMATION

Professionals were as likely to report that there was sufficient information available to the families of people with epilepsy and intellectual disability as they were to report that more information was required. In contrast, both paid caregivers and family members typically reported that the amount of information they could access was minimal or non-existent.

“Lots of information and research continues. Websites are good and accessible for those who have access to the internet and the reading ability to digest the info.” (Professional Q4)

“It is not easy to get access to these resources unless you or your service is linked to a university where staff can access journals, making these resources more available would be of benefit to services and clients.” (Professional Q4)

"I search articles on the internet, I don't think there is enough readily available information. I get a monthly newsletter from [named patient support group] which can be helpful and put me on to this survey. Other than that I do find it difficult to find information." (Family – Q4)

2.6.2 KNOWLEDGE TRANSFER - THE QUALITY AND SOURCE OF INFORMATION

Support groups and internet sources were noted by many as providing useful information. All three respondent groups, however, noted that while there was a large amount of information available to people on the internet this source posed its own problems. Some people highlighted that people without internet access were at a disadvantage, while others noted that it was difficult for families to judge the accuracy of the many sources available. Professionals stated that they found support groups and 3rd sector organisations to be useful sources of information and referred families to these resources.

"There is a lot of information on the treatment and support of people with epilepsy and ID, However, it is not easily accessible to many individuals. One must be able to sift through the abundance of information on the Internet and be able to assess the credibility and integrity of what they are reading. People who live in areas with no or minimal access to the World Wide Web, who are illiterate, or do not understand the medical lingo are at a disadvantage. Frequently, the best sources of information come from patient advocacy groups such as Dravet.org or the Lennox-Gastaut Syndrome Foundation, These groups reach out to families and the medical community to help share information and raise awareness." (Family Q4)

2.6.3 KNOWLEDGE TRANSFER – RELEVANT AND ACCESSIBLE INFORMATION

Some family members noted that many resources were very general in nature and did not cater for the complicated nature of epilepsy among people with intellectual disabilities, or for rare forms of epilepsy. These family members commented on the value of social forums where they could draw on the advice of families in similar situations.

“I think it’s difficult because needs are so varied. It seems to swing from one extreme to the other. Either advice is that epilepsy is not a problem apart from a bit of short term memory issues to severe disability issues. There is a lot in between that doesn't seem catered for. Also without a diagnosis (she has been tested for various genetic conditions, Dravets etc,) there is no "club" to join of people with similar experiences.” (Family Q4)

“There is a lot of information about epilepsy but it’s aimed at the common types, not at my son’s condition and none of the helplines could offer any meaningful advice. From what I have seen the literature seems to be aimed at average intelligence & epilepsy rather than people who have disabilities. But through social websites like [social network site] I have discovered it is actually quite common. It is surprising then that there is not more information out there.” (Family Q4)

All three respondent groups felt that easy read sources of information for people with epilepsy and intellectual disability were difficult to access, with some professionals noting the difficulties in providing adequate individualised information.

“There is a lack of patient information for people with a learning disability in easy read formats and I am expected to obtain resources or develop them myself. This is extremely time consuming and could be improved by access to a service who could develop resources on an individual basis when provided with relevant information.” (Professional – Q3)

"I think an area that really needs to be worked on is having information on epilepsy and treatment available in an accessible format for the individual with an ID, at the consultants' clinics. Also, an epilepsy liaison nurse in ID would be a huge support, but is not currently available in my experience." (Paid Caregiver – Q1)

2.6.4 KNOWLEDGE TRANSFER - UNANSWERED QUESTIONS?

Family members identified a number of information gaps. They were concerned that while there was ample information available at the professional level, the extent to which this information filtered down to support staff and family caregivers was perceived as ad hoc, and depended on individual clinicians' motivation and enthusiasm. While some families felt that they did not receive enough information from the clinical teams, and thus were forced to look for information themselves, others appeared satisfied to engage in information seeking activities outside of the clinical context. The inconsistency of information provision across areas was a cause for concern.

"From the many disability-related meetings I have attended over the years, the health care professionals think that information has been properly disseminated, when in fact it has not filtered down to the grass root level." (Family Q4)

"I feel the Neurologists don't tell us enough of the details about her epilepsy, perhaps because it is a complex condition, but I still do not know much about what type she has." (Family Q4)

"No - still confused over my daughter's diagnosis - if I read about meds on the internet that she has been prescribed it suggests lennox gautaut (sic) syndrome - but my neuro has given no indication that this is what her diagnosis is or not." (Family Q4)

PROPOSED ACTION 9

Accessible information on all aspects of epilepsy management should be made available in services and on the ILAE/IBE websites.

PROPOSED ACTION 10

Mechanisms for improving communicating information in clinical situations should be explored. These include the use of shared decision methodology and option grids.

3. SERVICE DELIVERY

Specialist services, though these were not defined, were generally thought of as optimal for the diagnosis and medical management of epilepsy in people with an intellectual disability.

3.1 SPECIALIST SERVICES

Respondents' recognized and valued specialism, identifying the importance of multidisciplinary teams and specialist nursing in particular.

3.1.1 SPECIALIST SERVICES – MULTIDISCIPLINARY WORKING

Multidisciplinary teams were felt to be particularly effective in facilitating optimal care in complex cases. Respondents commented on the value of shared working among clinicians with expertise in epilepsy, clinicians with expertise in intellectual disability, epilepsy specialist nurses and other professionals.

“In our area most people with learning disability and epilepsy come through to the general neurology clinic and are seen by me. There is an advanced nurse practitioner in epilepsy from the learning disability service. We do see some people in a joint clinic with a learning disability psychiatrist and this works really well for the limited number of people who can access it.”
(Professional Q3)

“Close liaison between the Epilepsy Specialist Nurse employed by the local acute hospital and multi-disciplinary representation from learning disability services has led to greater identification of those who require more support and their specific needs.” (Professional Q3)

3.1.2 SPECIALIST SERVICES – SPECIALIST NURSES

Nurse specialists in epilepsy are involved in the treatment, education and provision of risk assessment in people with epilepsy. In general such nurse specialists are attached to neurology services. Nurses with considerable experience in epilepsy also work in community services for people with an intellectual disability. Such nurse specialists were viewed very favourably, being frequently cited by clinicians and caregivers alike as being able to provide training and expertise in the management of epilepsy and intellectual disability. They were also valued for their role in facilitating liaison with specialist services and their support for families.

