

EpilepsyPOWER

Operational Framework and Learning Methodology Report: Knowledge Transfer, Literature Review and Target Groups Survey



Co-funded by
the European Union

This project has been funded with support from the European Commission. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

EpilepsyPOWER

Epilepsy People inclusion Overcoming Workplaces European maRginalization



2021-1-IT02-KA220-ADU-000028349

The goals of EpilepsyPOWER project aim at improving opportunities of inclusion in job market for people with epilepsy (PwE). The final objective is to increase the number of people engaged in relevant corporate social responsibility epilepsy-friendly initiatives; to spread a culture and a practice for the implementation of inclusion systems for epilepsy people, based on the enhancement and valorization of their abilities; support universities, companies, micro and small enterprises in inclusion improvement. EpilepsyPOWER project brings together 6 partners from 5 countries: Italy, Germany, Bulgaria, Ireland and France.

Project results

PR1: Operational framework and learning methodology - a methodological document guiding the development of PR2, PR3 and PR4. Its development will be preceded by knowledge transfer, literature review and target groups survey.

PR2: Integrated online platform for digital integrated learning, multilevel cooperation and resources sharing - innovative and integrated web platform with an attractive design and available in all partners' languages and a user-friendly project website.

PR3: Collaborative labs for best practices – their aim is to arrange specific discussion and working labs (onsite and online) to involve the staff of the Partners with the target groups and main stakeholders of EpilepsyPOWER project. Participants will evaluate and discuss PwE needs about their employability with a particular focus on work placement opportunities, safety in workplace and communication with employer/co-workers as emerged by previous project results and by the labs.

PR4: Learning contents and classroom guidelines – its main aim is to ensure a successful sectorial and country transmission by a cross-cultural approach. A preliminary analysis of the first version of the learning materials will be done during the "Collaborative labs for best practices" with invited target groups in each Partners' country. All the learning products developed during the EpilepsyPOWER project will be freely available online via the open access platform for everyone to use. This will be further facilitated by the fact that the 14 modules will be published online in 5 languages (EN, IT, DE, FR, BG).

PR5: Assessment online tool and epilepsy label – Considering that the project learning modules, available in each path, are designed and organised with a sequential logic, each participant should pass the specific module test to access to the next learning module of one of each learning path. The EpilepsyPOWER Certificate of Achievement is the final document that will certify the full completion of each learning path provided by the online platform. For organisations the responsible that will participate to the online assessment will receive the EpilepsyPOWER label that will be possible to use in own communication initiatives and on own University or company website.

EpilepsyPOWER - Final Report

1. INTRODUCTION	4
2. PARTNERS' KNOWLEDGE TRANSFER	6
2.1 Epilepsy	6
2.1.1 Definition	6
2.1.3 Classification of seizures	6
Focal onset seizures	7
Generalised onset seizures	8
2.1.4 Aetiology and Classification	8
2.1.5 Epilepsy Treatment	9
2.1.6 Epidemiology and social burden	9
3. LITERATURE REVIEW	11
3.1 Background	11
3.2 Employment rate of individuals with Epilepsy in Europe	12
3.2.1 Methods	12
3.2.1.1 Strategy research	12
3.2.1.2 Inclusion criteria	13
3.2.1.3 Study selection	14
3.2.1.4 Employment status	14
3.2.2 Results	14
3.2.2.1 Employment status and rate of unemployment.	14
3.2.2.2 Factors contributing to unemployment and underemployment	16
3.2.2.3 Underemployment and lower salaries	17
3.2.2.4 Factors favouring employment	18
3.2.2.5 Long term outcomes and specific conditions	19
3.2.2.6 Disclosure issue	20
3.2.2.7 Employers and colleagues' attitudes	20
3.2.3 Employment programmes and interventions for PwE in Europe	21
3.3 Discussion	21
4. SPECIFIC TARGET GROUP SURVEYS	23
4.1 Introduction	23
4.2 Methods	23
4.3 Results	24
4.3.1 Overall questions	24

4.3.2 PwE’s surveys	24
4.3.3 HEI surveys	35
5. STATE OF THE ART OF THE INCLUSION SYSTEMS IN COMPANIES IN EACH PARTNER COUNTRY	43
5.1 Italy	43
5.1.1 Current situation	43
5.1.2 National Legislation	43
5.2 Bulgaria	44
5.2.1 Current situation	44
5.2.2 National Legislation	50
5.3 Ireland	52
5.3.1 Current situation	52
5.3.2 National Legislation	52
5.4 Germany	53
5.4.1 Current situation	53
5.4.2 National Legislation	56
5.5 France	58
5.5.1 Current situation	58
5.5.2 National Legislation	59
6. “Study on the recent research and advances on the impact of epilepsy in the workplace” in each partner country	63
6.1 Italy	63
6.1.1 Projects and initiatives	63
Position Paper	63
Narrative Medicine Project	63
6.2 Bulgaria	64
6.2.1 Projects and initiatives	64
6.3 Ireland	70
6.3.1 Projects and initiatives	70
6.4 Germany	73
6.4.1 Projects and initiatives	73
6.5 France	76
6.5.1 Projects and initiatives	76
7. ANALYSIS OF PROJECT TARGET GROUPS OF LEARNING FEATURES AND NEEDS	78
8. TWO KEY PERFORMANCE INDICATORS (KPI)	81

Stigma	81
Seizure severity	81
9. SUCCESSFULLY INCLUSION CASES FOR EACH PARTNER COUNTRY	83
Italy	83
Case N.1	83
Case N.2	83
Bulgaria	84
Case N.1	84
Case N.2	84
Ireland	85
Case N.1	85
Case N.2	86
Germany	87
Case N.1	87
France	88
Case N.1	88
Case N.2	90
Case N.3	91
10. BIBLIOGRAPHY	93

1. INTRODUCTION

Epilepsy is a chronic neurological disease that affects 0.4-1 per 100 people worldwide. The number of adolescents, students and working-age adults with active epilepsy in Europe is estimated at 3 million people (Forsgren et al., 2005). Epilepsy is characterised by recurrent seizures, which are brief episodes of cognitive impairment or involuntary movements of a part of the body or the entire body and are sometimes accompanied by loss of consciousness and control of bladder. Since seizures manifest often unpredictably and do not remain hidden in the social context, epilepsy is a disruptive condition associated with great barriers and low social acceptability that strongly interferes with employability. Half of the people with epilepsy (PwE) report feeling stigmatised, have a salary equal to half of those of the general population and often have greater difficulty keeping their jobs. Consequently, they have higher rates of unemployment, underemployment and bad utilisation.

Half of PwE workers conceal their condition to potential employers when applying for jobs, since they are afraid of discrimination.

Many employers refuse to hire workers with epilepsy because they mistakenly believe that they are more susceptible to work-related injuries and absenteeism from work. Job restrictions imposed on PwE are mostly unfair and based on prejudices and misconceptions. These factors could be successfully overcome through an improvement of education of adult people involved in the higher education institutions (HEI) and job market. At the same time, a deeper education of PwE on epilepsy-specific medical risks linked to the job environment could lead them to a more informed and accurate choice of the most suitable job for their own medical condition.

The ambitious objectives of EpilepsyPOWER project aim at improving PwE opportunities of inclusion in the job market. The final objective is to increase the number of people engaged in relevant corporate social responsibility epilepsy-friendly initiatives; to spread a culture and a practice for the implementation of inclusion systems for PwE, based on the enhancement and valorisation of their abilities; support universities, companies, micro and small enterprises in inclusion improvement.

The core organisations involved in it bring in experience from South of Europe – Italy, East – Bulgaria, Central – Germany, as well as from North Europe – Ireland.

Through the project, partners will achieve their main objective to improve and widen the services they provide to their usual end-users. Luiss, Campus-Bio-Medico and Grenoble Universities will improve their formative offers through specific learning modules on disability management and epilepsy, for both higher education students and MBA/executive managers. The epilepsy patient's association (Epilepsy Alliance Europe, EAE) will promote good

practices concerning one of the main determinants of the life quality of patients themselves. The Chamber of Commerce of Vratsa and Emcra consulting company will promote the recruitment opportunities of PwE in their associated companies and networks. Throughout the project, partners will reach their third mission, promoting the inclusion of a numerous group of marginalised people, widening the educational offer of their usual customers. The proposed multidisciplinary approach (patients, physicians, professors, researchers, managers, lawmakers, etc.) related to the issue of workplace inclusion of disadvantaged people will help Partners to spread through their learning contents an innovative and more sustainable way of workplace inclusion for people with epilepsy.

2. PARTNERS' KNOWLEDGE TRANSFER

2.1 Epilepsy

2.1.1 Definition

Epilepsy is a common neurological disorder characterised by “an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure”.

An epileptic seizure can be defined as the occurrence of a transient symptom.

The International League against epilepsy task force proposed a practical definition, to facilitate epilepsy diagnosis, “Epilepsy can be considered to be a disease of the brain defined by any of the following conditions: (1) At least two unprovoked (or reflex) seizures occurring >24 h apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome” (Fisher et al., 2014).

2.1.2 Seizures

A seizure is defined as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2005).

Symptoms occurring during the seizures could be different, depending on the brain area involved.