“Yes we are lucky we have a clinical epilepsy nurse living close by, whom we can call but I wouldn't call her as she is very busy unless it was necessary.” (Family Q3)

“Epilepsy specialist nurses are invaluable. Support services often have misconceptions and sometimes fear or ignorance about epilepsy which leads to poor care” (Professional Q3)

PROPOSED ACTION 11

The ILAE should promote the development of epilepsy specialist nurse provision with a particular relevance to those supporting people with an intellectual disability either in specialist epilepsy services or in services providing health care to people with an intellectual disability.

3.2 ACCESS TO LOCAL SERVICES

Inconsistency and inadequacy of local services were recognized by professionals, paid caregivers and family members.

3.2.1 ACCESS TO LOCAL SERVICES – INCONSISTENT SERVICE PROVISION

Professionals cited a number of concerns regarding the inconsistent delivery of health services. They commented on the variability of resources across different services, the lack of transition planning between child and adult services, and on the inconsistencies in the agents who delivered services, including neurologists, psychiatrists and primary care professionals. Respondents also commented that services varied markedly by locality.

“Patchy [-] some areas have epilepsy liaison support some don’t. This is important as intervals between consultant appointments is so long and often issues arise [-]changes need to be made between appointments, some patients see specialist epilepsy neurologists some see general neurologists” (Professional Q1)

“I think services can vary greatly from county to county, Sometimes people with epilepsy and ID are seen in neurology services some in specialist learning disability teams. I have experienced positives and negatives in both. It is important that the person with the ID and their carers if necessary are given enough time & resources to support them with the condition. It helps to have medical and nursing staff who understand both epilepsy and ID.” (Professional Q3)

PROPOSED ACTION 12

Guidance, including minimum standards, should be developed on multidisciplinary team working for individuals with epilepsy and intellectual disability.

3.2.2 ACCESS TO LOCAL SERVICES – FAMILY ACCESS TO LOCAL SERVICES

Families expressed concern and frustration with some of the limitations in the services and support they were able to access.

“Not good at all [-] the only help my son has received that could not be faulted was off the portage³ worker and the specialist health visitor. Everything else has been a fight to get help. People with disabled children are already tired from the care they have to give to the child with no help from others as there is always funding issues or just no funding at all.” (Family – Q3)

“I think services vary from one local health authority to another. We have been fortunate in having a consultant who treats her with respect and dignity and equally with any other patient.” (Family Q3)

“No service has been provided. It is a disgrace.” (Family Q3)

³ Portage is a home visiting educational service for pre-school children with additional support needs and their families

3.3 PRIMARY HEALTH CARE

Professionals working in the area of epilepsy and intellectual disability perceived a lack of epilepsy specific knowledge and experience at primary care level which they perceived resulted in a less than optimal service.

“Sometimes if there is only GP involvement with patient it can mean that guidance, review and feedback is a bit patchy” (Professional Q3)

Both family members and professionals reported problems at primary care level with the prescribing of rescue medications, the prescribing of branded versus generic drugs and with the monitoring and changing of medications. Some professionals suggested that the level of interest at primary care was variable, with the level of engagement of primary care physicians impacting on the standard of care provided.

“GPs are not always aware of the new AEDs, and we have had issues with willingness to prescribe [AED brand name] due to licensing concerns.” (Professional Q2)

On a more positive note, families and caregivers described the characteristics of primary care physicians whom they felt were supportive. These characteristics included being vigilant in monitoring the impact of medication and providing swift referrals to specialist services when required.

“It can be really difficult to see the medical professionals when you need to on an urgent basis. It really helps to have a great Dr (GP) who can access the specialists when needed.” (Family Q1)

3.4 QUALITY AND LENGTH OF CONSULTATION

As was mentioned previously (2.2.1), all groups reported that short appointment times and long waiting lists for and between appointments were problematic. The respondents proposed that people with an intellectual disability would benefit from longer appointments which would give clinicians adequate time to explain issues to patients with an intellectual disability and assess their response.

“My daughter was referred to a neurologist and seen within weeks. However this neurologist's specialty was not epilepsy. I then sought an appointment with another neurologist in [named city] who is very highly regarded. I waited for 2.5 years for an appointment.” (Family Q1)

“The after care needs to be looked at, although the person I look after now has a consultation once every six months, was once a year, it's brief lasting about quarter of an hour. Cannot see what they can redeem out of such a short consultation.” (Paid Caregiver Q1)

“There can be long waiting times for appointments and it is not unusual to meet a different doctor at each visit, this is particularly difficult for the person with ID. Often doctors and nurses don't know how/have not got the time to listen and talk to the person with ID.” (Paid Caregiver Q3)

PROPOSED ACTION 13

Guidance should be developed on appropriate durations of consultations with people with complex communication problems.

3.5 TRAINING – SKILLED CARE DELIVERY

The need for appropriate training in issues specific to epilepsy and intellectual disability was identified for many working in the delivery of health care. Concerns were expressed that where the training needs were left unmet, the medical care of people with an intellectual disability and epilepsy suffered. Respondents identified specialist nurses, in particular, as being in a unique position to deliver training across a variety of contexts.

“Well we manage my daughter’s care via a direct payment, and we could NOT access up to date training for her staff when she suffered a cluster. I had to find a trainer (a very good one) to provide the training to the staff. Training should be delivered by someone with epilepsy not clinical people, I found this totally inadequate.” (Family Q3)

“I make every effort to ensure that my general trained colleagues are aware of issues relating to learning disabilities and at every staff meeting I provide updates on the latest efforts to promote good health.” (Professional Q3)

PROPOSED ACTION 14

The ILAE working with the IBE should develop training manuals to support non-specialist services managing epilepsy in community settings.

4 EDUCATION AND EMPLOYMENT

The impact of epilepsy and intellectual disability on individuals’ education and employment opportunities was considerable. Respondents commented that while either condition could cause

challenges for individuals' participation in school or in the workforce, people with both epilepsy and intellectual disability were extremely disadvantaged in these life domains.

4.1 SCHOOLING AND EDUCATION

There was a wide range of commentary on the issue of schooling and education. Many participants, however, reported frustrating experiences in securing and maintaining education.

4.1.1 SCHOOLING – RESTRICTED PARTICIPATION IN EDUCATIONAL ACTIVITIES

Epilepsy was cited by a number of respondents as limiting students' participation in school activities. Respondents spoke of issues relating to the inappropriate management of seizures and issues relating to rescue medication. In the latter case, respondents observed a reluctance to administer rescue medication which resulted in children being sent home unnecessarily from school and being excluded from school outings.

"Young people under my care frequently report that if they have a seizure in school- they often got sent home even though they had recovered. Most felt that they could have done better with improved support." (Professional – Q6)

"I think if in a special school with nursing support this can be easier. However, ironically I have had a problem where school staff not willing to take on buccal midazolam training in special school when taking a child on school trip, because in school setting the nurses would take this on, but they have to stay in the school premises, so that a child couldn't participate fully in school activity because of their epilepsy." (Professional Q6)

Similar limitations were imposed on older students attending short courses delivered in community colleges. One respondent, for example, described how a student was requested to be accompanied by support staff despite the presence of a family member who was also enrolled in the course.

“There have been difficulties locally for us in people accessing further education, especially if they require rescue medication. This can be a significant barrier that we are struggling to overcome.” (Professional Q6)

4.1.2 SCHOOLING – EDUCATIONAL PROVISION AND RELUCTANCE TO TAILOR CURRICULUM CONTENT

Respondents had mixed experiences with mainstream and special schools. Mainstream education was found by some to provide insufficient supports for children with intellectual disability and epilepsy. Special schools were similarly criticised for their failure to provide optimal education opportunities for their students, and also for being geographically harder to access.

“Because of his epilepsy I have to consider a placement that will meet his medical needs. The two conditions combined and in particular the severity of each of them mean that there is no chance he can go to the local mainstream that his brother will go to. But I worry also that even at a school that caters for children with medical difficulties that they won't be able to manage his epilepsy either.” (Family Q6)

“Even though my daughter went to a special school, teachers didn't recognise when she was having absences, and therefore didn't always make allowances for her missing parts of the lesson, and just assume she didn't understand, when what she needed was further explanation. It would help if teachers had more knowledge of epilepsy.” (Family Q6)

A number of parents also commented on the appropriateness of the curriculum content for their children. They stated that despite some course material being clearly irrelevant for their children, schools were reluctant to deliver non-curriculum material which parents felt would be more beneficial.

“My son attended a special school as he would not have been able for mainstream school - unfortunately under the auspices of the department of education a curriculum had to be followed which had no relevance whatsoever.” (Family Q6)

4.1.3 SCHOOLING – IMPACT OF EPILEPSY AND INTELLECTUAL DISABILITY ON LEARNING

Both parents and professional reported on how the children’s disabilities impacted on their ability to learn and attend school, sometimes despite positive efforts to support them.

“Yes it has an impact as she forgets quite a lot what she would have studied in recent times. She finds it difficult to understand sometimes very simple things. What helps is support from me which can be exhausting.” (Family Q6)

“My daughter has had a really difficult time gaining control of her seizures. As a result she has had to have more time off school than I would like. The medication can affect her energy levels and concentration levels. She has had to have half days at school whenever her meds are changed or increased. As a result she is not performing at a level she is capable of, and is making slower progress than her peers.” (Family Q6)

Some parents reported anxiety that their child's disability would result in them missing key educational mile-stones such as state examinations or the possibility of attending college.

"The neurologist always asks how is school going. We will be discussing this issue with the school this year as our son is doing his junior certificate⁴ and if a seizure occurs during the exams he could miss 2 days of exams. I hope there are supports in place but we are not sure. We are only going down this road now so not sure what are the problems or what helps." (Family Q6)

4.1.4 SCHOOLING – POSITIVE ADAPTATIONS

Respondents identified a number of initiatives which they perceived improved the educational experiences of students with epilepsy and intellectual disability.

Health teams, including paediatricians and epilepsy nurses, were identified as a source of knowledge to reduce anxieties for educators. The development of seizure care plans and individualised support programmes were also cited as reducing anxieties and clarifying appropriate actions in the event of a seizure.

"Once we started getting specialist help from hospital and kept diary and medication controlled seizures better, we were able to send her to college on days she had seizures, as staff were trained and we felt confident they could handle the seizures and after effects. Good training of other people involved with the person with LD essential to have confidence in being able to leave them with other people and know seizures will be managed properly." (Family Q6)

⁴ National examination for students aged approximately 14-16 years in one of the participating countries.

Schools themselves were praised for fostering positive attitudes towards disability, providing suitable social opportunities for students with epilepsy, and for providing flexibility in the course curriculum. One family member noted that home schooling over a short period had been invaluable in providing a protected space for students with epilepsy and ID prior to joining a class of peers.

“Our son is generally happy in his own company, and doesn't want a busy social life. At school he enjoyed a social club during lunch times when older students played board games with those who struggled with social interaction.” (Family Q7)

PROPOSED ACTION 15

The ILAE in association with the IBE should establish a Task Force with a wide ranging remit to establish guidance on all aspects of schooling for people with an intellectual disability and epilepsy.

4.2 EMPLOYMENT

Employment was perceived as a key factor in individuals' on-going personal development and fulfillment in adult life. Many respondents, however, across all three categories cited difficulties in securing and maintaining employment opportunities for people with intellectual disabilities and epilepsy.

“It greatly reduces their ability to maintain employment, especially if they want to work independently and not be supported. Other staff often don't know how to engage with them or feel uncomfortable working with them.” (Paid Caregiver Q5)

4.2.1 EMPLOYMENT – CONCERNS OVER HEALTH AND SAFETY

Access to employment was perceived as difficult, largely due to the perceived risk of individuals experiencing seizure in the workplace. Respondents suggested that this perception was in part due to poor knowledge on epilepsy.