Seizures can be provoked and unprovoked. A seizure provoked by a transient insult to the brain, does not allow an epilepsy diagnosis (e.g., seizure provoked by brain injury). This condition differs from any disorder providing the brain an enduring predisposition to make seizures (e.g., brain tumour/focal dysplasia). Thus, we cannot diagnose epilepsy when a provoked seizure occurs, since it represents a reversible condition linked to an acute insult.

2.1.3 Classification of seizures

Basing on clinical manifestations and on neuronal network involved seizures can be classified as follow:

- focal onset seizures;
- generalised onset seizures;
- seizures with unknown onset.

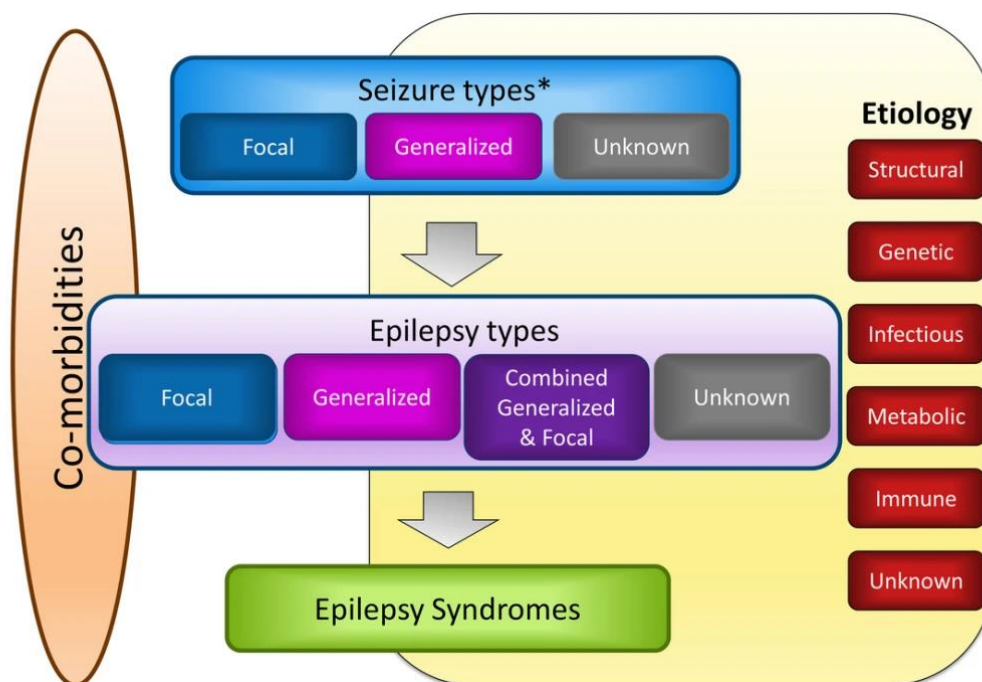


Figure 1 - Framework for classification of the epilepsies (Fisher et al., 2017)

Focal onset seizures

Focal onset seizures originate in a single hemisphere in a cortical and/or subcortical area. One relevant feature of focal seizures is impairment of awareness. Awareness can be defined as “knowledge of self and environment”. Thus, among focal seizures we can distinguish:

- focal aware seizures: self-knowledge and capacity to interact with environment are preserved;
- focal seizures with impaired awareness: with impairment of self-knowledge and interaction with the environment.

Further classification of focal seizures, imply a distinction between focal seizures with motor onset/non motor onset.

Focal motor onset behaviours include these activities: atonic (focal loss of tone), tonic (sustained focal stiffening), clonic (focal rhythmic jerking), myoclonic (irregular, brief focal jerking), or epileptic spasms (focal flexion or extension of arms and flexion of trunk).

Non motor focal seizures comprehend: sensory seizures (somatosensory, olfactory, visual, auditory, gustatory, hot–cold sense, or vestibular sensations), cognitive seizures (deficits in language, déjà vu, jamais vu, hallucinations, illusions, and forced thinking), autonomic seizures (gastrointestinal sensations, a sense of heat or cold, flushing, piloerection (goosebumps), palpitations, sexual arousal, respiratory changes), emotional seizures (manifesting with fear, anxiety, agitation, anger, paranoia, pleasure, joy, ecstasy, laughing (gelastic), or crying (dacrycitic)).

Another type of seizure mentioned in ILAE's classification is focal to bilateral tonic-clonic seizure: this kind of seizure starts as a focal one, but seizure activity rapidly propagates to both hemispheres.

Symptoms can be pathognomonic of a specific pathway involved in some occasion.

Epilepsy and seizures mainly reflect dynamic processes related to brain circuits involved in the disorder.

Generalised onset seizures

Generalised seizures derive from pathological and simultaneous activation of both the brain hemispheres, most of them imply impairment of awareness. This kind of seizures can be classified in:

- motor: tonic-clonic, clonic, tonic, myoclonic, myoclonic-tonic-clonic, myoclonic-atonic, atonic, and epileptic spasms;
- non-motor (absences typical and atypical).

Differential diagnosis between generalised onset and focal onset seizures may be difficult, thus further diagnostics exams, as electroencephalogram and MRI could be useful for distinguishing them.

If the onset is not clear, seizures may be defined as unknown onset seizures.

2.1.4 Aetiology and Classification

A wide range of causes can explain epilepsy, thus, in order to facilitate the diagnosis, we can use EEG and MRI. The ILAE proposed an etiological classification involving 6 different types of epilepsy:

1. structural epilepsy: a structural abnormality of the brain (genetic or acquired) can justify the increased risk of presenting a seizure (stroke, trauma, cortical dysplasia etc)
2. genetic epilepsy: seizures derive from the effects of a genetic mutation (known or presumed) (e.g., mutation of KCNQ2)
3. infectious: seizures occur because of an acute infection as meningitis/encephalitis.
4. metabolic: some metabolic disorders, often with a genetic base, could explain the predisposition to present seizures.
5. immune: it derives from a specific inflammation of central nervous system
6. unknown: it means that the cause of the epilepsy is not yet known.

2.1.5 Epilepsy Treatment

Epilepsy treatment is preventive, not curative: in most cases, it is based on medical therapy. Anti-seizure medications do not treat the disorder, but they are used to reduce the risk of seizure recurrence.

First anti-seizure medications were discovered at the beginning of 1900. We dispose of more than 20 antiseizure medications. Neurologists can choose among all those medications, tailoring the therapy on individual characteristics (sex, age, syndrome), comorbidities, and concomitant therapy. Usually, they start with a single drug, but sometimes they need to take more than one drug to control seizures (Glauser et al., 2013).

About 30% of people with epilepsy fail to control seizures with adequate trials of two antiseizure medications, chosen appropriately and well tolerated (Kwan 2011).

Treatments for drug-resistant epilepsy include:

- surgery (therapeutic or palliative)
- Deep brain Stimulation
- Vagal Nerve Stimulation
- Ketogenic diet.

2.1.6 Epidemiology and social burden

Epilepsy incidence worldwide reaches 61.4 per 100,000 population per year, it varies with age and has two peaks in childhood and older age.

Epilepsy also leads to higher disability, increased mortality, morbidity, stigma, and social costs (Beghi, 2020). Although advances in diagnosis and therapy (surgical and pharmacological) allow the vast majority of PwE to reach seizure control (about 70%), social integration is still hard to manage. Epilepsy is a complex and heterogeneous disorder affecting numerous and different aspects of an individual life. Cognitive functioning may be impaired by disease or by the effects of anti-seizure medications, thus people with epilepsy often gain low educational attainment and they become under-skilled. Driving restrictions contribute to stigma, reduced quality of life and underemployment. Epilepsy impairs even social integration, social status and marital status.

Another relevant factor is the presence of psychiatric comorbidities, more common than in the general population, as anxiety and depression (Keezer et al., 2016).

Beyond internal factors, we might mention external barriers in particular stigma (perceived and enacted), false myths, misconceptions, ignorance, low social and family support.

Epilepsy *per se*, leads to increased costs, especially as regards long-term medical and surgical treatments. Indirect costs are linked to unemployment, but loss of earnings may be difficult to estimate.

All these factors, together with the unpredictability of seizures and poor seizure control, represent the reasons behind an impaired quality of life, difficult social integration and an increased marginalization of people with epilepsy (Beghi, 2016; Keezer et al., 2016; Kerr, 2012).

3. LITERATURE REVIEW

3.1 Background

Epilepsy is a common neurological disorder, affecting all aspects of individual life, including social integration. Seizures represent only a small piece of the complex and heterogeneous picture of this disorder. Indeed, side effects of drugs, psychiatric comorbidities, and cognitive deficits, belong to individual characteristics that increase the burden of epilepsy (Bautista et al., 2014; Beghi, 2020). All these factors negatively impact educational attainment and employment.

On the other hand, false beliefs, misconceptions and employers' concerns contribute to unemployment in PwE (Collings & Chappell, 1994; Gloag, 1985; Jacoby et al., 2005).

Thus, we can describe the employment situation in PwE as a combination of internal factors (seizures, cognitive deficits, etc.) and external factors (stigma, employer's attitudes, etc.).

Indeed, despite good seizure control, unemployment is far more common in people with epilepsy than in the general population.

Although epilepsy is one of the most common neurological disorders and accounts for the highest disability adjusted life years, among neurological disorders (Beghi, 2020), lack of specific legislation and of inclusion programs, make the employment integration difficult.

Three main exceptions must be cited: the Americans with Disabilities Act (ADA) in the USA, the Health and Safety at Work Act (1974) and the Equality Act (2010) in Europe.