“Even without ID, epilepsy poses a huge barrier to getting and keeping employment. Employers are concerned about the safety of their workers and do not want to be liable for injuries sustained on the job as a result of a seizure, Many people do not understand what epilepsy is and are afraid of it. Add ID into the equation and the likelihood of an affected person acquiring gainful employment drops significantly.” (Family Q5)

“People with ID may require higher level of support to get and maintain employment - this is support employers have indicated that they are not in a position practically or financially to provide; also there is a concern of higher levels of sick leave due to epilepsy if poorly controlled.” (Professional Q5)

4.2.2 EMPLOYMENT – DISABILITY AWARENESS

Many respondents from all three categories cited the nature of intellectual disability and misunderstandings of this type of disability to cause challenges in securing and maintaining employment. In particular, issues regarding appropriate levels of support were raised, both in the context of inappropriate demands for an individual with ID to be supervised at all times, and in the context of a lack of sufficient supports to enable a person to maintain employment.

“My daughter worked in a care home and an office before that but due to memory problems was asked to leave!!” (Family Q5)

“So far (my son is 23 years old) he hasn't had any employment but feel this would be very difficult as firstly we haven't found anything to meet his abilities and secondly I know he would require a great deal of ongoing support. Support is usually given at first in a job and tailed off but my son would require support always - not something authorities etc. can get their head around!” (Family Q5)

4.2.3 EMPLOYMENT – STIGMA, DISCRIMINATION AND LOW EXPECTATION

Respondents commented on the challenges of sourcing appropriate employment opportunities for people with disabilities. Concerns raised by respondents including issues of bullying and the limitation of jobs on offer, some of which were perceived to have little chance of progression.

“No one that I have ever supported with epilepsy, down syndrome, autistic spectrum disorder, stroke affected, dementia, and other learning difficulties or mental health issues has been a paid worker, and even the minority who were volunteers still encountered teasing/bullying a sense of never progressing and of being stuck in a rut or monotonous routine while their "colleagues" went on training got 'moved around' and promoted. My colleague who has a learning difficulty has been working on a mental health assessment unit and respite care home has been there for more than two decades, 4 days a week, laying tables and pushing trolleys up and down corridors, while everyone else works different shifts over a 24/7 week and gets involved with varying degrees of care, assessment and planning. Why is it assumed that people of difference have no yearning for fulfilment either professionally or personally or a sense of ongoing self-development?” (Paid Caregiver Q5)

“Employment is hard enough for anyone to attain without a disability. There is still a stigma and a big lack of knowledge around epilepsy that prevents people being employed.” (Professional Q5)

"A double stigma..... usually individuals are expected to take a caregiver with them to their employment "just in case", lack of understanding from employers." (Professional Q5)

4.2.4 EMPLOYMENT – PRACTICAL CONCERNS

Some parents identified practical issues to gaining employment that were specifically related to the individual's intellectual disability. These issues included a lack of experience and qualifications, and issues related to communication skills and self confidence.

"Huge problems. Having uncontrolled epilepsy and resulting intellectual disability reduces her ability to learn. Reduces her rationality of behaviour at times. Reduces her social skills and reduces people's confidence in taking her on, I cannot see anyone employing her while her seizures remain uncontrolled." (Family Q5)

"I do not anticipate that my son would be able to find work. The problems are lack of experience and qualifications, combined with the fact of having epilepsy." (Family – Q5)

4.2.5 EMPLOYMENT – IMPACT ON PARENTAL EMPLOYMENT

A number of parents mentioned the impact of caring for someone with a complex disability on their own ability to stay in employment, with several stating that they had been forced to leave employment due to the demands of caring for a child with complicated medical needs.

"Basically I have had to give up working outside the home as my son requires a great deal of care and with regular seizures and illnesses I had to take a lot of time off when I was working. While he attended a special school they would ring regularly to collect him as he was "upset", making it impossible to keep a job." (Family Q5)

"I have had to leave work to care for my son. If he simply had a learning difficulty I am sure I would have been able to find care for him so I could return to work but his epilepsy means that I can't get anyone to look after him for me - no nursery or child minder would have him - and he spends so much time in hospital as a result of his seizures that I'd never be in work anyway."
(Family Q5)

4.2.6 EMPLOYMENT – POSITIVE ADJUSTMENTS TO THE WORK ENVIRONMENT

Respondents from all three categories suggested a number of strategies that were deemed to have a positive effect enabling people with epilepsy and intellectual disability to secure and maintain employment. These facilitators to employment included an openness to address the individual's disability, a disability aware workforce, the input of specialist disability employment services, flexible funding to finance personal assistants, the introduction of quotas for the employment of people with disabilities, adaptations within the working environment, and input from epilepsy specialists to address employers' concerns.

"In my experience, the best way to help is for an epilepsy specialist nurse to talk to the employer about general risks and if necessary (and with the individual's permission) to produce a report to enable the employer to adopt sensible risk assessments for the individual based on their specific needs." (Professional Q5)

PROPOSED ACTION 16

The IBE should establish a Working Group that will establish links with organisations involved in providing employment, including supported employment, to advise on reducing barriers to employment for people with an intellectual disability who have epilepsy.

5. SOCIAL, ROMANTIC AND FAMILY LIFE

People with an intellectual disability had profound difficulties in achieving social and romantic involvement. Additionally, and most probably as a direct impact of both the intellectual disability and the epilepsy, family life was impacted upon considerably.

5.1 SOCIAL ACTIVITIES AND FRIENDSHIPS

Barriers were cited relating to individuals' engagement in social activities and in relation to their opportunities to form friendships. These barriers included logistical problems, lack of social opportunities, and restrictions based on what was perceived to be to exaggerated safety concerns and misunderstandings regarding the nature of epilepsy.

5.1.1 SOCIAL ACTIVITIES AND FRIENDSHIPS – CONCERN OVER HEALTH AND SAFETY

Epilepsy itself was perceived as a considerable barrier to engaging in social activities. People with epilepsy and intellectual disability were thought to require the support of others to participate socially, with those in the supporting role needing to be epilepsy aware. Concerns, which were perceived to be exaggerated, regarding health and safety and the nature of epilepsy were thought to result in inappropriate restrictions on social activities. "Epilepsy myths", such as considering all individuals to be photosensitive, were thought to remain problematic.