Employment is one of the main determinants of economic independence, self-worth, and individual identity. Being unemployed prompts lack of independence, reduced self-esteem, increased feeling of stigma and, consequently, lower quality of life (Jahoda & Marie, 1982).

Unemployment can contribute to emotional and behavioural problems in people with epilepsy (Taylor et al., 2011).

One strategy to improve employment of people with epilepsy is to develop programmes to provide them information to seek the most appropriate job, fighting misconceptions and ignorance in the workplace. Nishida recently demonstrated that the risk of seizure-related accidents is comparable to that of injury not related to seizures (Nishida et al., 2020).

Even if absenteeism and accidents are not higher in employees with epilepsy, PwE salaries appear to be lower than ones of the other colleagues (Lassouw et al., 1997).

Although studies demonstrated a higher risk of accidents among PwE, we might notice these injuries in the workplace are not related to seizures (Cornaggia et al., 2006). Although many authors attempted to describe the employment situation worldwide (Bautista et al., 2014; Smeets et al., 2007; Wo et al., 2015), estimating the real rate of unemployment is still challenging.

Epilepsy can be a “hidden condition” and people with epilepsy can conceal their disease to employers, because of fear or stigma, even if this can be interpreted as a break of trust (Jacoby et al., 2005). Therefore, another key issue of employment is disclosure. In order to define the employment in Europe, we made a systematic review considering articles about employment in people with epilepsy and factors influencing their employment.

3.2 Employment rate of individuals with Epilepsy in Europe

3.2.1 Methods

3.2.1.1 Strategy research

We searched on Pubmed and GoogleScholar articles about epilepsy and employment. Our search string was composed as follows: “Epilepsy AND Employment OR Job OR Work”. We used the RAYYAN review system to screen a total of 7272 articles.

Using the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines, we performed a systematic review on epilepsy and employment (Liberati et al., 2009). We selected 55 articles from 1958 to 2022, excluding those with the wrong type of publication (20) or wrong population (30).

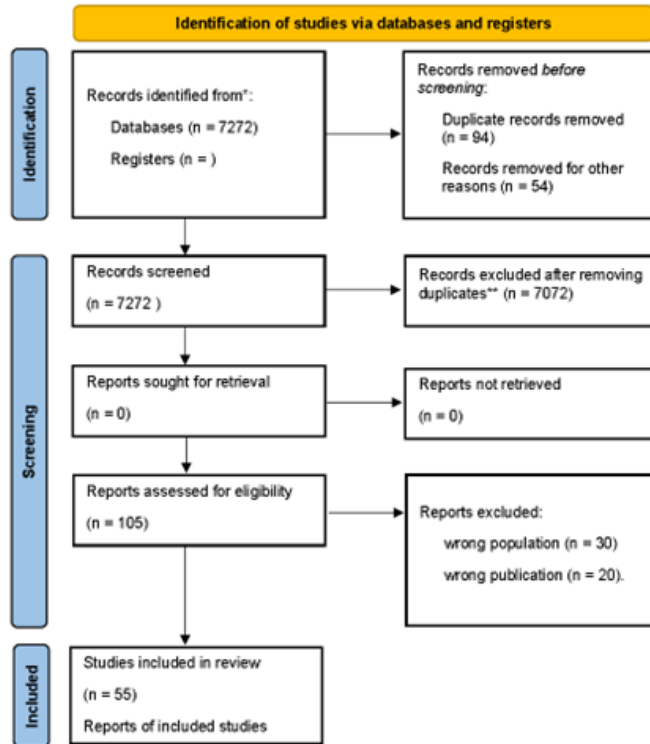


Figure 2 Preferred Reporting Items for Systematic Reviews and Meta-analyses method

We divided those articles between papers reporting employment status and papers only describing factors contributing to employment and unemployment. We also considered particular cases: PwE undergoing to brain surgery and people with specific syndromes (e.g., childhood onset epilepsy). We finally evaluated, as part of external factors contributing to unemployment, articles analysing employer's attitudes.

3.2.1.2 Inclusion criteria

We included articles in English, excluding those written in other languages. We included articles regarding people living in Europe and the UK, since it is part of the geographic area of the European Union and even politically included in the EU until 2020.

We have even considered articles about surgical outcomes and specific syndromes (myoclonic epilepsy, childhood onset epilepsy, absence epilepsy).

3.2.1.3 Study selection

Papers were screened using the Rayyan review system. We have screened articles on the title and the abstract. We selected all papers containing employment and/or employed in title or in the abstract.

Two reviewers read all the articles and categorized them as follows:

- 41 articles reported employment status (6 included surgical PwE);
- 6 articles about surgical outcomes;
- 4 articles reporting employer's attitudes;
- 7 articles reporting factors contributing to employment/unemployment;
- 6 articles mentioned disclosure issue;
- 3 articles regarded special situations: childhood onset epilepsy, absence epilepsy and myoclonic epilepsy (JME).

3.2.1.4 Employment status

Selected articles considered different sample size and they often did not report the specific rate of employment/unemployment. Some articles considered unemployment in different conditions such as housewives, receiving disability pension, etc. For all these reasons, the evaluation of the real rate of unemployment was not clear, so we decided to divide articles between those reporting the same rate of employment/unemployment compared to the general population, and articles reporting a different rate.

3.2.2 Results

3.2.2.1 Employment status and rate of unemployment.

Rates of unemployment among PwE were different around Europe.

Most of the articles screened were from the UK (12), other articles analysed the situation in the following countries: Netherlands (6), Germany (5), Sweden (4) Estonia (3) and Spain (3) Ireland (2), Denmark (2), Poland (2) Finland (2).

Only some articles reported the comparison with the general population.

SIMILAR RATES: Scambler in 1980, throughout an interview in general practitioner studies, managed to describe the following employment situation in UK: 31/42 (74%) of men in working age, 6/19 (32%) of married women and 5/12 (42%) of unmarried women were employed, with respective rates in general population 81% (men); 48% (married women); and 42% (unmarried women) (Scambler & Hopkins, 1980).

A lot of studies conducted by Ann Jacoby have analysed the employment situation in the UK in the 90s, both from the employers and employees' point of view (Jacoby, 1992, 1995; Jacoby et al., 2005). Among those studies, in 1992 and 1995, they demonstrated in people with well-controlled epilepsy a similar rate of employment compared to the general population.

In 1992, the employment rates were 91% of men and 74% of women under 60; of those unemployed only 3% reported epilepsy as the main reason (Jacoby, 1992).

Similar results were described in 1995: among 494 PwE in working age 71% employed, 26% unemployed and 3% of those unemployed reported seizures as the reason of unemployment (Jacoby, 1995). In more recent years, Herodes and Rätsepp both demonstrated similar rates of unemployment compared to general population in Estonia (Herodes et al., n.d.; Rätsepp et al., 2000). Even Geerts reported similar rate of employment compared to general Dutch population in a follow-up survey conducted among people with childhood onset, regardless the syndrome or the specific kind of epilepsy: idiopathic epilepsy 91.5%, symptomatic epilepsy 91.3%, cryptogenic epilepsy 97.1%, epilepsy in remission 93.2%, active epilepsy 91.2%, all compared with Dutch age peers 92.0% (Geerts et al., 2011). Recently, in a cross-sectional multicentric epidemiological study in Spain similar rates of employment and unemployment were evidenced in PwE compared to the general population. (Marinas et al., 2011). Finally, even in specific cases, considering surgical treatment outcomes, Reinholdson showed that PwE seizure free with IQ>70 gain the same level of employment of the general population (Reinholdson et al., 2020).

DIFFERENT RATES: In 1992, Callaghan described the employment situation in Ireland in a population of 343 PwE: 34% of males 28% of females were unemployed; 53% of males and 24% of females were gainfully employed; 1% of males and 41% of females did house duties; 8% of males and 7% of females were involved in sheltered employment; 4% of males and <1% of females were retired. They also compared rate of unemployment of men (34%), with that of the general population (14%) in the same years and highlighted higher underemployment in people with epilepsy (Callaghan N, 1992).

Even Collings et al reported a rate of unemployment of 12% compared to 9% of national unemployment rate in the UK in 1994. (Collings & Chappell, 1994)

Recently, Kourchounov evidenced a higher rate of unemployment in PwE in Germany, despite the promulgation in 1996 of the Law on Support of Employment (LSE) (Korchounov et al., 2012). Eldevik compared in a prospective longitudinal Swedish study the rate of employment of seizure-free patients after surgery: in the general population, 65% to 71% of those between 25 and 54 worked full time, compared to the 36% in seizure-free patients 5 years after surgery and the 65% 10 years after surgery (Edelvik et al., 2015)

As regards Poland, Majkowska demonstrated lower rates of employment in PwE (49%) compared to that of Polish and European population (59,3% and 64,6% respectively). (Majkowska-Zwolińska et al., 2012)

3.2.2.2 Factors contributing to unemployment and underemployment

In general, factors contributing to unemployment and determinants of employment are multiple and different, but we can posit that unemployment and underemployment in PwE derive from a combination of external and internal factors.

Internal factors comprehend individual characteristics, clinical features and self-concepts.

Work atmosphere, knowledge and employers' attitudes represent main external determinants of employment status in epilepsy.

Among individual factors, **younger age** and **early onset of disease** seem to affect the capability of searching and gaining a good job position (Gordon & Russell, 1958; Herodes et al., n.d.; Jennum et al., 2021; Walther et al., 2018).

Other studies reveal opposite results: in a Finnish study, Sillanpää evidenced that onset at age >6 is one factor promoting good employment in PwE (Sillanpää & Schmidt, 2010).

Indeed, Geerts et al, in recent years revealed that **childhood-onset epilepsy** is strictly connected to lower educational attainment which represents a possible cause of lower job attainment (Geerts et al., 2011).

On the other hand, Haag demonstrated that **older people** had lower probability of being employed. Similar results were demonstrated by Jacoby et al in 1996 in a large cohort study in the UK (Jacoby et al., 1996).

When taking in account clinical factors, the most important determinants of a good employment are **seizure freedom** and **seizure remission**. Multiple studies reported seizure severity as the main explanation for the unemployment situation in PwE: in 1992, Jacoby focusing on a population of well-controlled PwE, stated that active epilepsy (seizures occurring in the last 2 years) affected employment conditions (Jacoby, 1992). Three years later, the same group established in a similar population that seizure severity, frequency and controllability were correlated to employment in PwE (Jacoby, 1995).

Refractory epilepsy may impair long term social outcomes of PwE, including employment (Marinas et al., 2011). On the contrary, seizure remission and having no history of status epilepticus are positive factors in people with childhood onset epilepsy (Sillanpää & Schmidt, 2010)

Later, other authors demonstrated that **higher seizure frequency** was linked to unemployment (Chaplin et al., 1998; Geerlings et al., 2015; Herodes et al., n.d.; Jacoby, 1995;

Majkowska-Zwolińska et al., 2012; Rätsepp et al., 2000; Reinholdson et al., 2020; Scambler & Hopkins, 1980). When considering long-term outcomes, since **treatment with anti-seizure medications** prompts seizure control and in most cases seizure freedom, it is another clinical factor connected to employment (Jennum et al., 2011; Schneider-Von Podewils et al., 2014). Even seizure type influences employment: tonic-clonic seizures are related to a worse employment status (Jacoby, 1995; Schneider-Von Podewils et al., 2014).

Another relevant factor is **cognition**: cognitive deficit and intellectual constraints impair job attainment consistently (Geerlings et al., 2015; Gordon & Russell, 1958; Thompson & Oxley, 1988). Even school difficulties and lower education contribute to unemployment (Mclellan, 1987; Mireia et al., 2021).

Other aspects, such as **psychiatric comorbidities** (Mireia et al., 2021; Pond & Bidwell, n.d.; Sillanpää & Schmidt, 2010), in particular, anxiety and depression (Jacoby, 1995; Mclellan, 1987; Mireia et al., 2021) impair employment in PwE. Even **polytherapy** can affect employment status and quality of life (Haag et al., 2010; Marinas et al., 2011).

Attitudes of employers and **stigma** belong to external factors contributing to unemployment. Indeed misconceptions, false myths surrounding PwE prompt discrimination from employers and self-denial of employees in workplace (Chaplin et al., 1998; Scambler & Hopkins, 1980; Thompson & Oxley, 1988).

Employers' attitudes and unsupportive familiar environment can hamper gaining a good employment position (Elwes et al., 1991; Geerlings et al., 2015; Jacoby et al., 2005; Thompson & Oxley, 1988).

Limits posed by specific work issues, such as working with machinery or driving licence restrictions can affect employment status in PwE (Elwes et al., 1991; Schulz et al., 2013).

To summarise, we can refer to Gloag's paper in which he highlighted three aspects impairing job position in PwE: the hazards posed by some jobs in case of seizures; anxiety and prejudice on the side of employers and fellow workers; behavioural and mental abnormalities (Gloag, 1985)). Geerlings et al., have also drawn a specific predicting risk profile scores made up of unsupportive family environment, lower intelligence, and higher seizure frequency and ongoing seizures (Geerlings et al., 2015).

3.2.2.3 Underemployment and lower salaries

Some papers, even if they have not reported higher unemployment, evidenced disadvantages for PwE in the workplace. In particular, some of them evidenced that PwE earned lower salaries (Jennum et al., 2011; Lassouw et al., 1997), some other articles demonstrated that PwE were underemployed compared to general population (Callaghan N, 1992; Olsson &

Campenhausen, 1993; D. P. Shackleton et al., 2003). This may derive from lower educational attainment (Geerts et al., 2011), employers' attitudes, misconceptions and self-denial.

3.2.2.4 Factors favouring employment

Employment is favoured by factors opposite than those described previously. Indeed, one of the most reported factors favouring employment is seizure remission or good seizure control (Beghi et al., 2000; Chaplin et al., 1998; Collings & Chappell, 1994; Majkowska-Zwolińska et al., 2012; Sillanpää & Schmidt, 2010). Some experiences in Ireland, UK and Belgium, demonstrated that **training and job and counselling** favour employment of PwE more than other factors (Carroll, 1992; Chaplin et al., 1998; SOREL, 1972) Indeed, **good education** allows PwE to reach higher levels of school and job attainment (Edelvik et al., 2015; Graham Jones, 1965; Herodes et al., n.d.; Koponen et al., 2007; Rätsepp et al., 2000). A good atmosphere at work made up of good relationships and good individual perception make being employed more likely (Collings & Chappell, 1994; Graham Jones, 1965). As stated before, even clinical factors as **lower number of antiseizure medications** contribute to a good employment situation (De Boer, 2005). As a matter of fact, people with **normal intelligence** are prone to get a better education, and, consequently, a better employment position (Reinholdson et al., 2020; Sillanpää & Schmidt, 2010; SOREL, 1972). Focusing on specific functions, Partanen demonstrated that better working memory and better executive functions were associated with improvement in employment status in surgical patients (Partanen et al., 2022).

As declared in the previous paragraph, employment status is strictly connected to **seizure control and seizure freedom** (Chaplin et al., 1998; Edelvik et al., 2015; McLellan, 1987; Schulz et al., 2013; SOREL, 1972; Walther et al., 2018). Finally, having a driving licence also contribute to independence and, so, it improves employment situation in PwE (Schulz et al., 2013)

When considering long-term outcomes, surgery has modest but significant influence on employment status in surgical candidates (Carreño et al., 2008; Dupont et al., 2006; Walther et al., 2018).

Taking in account external factors, apart from employers' attitudes, promulgation of laws favouring inclusion of PwE in the workplace represent one of the most relevant determinants supporting employment, as evidenced in Germany (Korchounov et al., 2012).

3.2.2.5 Long term outcomes and specific conditions

When analysing specific conditions as:

- In Sweden Olsson analysed long-term outcomes in people with absence epilepsy. In about 74% of cases, epilepsy impaired social aspects such as schooling, occupation, relationships, regardless of seizure control (Olsson & Campenhausen, 1993).
- Peña et al, focused on a population of people with refractory epilepsy, demonstrating lower outcomes in people with higher scores of anxiety and depression (Peña et al., 2009)
- Two studies focused on outcomes of people with childhood-onset epilepsy: Geerts et al evidenced lower job attainment of people with childhood onset epilepsy, despite remission (Geerts et al., 2011). On the other hand, Sillanpaa et al demonstrated better employment outcomes in people with normal intelligence, onset of epilepsy >6 years old, good vocational education, uninterrupted remission and no history of status epilepticus (Sillanpää & Schmidt, 2010).
- Reinholdson et al proved that outcomes after surgery in childhood depend on normal intelligence, seizure freedom and higher age at surgery (Reinholdson et al., 2020). Even Partanen in Finland revealed that normal cognitive functions are correlated with better social outcomes after surgery (Partanen et al., 2022).
- Edelvik evaluated long-term outcomes after resective surgery: younger people, seizure-free patients and people employed/studying at baseline develop better outcomes (Edelvik et al., 2015).
- In cases susceptible of surgical treatment, surgery seems to improve employment status in PwE: indeed, we can arrive at this conclusion comparing outcomes in people who do not undergo surgery (Carreño et al., 2011) and people who undergo surgery (Dupont et al., 2006). Extratemporal surgery leads to a better quality of life, and, consequently, a better psychosocial outcome, especially in people gaining seizure freedom (Walther et al., 2018).
- Schneider-von Podewils drew the special situation of people suffering from Janz syndrome: they evidenced that a higher number of GTC seizures was associated with a worse outcome (Schneider-Von Podewils et al., 2014).
- Dupont focused on surgery in Medial Temporal Lobe Epilepsy, demonstrating the intrinsic positive value of surgery on employment status (Dupont et al., 2006).

3.2.2.6 Disclosure issue

Even if it was not our primary aim, we cannot leave unmentioned papers that shed light on a tricky matter, as disclosure. Most people with epilepsy fear discrimination and bad consequences when revealing their condition, thus they frequently conceal their disease especially if they are well controlled (Collings & Chappell, 1994; Jacoby, 1992; Pond & Bidwell, 1960). Frequently, they are worried about not getting a job, or being fired or demoted. In different studies, about one half or one third of the population examined did not disclose their condition (Graham Jones, 1965; Majkowska-Zwolińska et al., 2012; Scambler & Hopkins, 1980). Later in 1997 Lassouw, evidenced that in a Dutch working population 77% of respondents disclosed their disease, although they refused to answer questions about epilepsy impact on their job (Lassouw et al., 1997).

3.2.2.7 Employers and colleagues' attitudes

Concerning external factors, employers' standpoint seems to influence employment status and workplace atmosphere.