"Lack of understanding about epilepsy can put unnecessary restrictions on a person's social activities. Flashing lights are automatically considered a risk by some people providing social activities, when in fact this is not the case for many people with epilepsy." (Professional Q7)

"For persons with ID living in services it can be very difficult as only those trained in administering rescue meds can accompany the individual out, limiting social experiences due to lack of resources." (Paid Caregiver Q7)

5.1.2 SOCIAL ACTIVITIES AND FRIENDSHIPS – DISABILITY ISSUES

Parents reported a number of considerations related to their child's disability that they believed restricted their ability to socialise and form friendships. These included issues relating to seizures, intellectual disability and behaviours that challenge.

"Social activities are very limited due to associated behaviour problems e.g. we can't go out to eat, cinema or visit friends." (Family Q7)

"Epilepsy often frightening to general public, friendships do not develop because we still legally segregate people with learning disabilities from their non disabled peers." (Professional Q7)

"My daughter has limited social skills and struggles to make friends and join in with other children because of her language delays." (Family Q7)

5.1.3 SOCIAL ACTIVITIES AND FRIENDSHIPS – FACILITATORS

Other parents reported having very sociable children who when supported appropriately in school etc. were able to develop social lives and attend social activities, while only occasionally missing events due to seizures. Factors that seemed to facilitate this process included being open about the condition and appropriate support.

"[Child's name] is very sociable. She enjoys Special Olympics and does Badminton and Golf. However she still needs someone to take her on all social outings." (Family Q7)

“Because of my daughters increased absences she has had a bit of trouble maintaining relationships at school. However she is lucky to have an amazingly supportive school environment and on the whole she is not treated any differently from other children at school. Her seizures have led her to miss out on some social activities such as birthday parties if she has had a seizure and is recovering.” (Family Q7)

“My son's close friends all know he has epilepsy. It is accepted & no one really talks of it or worries about it because it is matter of fact.” (Family Q7)

5.2 ROMANTIC LIVES

Barriers to achieving romantic relationships were identified as including the perceived stigma associated with epilepsy and intellectual disability, individual vulnerability and the lack of social opportunities afforded to this population.

5.2.1 ROMANTIC LIVES - STIGMA

Respondents commented on the stigmatising nature of epilepsy and intellectual disability, stating that potential partners could be fearful of forming relationships with people with these disabilities.

“My daughter has only had one boyfriend. She does not go out so probably will not meet anyone. She thinks nobody will want her because of the seizures.” (Family Q8)

“When someone of the other sex finds out that the person they are talking to [has a disability] they just seem to turn their back on them.” (Family Q8)

“Fear and misconceptions about the disorder may stop a potential relationship as one party may not want the responsibility of caring or the risk of passing onto potential offspring. Knowledge helps.” (Professional Q8)

“Well he’s only seven and so far he has asked many nurses, teachers and really any pretty female to marry him, so far it isn’t holding him back, I think it will come down to attitudes to and from him.” (Family Q8)

5.2.2 ROMANTIC LIVES – BARRIERS

Some respondents cited barriers to the formation of relationships. These barriers included a lack of interest by individuals in finding a partner, a lack of support by caregivers to encourage a relationship, and the limited opportunities individuals with epilepsy and ID have to meet people.

“In his own words, he’s “not ready for it” and I wouldn’t be surprised if it stays that way. He doesn’t like being pressured into conforming to other’s expectations.” (Family Q8)

“The main problems I have experienced are from caregivers paid or unpaid. Sometimes well meaning but they can easily thwart a relationship or influence a person against seeing someone. The problems I see are more to do with the ID than the epilepsy and I have never found that to be an issue. Actually being able to meet and spend time together would be a big issue for some people in a rural county especially.” (Professional Q8)

“Lack of facilities where such young people can meet and interact.” (Professional Q8)

Respondents also spoke of the impact of epilepsy and intellectual disability on maintaining existing relationships.

"I see one man who has separated from his wife because the emotional pressure when his mood is affected by his seizures, coupled with her inability to cope with the responsibility of caring for him, evolved into domestic violence. They now live separately and spend time together most days and the relationship is much more stable as a result." (Professional Q8)

5.2.3 ROMANTIC LIVES – VULNERABILITY OF POPULATION

There was considerable concern over the vulnerability of this population. Some respondents suggested that people with intellectual disability had problems understanding sexual desires and subjects such as contraception. Caregivers, in particular, were identified as being overly protective and untrained in addressing sexual issues.

"Parents get in the way! I have a few clients who are romantically attached but their parents are overprotective. I can think of two marriages. Dating is definitely more difficult for people with an intellectual disability." (Professional Q8)

"Parental disapproval and restrictions in care homes are the main problems. If one set of parents disapprove or the care home doesn't allow them private time with their partner there is little chance of any relationship progressing to anything more than a 'romance'. There is little or no training for staff about relationships or sexuality so clients get little support there either." (Paid Caregiver Q8)

5.2.4 ROMANTIC LIVES – FACILITATORS

A number of strategies that would facilitate relationships were cited by respondents. These facilitators included clear policy guidance on sexual relationships and appropriate training for partners.

“Lack of appropriate legislation, advocacy services and national policy around the area of adults with ID and romantic relationships is a significant issue.” (Professional Q8)

“Partners can be nervous about using rescue treatments and require lots of support and training. Without that relationships can fail.” (Professional Q8)

PROPOSED ACTION 17

The ILAE in conjunction with IBE should establish a Working Group to provide guidance to family members and those working in the epilepsy and intellectual disability fields on how epilepsy related risk can be minimized in order to promote the full inclusion of this population in social and romantic relationships.

5.3 PUBLIC PERCEPTIONS OF PEOPLE WITH EPILEPSY AND INTELLECTUAL DISABILITY

A pervasive concern over how individuals were perceived by the public was identified by respondents. This public perception was reported to result in social isolation and on occasions the physical abuse of people with intellectual disability who have epilepsy.

5.3.1 PUBLIC PERCEPTIONS - A NEGATIVE REACTION

Reflecting issues expressed earlier when identifying stigma, family members in particular described some negative reactions they experienced from members of the public. Epilepsy helmets were again cited as a very visible statement of difference.

“Other kids look at my daughter strangely - I wonder can they see that she has down syndrome.... one little girl wondered why her eyes were funny.... others wonder why she wears a helmet indoors or her head bumpa band... it makes her stick out even more from the crowd.”
(Family Q9)

“People are wary because they don't know what to do if she has a seizure and because of the intellectual disability, she cannot adequately express herself.” (Family Q9)

5.3.2 PUBLIC PERCEPTIONS – SOCIAL ISOLATION AND ABUSE

The impact of negative public perceptions was highlighted by respondents who spoke of individuals being socially isolated and lonely.

“There is a lot of stigma attached. This causes isolation.” (Professional Q9)

“I have seen a lot of ignorance shown by people generally towards anyone with epilepsy and towards people with intellectual disabilities. It causes problems in that some people can be very condescending. I have noticed in other countries that my son has been made very welcome and talked to and treated very well and he has loved this but the prevailing attitudes at home are to try to pretend he is not there, ask me questions instead of asking him directly and things like

that. Sometimes it is very frustrating especially when treated this way by people in the medical profession who should know better.” (Family Q9)

At the extreme end of this spectrum were reports of ridicule, bullying, abuse and hate crimes.

These experiences were thought to explain some of the over-protective actions of caregivers.

*“It has been the learning disability that is noticed more by other people and which we have had some negative situations varying from staring, ridiculing to physical abuse. Not pleasant for any of us! I think other people are sometimes wary of anyone who is "different" and we have, in general, tried to take things in our stride and keep smiling, especially as our daughter, generally, seems oblivious to the stares and comments - "If she is happy, we are happy" is our motto.”
(Family Q9)*

“There is an awful lot of prejudice. There needs to be greater emphasis on disability hate crime so that eventually people who no more think about making fun about a person's disabilities than they would about the colour of their skin.” (Family Q9)

“Parents can over-protect, but then they are a vulnerable group so this is probably in some respects in their interests.” (Professional Q9)

5.3.3 PUBLIC PERCEPTIONS – FAMILIES AS EDUCATORS

Parents reported on how they view themselves as playing a role in reducing the stigma experienced by people with disabilities. Personal contact with their family members was seen as a way of improving awareness and acceptance of people with intellectual disability and epilepsy.

“Amongst our friends we have been told that they have not experienced meeting someone at first hand with a learning disability/epilepsy, so think we have helped allay/answer their concerns/queries regarding this.” (Family Q9)

“People are awkward at first, but it is just because they don’t know what to do or say so I just tell them and then they just do it too.” (Family Q9)

“For the most part people are fine but there is also a certain amount of instances where people through fear or ignorance can be hurtful, I have an older daughter who is acutely aware of epilepsy and through her, her friends have a little more understanding of epilepsy and that’s a good thing.” (Family – Q9)

“I learn as I go, mainly from the specialist at the hospital, I find that as a parent you end up being an expert and often I have to correct some of the popular myths that are out there. It is my role to help educate the school also.” (Family Q4)

5.3.4 PUBLIC PERCEPTIONS - FACILITATORS

Educational activities and public awareness campaigns were identified as interventions that may help challenge negative perceptions of epilepsy and intellectual disability.

“Public have a lack of knowledge of epilepsy and the steps to take when someone is suffering from a seizure, increased knowledge of the general public of how to keep someone safe whilst seizing would be beneficial.” (Paid Caregiver Q9)

The greater visibility of people with intellectual disability within their local communities was perceived to result in more opportunities for the general public to meet people with disabilities. This greater personal contact was thought beneficial in dispelling fears regarding disability.

“People are more in the community and mix more, use the same shops, pubs etc. People still will often be seen as the disability first until they are known - and we have seen this in a local community over time where people living locally become a part of their local communities.” (Professional Q9)

5.4 FAMILY LIFE AND COPING WITH COMPLEX NEEDS

Families reported how caring for an individual with an intellectual disability impacted on day to day family functioning. This pervaded across all family members. They also highlighted how positive professional input could alleviate some of these difficulties.

5.4.1 FAMILY LIFE – PRACTICAL CONCERNS

For many family members the challenge of caring for someone with epilepsy and an intellectual disability was seen as having a profound effect across the whole of family life.

“Affects every area of our life. We are quite isolated as outings, meeting others are very difficult. We tend to split up as a family - one parent with [child’s name], one with our 2 boys so that they can still take part, family and friends cannot really help with [child’s name] due to her difficulties and we are reliant on caregivers and respite center for any support with her. Lack of sleep due to [child’s name] sleep patterns has knock on effect on all family due to tiredness and irritability. [Child’s name] has no communication and limited play skills so cannot entertain herself very well. It is difficult for her brothers to have friends over as my attention needs to be on [child’s name], She does not cope well with waiting so cannot take boys to after school activities, even dropping off and picking up is traumatic. I could go on...” (Family Q10)

Medical needs were described as requiring constant attention. Respondents commented that the complexity of providing support led to only close family members undertaking these tasks. Day care and babysitting services were deemed unequipped to deal with these medical issues. As a consequence, the majority of parents’ time is taken up with caring activities leaving little time for anything else.

“My son’s epilepsy is so severe that no one else is able to care for him (we are currently in the process of trying to get a complex care nurse) so my husband and I are unable to do anything together.” (Family Q10)

“It causes a lot of difficulties for us as a family as it puts a huge strain on the family when our daughter is ill and in status we cannot leave the house for days at a time or else protracted stays in hospital [-] all affect the normal family day to day existence.” (Family Q10)

“Impact on all family members and family life becomes centered around care for epilepsy as it generates fear of unpredictable events happening at anytime.” (Professional Q10)

The unpredictable nature of some people’s epilepsy meant that families often had to cancel planned activities at the last minute, and had difficulty in planning events far in advance. This unpredictable nature of caring for an individual with complicated medical needs resulted in financial pressure on many families as in some situations one parent was forced to give up full time employment.