Some studies focused specifically on employers' attitudes, and they try to define them throughout surveys or questionnaires.

John and McLellan interviewed a group of employers, highlighting prejudice, lack of knowledge and concerning of employers in the Southampton area, especially as regards handling machinery. (John & McLellan, 1988) This may represent one of the most relevant obstacles for PwE in obtaining a job.

After this, in 1995, Cooper evidenced little knowledge and understanding of epilepsy in a population of epilepsy among employers. They also complained of a lack of means to include PwE in the workplace (Cooper, 1995).

In UK, Jacoby evidenced, throughout surveys, sources of concerns of employers when employing PwE: feelings of other employers when witnessing a seizure (73%), increase employer liability insurance costs (42%), disruption of workflow (38%), reduction of other employees' concentration levels (22%), reduction of company efficiency (14%), refusal of other employers of job assignments (12%). As regards disclosure, employers have also declared that even when in remission, people should declare their disease (Jacoby et al., 2005).

Finally, in 2014 in Poland Dorota developed a questionnaire for employees divided into three attitude components: knowledge, emotions and behaviour. Lowest scores were reached in knowledge subscale, whereas better scores in emotions component (Dorota et al., 2014).

3.2.3 Employment programmes and interventions for PwE in Europe

In Europe, little experience about inclusion programs was reported. In 1992, Carroll et al demonstrated the usefulness of a rehabilitation program in the Irish population: 58% of the population considered, had found employment at the end of the program. Furthermore, about 66% of the population surveyed thought that programs are useful to develop self-confidence and social skills (Carroll, 1992).

Even in Sweden, Wedlund demonstrated improvement in work and education participation in 38 among 124 PwE participating in a rehabilitation program (Wedlund et al., 2012).

3.3 Discussion

Although different rates of employment and unemployment are reported in literature, a clear disadvantage among conditions emerge from all European studies. Indeed, recent studies (Edelvik et al., 2015; Korchounov et al., 2012; Majkowska-Zwolińska et al., 2012) have demonstrated higher rates of unemployment in Germany, Sweden and Poland. Nonetheless similar rates of employment can be attained, PwE often experience underemployment or disadvantages as lower salaries, as a result of lower educational attainment, lack of protecting policy, stigma, false myths and employer attitudes (Callaghan N, 1992; Geerts et al., 2011; Jennum et al., 2011; Lassouw et al., 1997; Olsson & Campenhausen, 1993; D. Shackleton et al., 2003).

As for factors contributing to unemployment and favouring employment, contrasting results are shown regarding age and age of onset. Concerning clinical factors, unsurprisingly, seizure control is the most relevant and the most reported determinant of a good job position for PwE. Whether reached through drugs or surgery, control of disease and seizure remission are related to a better attainment in all social aspects (job, marriage, etc.). Seizure free people can live a “normal” life, without limitations, as for driving, cognition, marriage, and employment. They can get a good educational attainment, also they can aspire to the right job position.

Even stigma and external attitudes, both from ignorant employers and unsupportive families hamper job attainment and quality of life of PwE. Misconceptions and restrictions related to epilepsy represent one of the explanations of perceived stigma in PwE. This feeling is eradicated in PwE and influences all aspects of daily life, leading to reduced ambitions and limits in job attainment, because of low self-esteem.

On the other hand, we should consider factors favouring employment. Studies have shown that employment rehabilitation programs and education are the most important determinants, especially in those with normal intelligence and absence of psychiatric comorbidities.

Thus, we can conclude that the formula to reach a good job position for PwE is made up of different factors: seizure control, normal IQ and good education, together with rehabilitation programs all lead to gaining the desired job position.

Epilepsy can remain as a hidden condition, thus the tendency is to not disclose the condition at work, unless necessary, even if this could represent a break of trust for most employers (Jacoby et al., 2005). Actually, most of PwE can work normally and would not present any seizure at work. A good atmosphere could favour disclosure of disease for PwE. This is one of the indications provided by IBE in the leaflet published in 2007. Other principles indicated that: PwE should have equal opportunities and should not experience "blanket restrictions", most of seizures do not impair working capability, whenever required personal information should be apart from job application, if a seizure occurs at work PwE should be provided with appropriate medical treatment, and, if re-employment is necessary because of the disease, rehabilitation programs should be available¹.

¹ <https://www.ibe-epilepsy.org/downloads/Employment%20Guidelines.pdf>

4. SPECIFIC TARGET GROUP SURVEYS

4.1 Introduction

In connection with the results from the research and the lack of sufficient information by official sources on crucial aspects regarding the employment of PwE, we realised two specific types of surveys for each target group.

The first target comprehends PwE, whereas the second one includes High education institutions' (HEI) staff and end users: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, adult people employed in organisations, recruiters, HR experts and recruitment agencies.

The survey for PwE was developed to explore employment opportunities and experiences of PwE in the workplace.

The survey for HEI concerned general knowledge about epilepsy and the individual relationship of HEI with PwE.

4.2 Methods

We used SurveyMonkey to develop two anonymous surveys.

Each survey has been created in English and then translated in each partner specific language: Italian, French, Deutsch, and Bulgarian.

We shared surveys sending emails and using official channels of ILAE Chapter (e.g. LICE site) and associations for PwE to promote them.

Even for HEI we shared surveys sending emails and using University channels (e.g. UCBM website).

The survey for PwE was made up of questions about demographic features (age, sex and residing country), clinical data (number of antiseizure medications (ASMs), seizure frequency, type of seizures), educational and job attainment, issues in workplace (disclosure, stigma, level of satisfaction).

The survey for HEI was made up of questions about demographic features (age, sex and residing country), understanding of epilepsy and its impact, opinions about unemployment and underemployment, experience with PwE, knowledge of epilepsy and medical aid in case of seizures, support for involvement of PwE.

4.3 Results

4.3.1 Overall questions

We collected a total of 567 answers from PwE (183 from Italy, 38 from Ireland, 123 from France, 25 from Germany and 198 from Bulgaria).

We collected a total of 291 answers from HEI (100 from Italy, 14 from Ireland, 67 from France, 10 from Germany and 100 from Bulgaria)

Most participants came from the Country for which the specific survey was realised (e.g., Italian surveys have been compiled almost exclusively from Italian participants).

4.3.2 PwE's surveys

As regards PwE we received a total of 567 complete answers.

First questions regarded demographic factors. In figures 3 and 4 can see age distribution and sex distribution for each country:

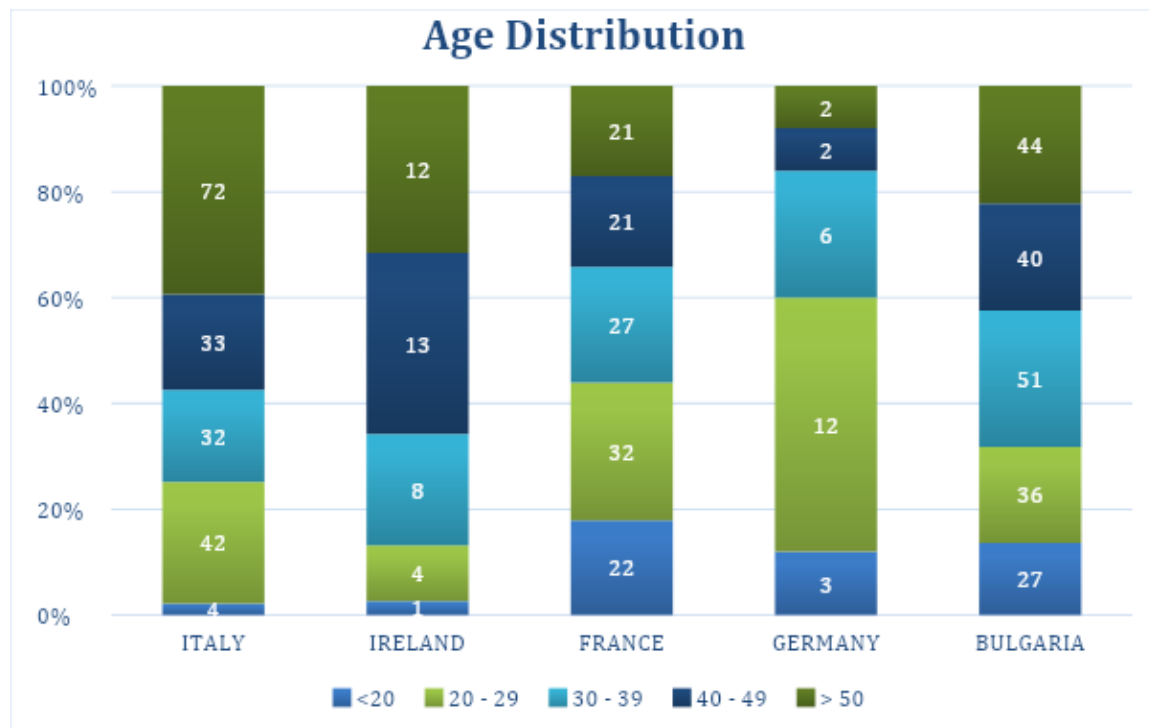


Figure 3 Age distribution of PwE

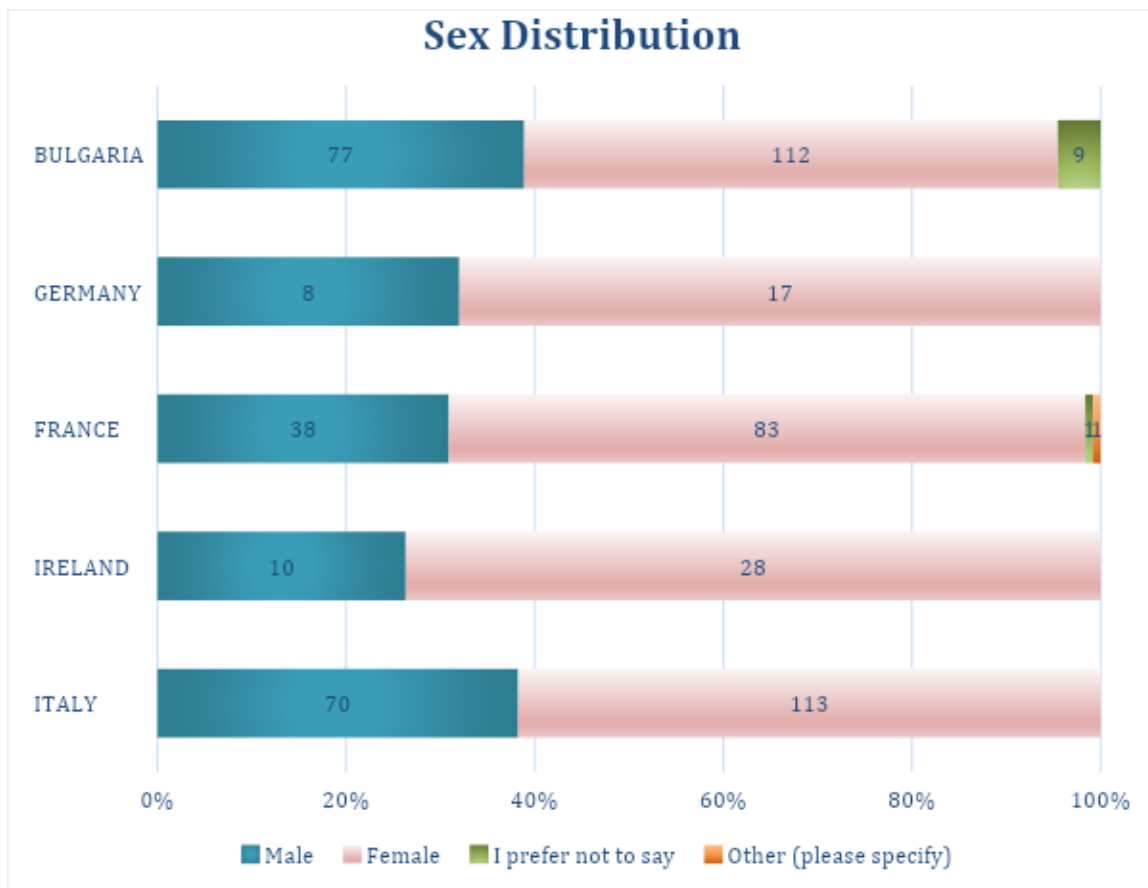


Figure 4 Sex distribution of PwE respondents

Most respondents were aged more than 40 years old. In each country women were more than men.

Answer	ITALY		IRELAND		FRANCE		GERMANY		BULGARIA	
Male	38,25%	70	26,32%	10	30,89%	38	32,00%	8	38,89%	77
Female	61,75%	113	73,68%	28	67,48%	83	68,00%	17	56,57%	112
I prefer not to say	0,00%	0	0,00%	0	0,81%	1	0,00%	0	4,55%	9
Other (please specify)	0,00%	0	0,00%	0	0,81%	1	0,00%	0	0,00%	0
	Answered	183	Answered	38	Answered	123	Answered	25	Answered	198

Table 1 Distribution of sex answers among PwE

As for geographic distribution answers come from different countries:

Italy 183; Ireland 31; Belgium 5; Bulgaria 192; France 113; Swiss 2; Austria 1; Germany 23; Denmark 1; Greece 2; Estonia 1; Non-EU Country 11 (Georgia 1; Bosnia Herzegovina 1; Turkey 1; other countries 7).

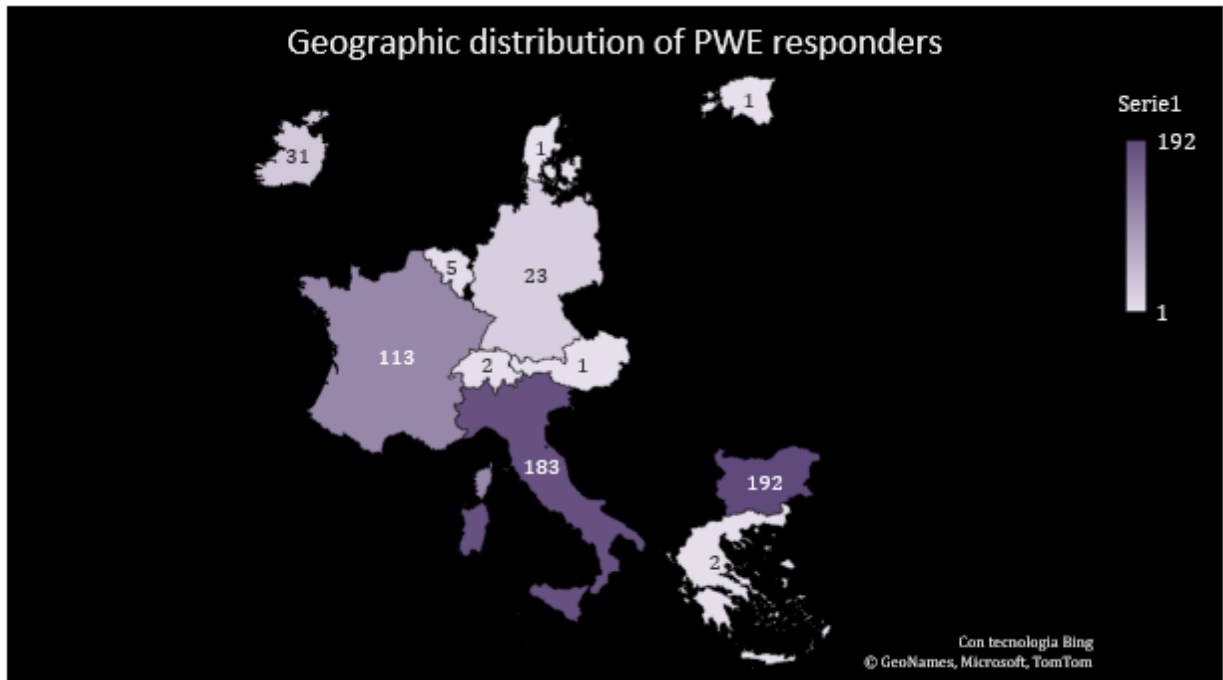


Figure 5 Geographic distribution of PwE

	Mean	Std deviation
ITALY	25,19	17,54
IRELAND	20,68	14,99
FRANCE	15,94	11,54
GERMANY	15,04	9,06
BULGARIA	16,55	11,02

Table 2 Mean age of onset of epilepsy among PwE respondents

When asking about clinical features, we asked about age of onset (see table 2), number of anti-seizure medications (see figure below), seizure freedom and number of seizures in last 3 months.