“As seizures can be stress-related, if we plan to do something (e.g. holiday, day out, etc.) she can become anxious due to the change and bring on seizures, so activity can be hit & miss. Have had to cancel outings at last minute many times. This has affected lots of things we have wanted to do with our son over the years as well, so sometimes we have not both been able to support him, either myself or my husband does an activity with my son, whilst the other looks after our daughter.” (Family Q10)

“We don't do as much activity stuff as a family as we would like to, partly because [child's name] gets tired so easily, and because there is always the need for a plan B in case it's a bad day for her. I have recently had to give up a well paid job because her care needs have escalated.” (Family Q10)

“Financially, we have not been able to do some routine home maintenance such as fixing some broken tile-flooring due to the added expenses of caring for our daughter.” (Family Q10)

Many families reported being reluctant or unable to participate in public, community or large family gatherings as a unit due to challenging behaviour or severe uncontrolled epilepsy. As a result families were often split for large periods of time. Parents described how they were unable to spend time together as a couple. Some parents reported that they were unable to sleep together as one always slept in the same room as a family member with epilepsy through fear of seizures. Siblings were also impacted, most notably with regard to being limited in participating in everyday activities.

"...my older son (who is only 3) is unable to do the things he should as I am often unable to leave the house with them both if [child's name] is at risk of having a seizure. This means the eldest doesn't get to go to the park as often as I'd like etc. Family occasions like weddings mean that half of us can go, but one parent has to stay at home with [child's name] - we can't risk taking him and him stopping breathing due to a seizure and having to call an ambulance to someone's wedding. Leaving the house at all is a logistical nightmare as we need to bring oxygen and a bag and mask everywhere we go as well as [AED brand name rescue medication] and [AED brand name], not to mention all his feeding equipment (he is NG fed⁵)." (Family Q10)

"In our family, like others, having a child with epilepsy and ID has significantly limited the things we do. We have to plan vacations carefully ensuring that the environment and local health care facilities are appropriate for our daughter. Our unaffected daughter has not been able to participate in team sports like her peers due to the complexities of finding care for her sister or bringing her along to these events. We avoid social outings which involve large crowds or other highly stimulating environments due to risk of seizure trigger or emotional melt-down." (Family Q10)

⁵ NG refers to nasogastric feeding

5.4.2 FAMILY LIFE – THE EMOTIONAL BURDEN

The emotional toll on families, and on the relationship between parents, was vividly described by respondents.

“Causes a lot of stress between myself and my husband. When my daughter is being particularly difficult it can cause big arguments.” (Family Q10)

“Emotionally both my husband and I are worn down. Life can never be anywhere near what we would like it to be. All the difficulties that epilepsy and ID bring are ceaseless. Added to this are several formal complaints against our local Social Services (upheld), the SEN Tribunal and DLA Tribunal (we won). I resent having had to battle for what should have been offered without question.” (Family Q10)

Some families spoke of their feelings of isolation in supporting their child and the challenges of securing any external assistance.

“It restricts our lives very much, not being able to get out and socialise without our daughter, not enough outside help.” (Family Q10)

“It has had a very negative effect on family life. We are a very active sporting family but cannot engage in any activities all together. We are always split up. We seldom get out together as a couple. It is difficult to get someone confident enough to mind her. She has temper tantrums like a toddler and can be extremely difficult to cope with.” (Family Q10)

"Families across England are becoming more isolated and unsupported if they care for a person with learning disabilities." (Professional Q14)

Often families reported feeling tired as a result of lack of sleep or lacking support in the in carrying out their caring responsibilities. In a number of cases parents reported that they may need to sleep with their child due to nocturnal seizures.

"As a caregiver, you have to take full responsibility, for meds, safety, she is not capable of taking responsibility, or knowing danger." (Family Q10)

"Daughter is 23 years old and still needs one of us to be with her at night. Even with alarm she doesn't like being left alone. Not sure if this stems from previous years of night time seizures and she is afraid, but as she cannot express her feelings difficult to know. We get tired and rarely sleep together." (Family Q10)

"Due to nocturnal seizures and sleep disruption, my husband and I take turns sleeping with our daughter and hence, never sleep in the same bed, We rarely go out on "dates" because we don't want to take advantage of family members who already help us out on a regular basis." (Family Q10)

Some parents commented on the impact on siblings. They spoke of how the structure of their family had altered, with siblings taking more responsibility for caring work than the parents would like. Parents also reported feeling guilty at being unable to prioritise time with unaffected siblings.

“It is having a lot of impact on the family especially my two other children, most of the attention is on the little boy and they need my attention too. And most times I am tired with looking after the little one.” (Family Q10)

“It effects the time we can spend as parents with the other children due to the amount of time we need to spend with our disabled son and we are often exhausted most of the time as we have been up through the night and then don't function as well in the day.” (Family Q10)

“My older son has felt over the years that he doesn't get treated fairly as my daughter needs so much time and attention. He is now a teenager and understands better but at the time it was hard to explain or split the time so both got the love and attention they needed as I am a single parent. It also has a huge impact on the decision not to have any more kids as I feel it wouldn't be fair to have more when my time is already stretched.” (Family Q10)

Respondents also spoke of the emotional impact for those with intellectual disability and epilepsy who perceive that they place a burden on their family. This burden was largely within the context of the impact of their seizures on others.

“She is always apologizing after an episode which I find upsetting as she is a young girl of 21 years. She is loving and always concerned about the rest of us, making sure they have their home work done etc. or telling me to sit down and relax she will then make me a cuppa. I worry about the future what it holds for her.” (Family Q10)

“A couple of people have said to me that they feel that they are a burden on their parents because of their epilepsy mainly.” (Professional Q10)

5.4.3 FAMILY LIFE – FACILITATORS

Many respondents cited small interventions that had positive effects on the family. These facilitators included practical accommodations such as respite services, nocturnal seizure alarms, and stable medication regimens. Social support from family, schools, and medical staff was also highly valued by families.

*“The good things are the amazing support we have received from school and from her Dr.”
(Family Q10)*

Family members also described how they had come to terms with their own perceptions of disability, from their early frustrations on diagnosis through to ‘learning to live with it’.

“We had to change our whole lifestyle, instead of fighting to get him normal to fit in with everyone, we changed life so his disabilities appear normal in our lives, it has helped instil him with confidence in himself and his abilities.” (Family Q10)

“When it happens first it is very hard to diagnose without tests, etc, and they can be very traumatic on the child and the family members. Once it is diagnosed it is very hard to accept for the person/child involved and the family but as time goes on and the medication works you learn to live with it.” (Family Q10)

Many families commented on the positive effects of having a child with complex needs on the rest of their family. Some suggested that they now focused more on the important things in life and drew pleasure from small achievements, while others suggested that unaffected siblings had gained positively from the experience, developing into compassionate open-minded individuals. Some spoke of the unique characters of their disabled children and of the enjoyment gained from coming to know them as individuals.

“Of our 4 children, the 2 younger ones have disabilities and still live at home. As they have always been on the autistic spectrum, it is our normality and we just work around it. No one knows how our family life would be had things been otherwise. They are a real joy and not a burden. There are a number of activities we can all enjoy together.” (Family Q10)

“I think it has made us her parents and her siblings more tolerant and understanding of her and other peoples’ difficulties, and grateful for what we have got. It’s certainly made me less paranoid about her siblings’ progress and relative areas of weakness.” (Family Q10)

“There are some good things: we have learned to appreciate the small blessings in our life that we might otherwise take for granted. We have had the opportunity to participate in the advocacy community and have been able to help other families who are experiencing the same difficulties we are.” (Family Q10)

PROPOSED ACTION 18

The ILAE in conjunction with IBE should establish a Working Group to create greater awareness of the stigmatisation and burden on family members and provide guidance to epilepsy and intellectual disability agencies on how to optimally support families using practical solutions such as respite and family social clubs.

6. SUMMARY OF PROPOSED ACTIONS

This survey has given voice to the powerful experiences of individuals caring professionally, and as caregivers whether paid or family, for people with an intellectual disability and epilepsy. Respondents spoke of the challenges in receiving a timely and accurate diagnosis, and questioned the standard of medical care afforded to this population, with some feeling they received sub-standard care which they described as discriminatory. They described the challenges of supporting patients who were not deemed to have capacity to manage their own care, and described how communication difficulties pervaded clinical consultations. All parties commented on the complexity of many presentations of epilepsy among people with intellectual disabilities. Complex regimens were described which required careful monitoring and vigilance for side effects. An overarching theme across many responses was an endorsement for specialist care, ranging from epilepsy nurse specialists through to multidisciplinary teams. Joint working across both epilepsy and intellectual disability fields was valued. Training for those without expertise was called for, as were longer and more individually tailored consultations.

In addition to exploring the medical care afforded to people with intellectual disability who have epilepsy, respondents were also asked how they felt these conditions impacted on a range of life domains. Across areas including employment, education and social life, respondents spoke of isolation and stigmatisation. Many told of poor experiences with the educational system, and how employment options were extremely limited. Frequently respondents spoke of how teachers, employers and others within the mainstream of society were fearful and untrained to support a person with an intellectual disability who has epilepsy. This lack of societal awareness resulted in families vividly describing the impact on their home life, from parents who slept apart to siblings who were overshadowed. While many respondents spoke of how some individuals had provided exceptional support, these incidents were perhaps more by accident than of design. In combination,

the overwhelming majority of respondents identify a population in particular need of considerable support.

The survey has no meaning without action. The Proposed Actions throughout this report give a strong guide for such action. The implementation of these actions needs further leadership from both the ILAE and the IBE. The actions cross over many areas of epilepsy management and social care yet if implemented will provide an impetus for change and an endorsement of the ability of the ILAE and the IBE to listen for a change.

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APPENDIX A – KEY THEMES

Key area	Key theme	Sub themes/ points of import
Diagnosis/treatment/medication	1. Complex medical needs	1. Complexity of presentation
		2. Complexity of treatment
	2. Communication in the consultation	1. Communication with person with intellectual disability
		2. Communication/ information gained from caregivers
		3. Attitude of clinicians
	3. Accessing investigations	1. Consent
		2. Practical/logistical concerns
		3. Discrimination
		4. Positive impact of successful investigation
	4. Medication	1. New AEDs
2. Concern over side effects		
3. Rescue Medication		
5. Monitoring treatment	1. Quality of information from caregivers	
	2. Aspects of disability that inhibit effective monitoring Communication problems	

		Behaviour/seizure confusion
		3. Concern over side effect/ seizure balance
		4. Treatment plans
		5. Monitoring in primary care
	6. Knowledge transfer	1. Availability of information
		2. Quality of information
		3. Relevant and accessible information
		4. Unanswered questions
Service delivery	1. Specialist services	1. Multi-disciplinary working
		2. Epilepsy nurses
	2. Local access to services	1. Patchy/ location dependent
		2. Family access to local services
		3. Respite
	3. Primary care	1. Good GP
		2. Bad GP
	4. Time	1. Consultations too short
		2. Waiting lists too long
	5. Training	1. Skilled care delivery

Schooling and employment	1. Schooling and education	1. Restricted participation in everyday activities
		2. Educational provision and reluctance to tailor curriculum content
		3. Impact of epilepsy and intellectual disability on learning
		4. Positive adaptations
	2. Employment	1. Health and safety concerns
		2. Inappropriate support provision
		3. Stigma, discrimination and low expectations
		4. Practical problems
		5. Impact on parental employment
		6. Positive adjustments
Social, romantic and family life	1. Social activities and friendships	1. Concern over health and safety
		2. Practical issues
		3. Success
	2. Romantic lives	1. Stigma
		2. Practical/ logistical problems
		3. Vulnerability of population

		4. Facilitation
	3. Public perceptions	1. A negative reaction
		2. Social isolation and abuse
		3. Families as educators
		4. Making a change
	4. Family life and coping with complex needs	1. Practical concerns
		2. The emotional burden
		3. Adapting to the situation