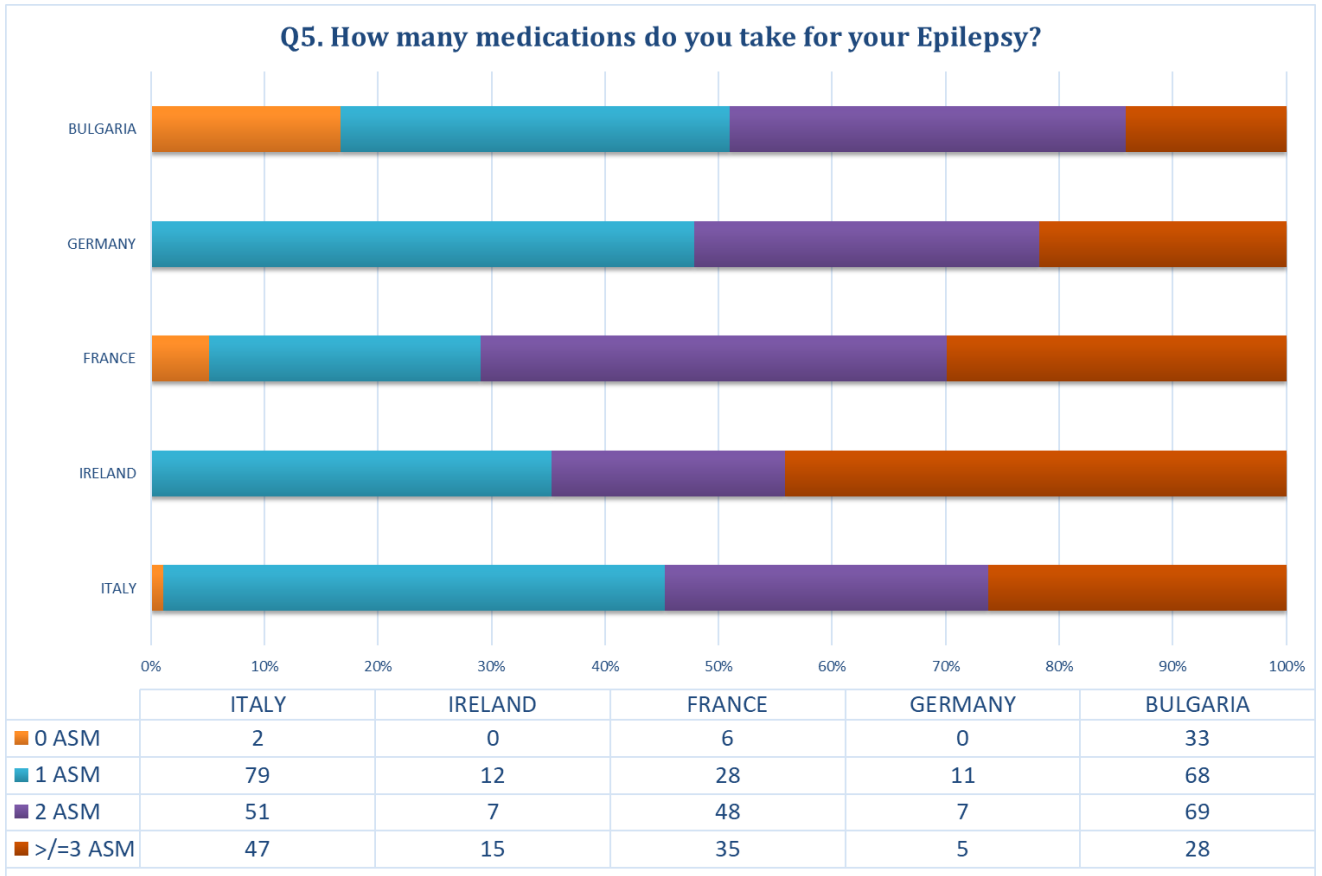


Figure 6 Number of Antiseizure Medication taken for epilepsy.

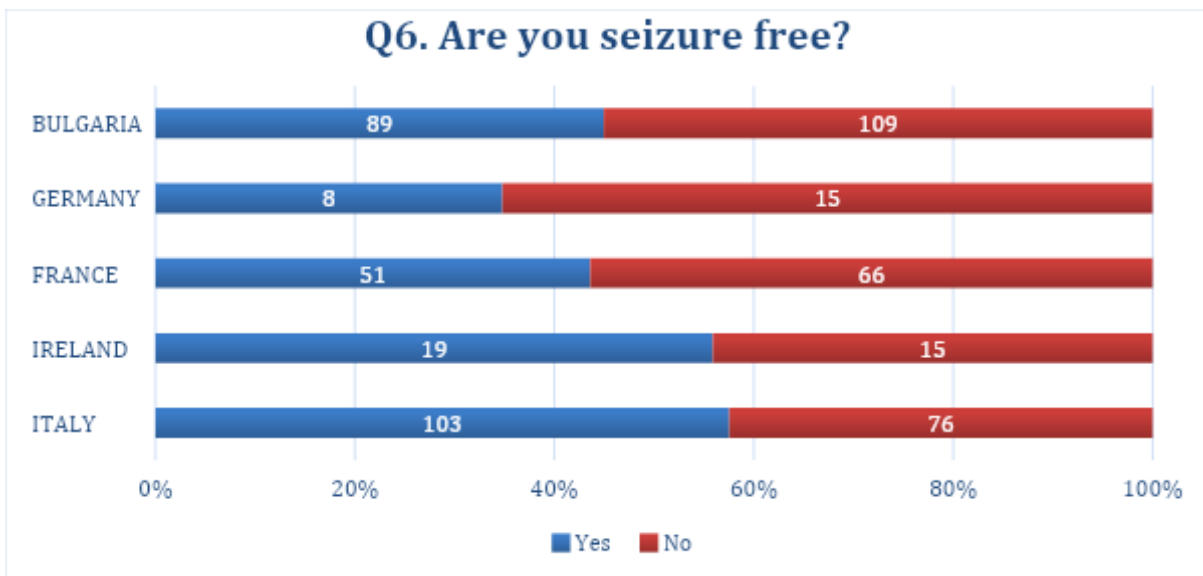


Figure 7 Question about seizure freedom

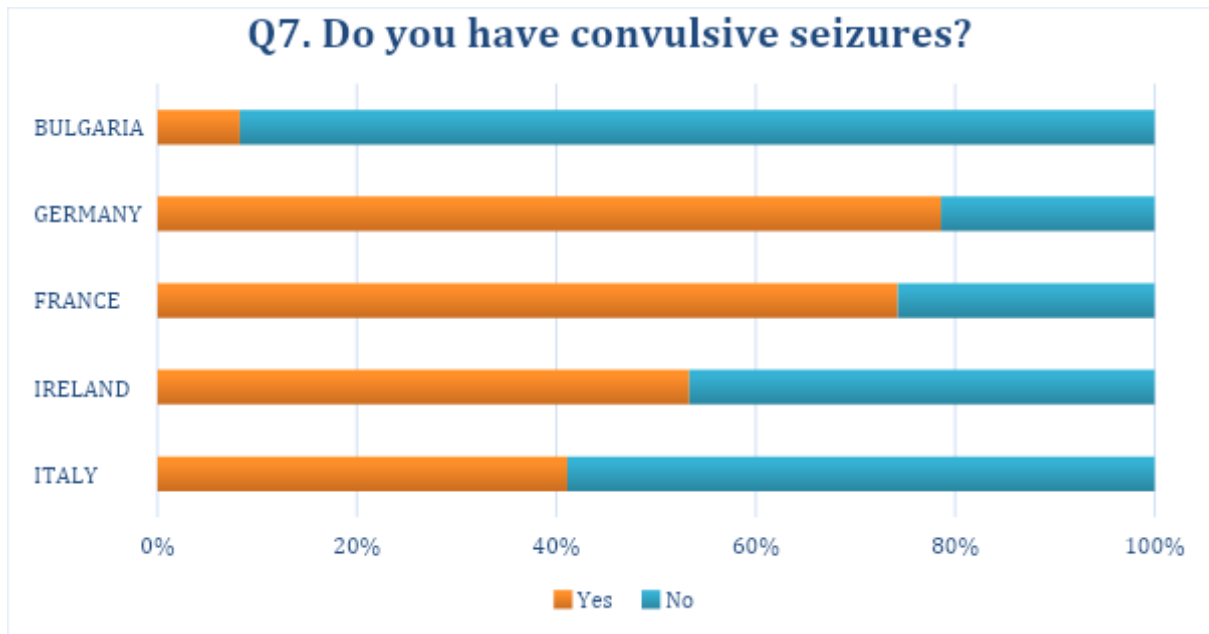


Figure 8 Question about having convulsive seizures

We also asked number of seizures in last 3 months (focal and generalised):

	MEAN	ST DEV
ITALY	13,04	24,58
IRELAND	27,86	45,03
FRANCE	44,63	225,10
GERMANY	28,54	47,54
BULGARIA	0,20	0,59

Table 3 Mean number of seizures in last 3 months

Regarding educational and job attainment we asked level of instruction and current employment status:

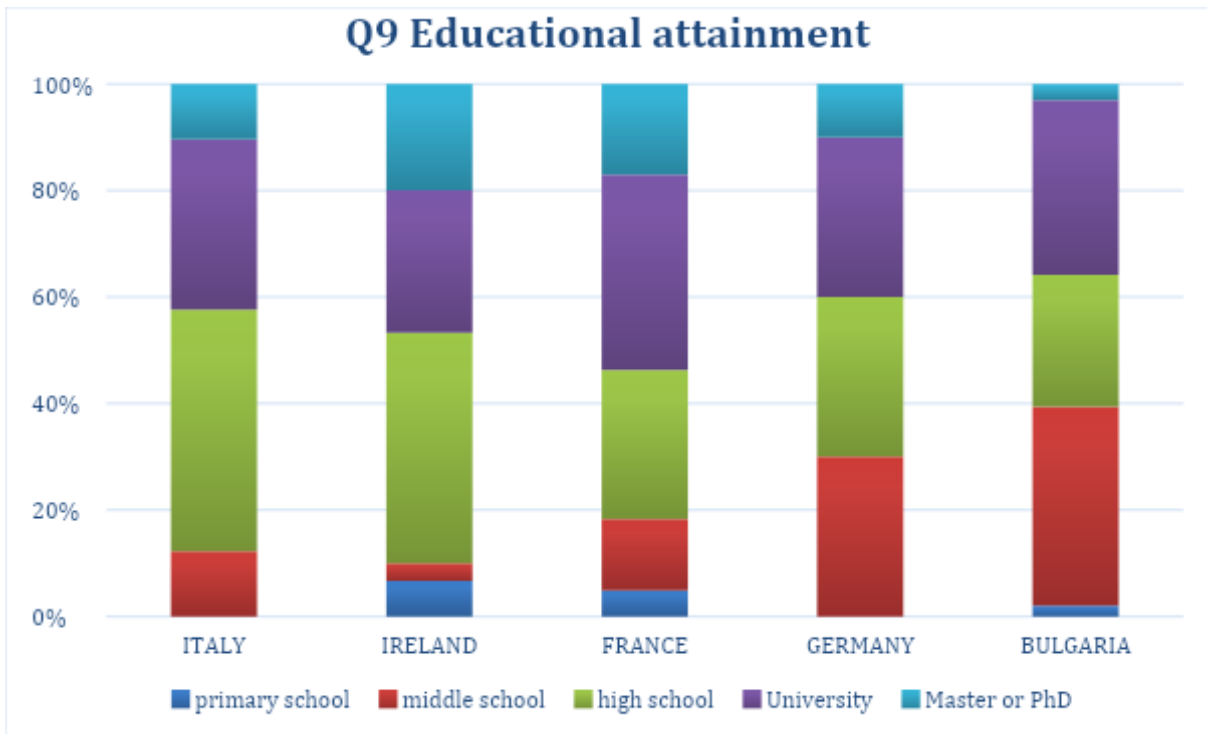


Figure 9 Level of educational attainment among pwe

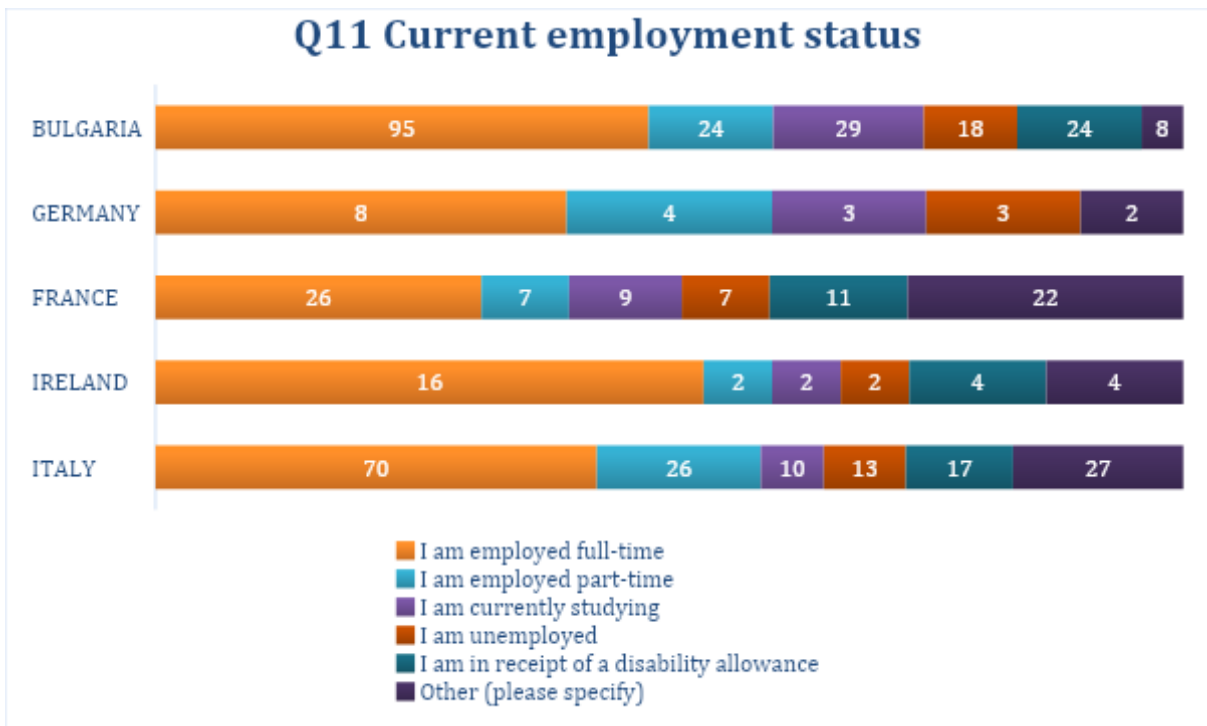


Figure 10 Employment status among PwE

Most of the respondents have gained a high school degree (45% in Italy; 43% in Ireland; 28% in France; 30% in Germany; 25% in Bulgaria).

Rates of unemployment ranges from 7,9% in Italy, 6,7% in Ireland, 8,5% in France, 15% in Germany, 9% in Bulgaria; whereas people employed full time were 42,9% in Italy, 53% in Ireland, 31,7% in France, 40% in Germany, 47,9% in Bulgaria.

We have also asked for an annual current salary and level of satisfaction with actual job position (see figures below).

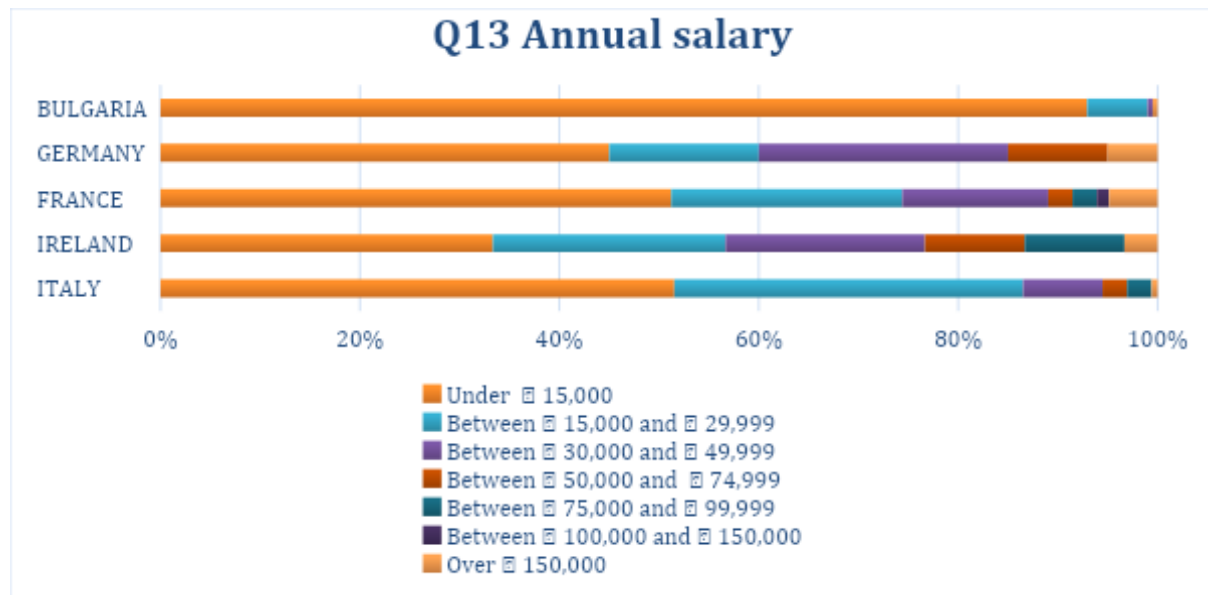


Figure 11 Current annual salary of PwE

Most of respondents earned less than €15000 in all countries.

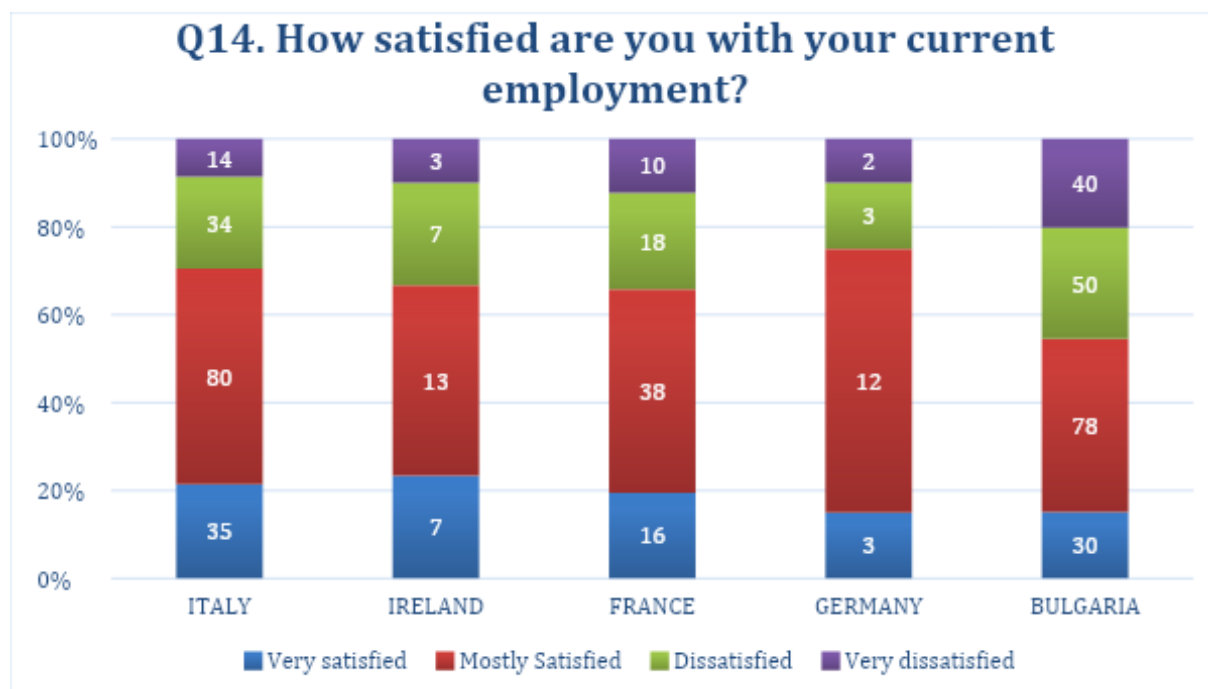


Figure 12 Level of satisfaction of PwE with actual job

Most of the respondents were very satisfied or mostly satisfied with their current employment.

As regards epilepsy in job place, we asked if PwE had experienced any seizure at work:

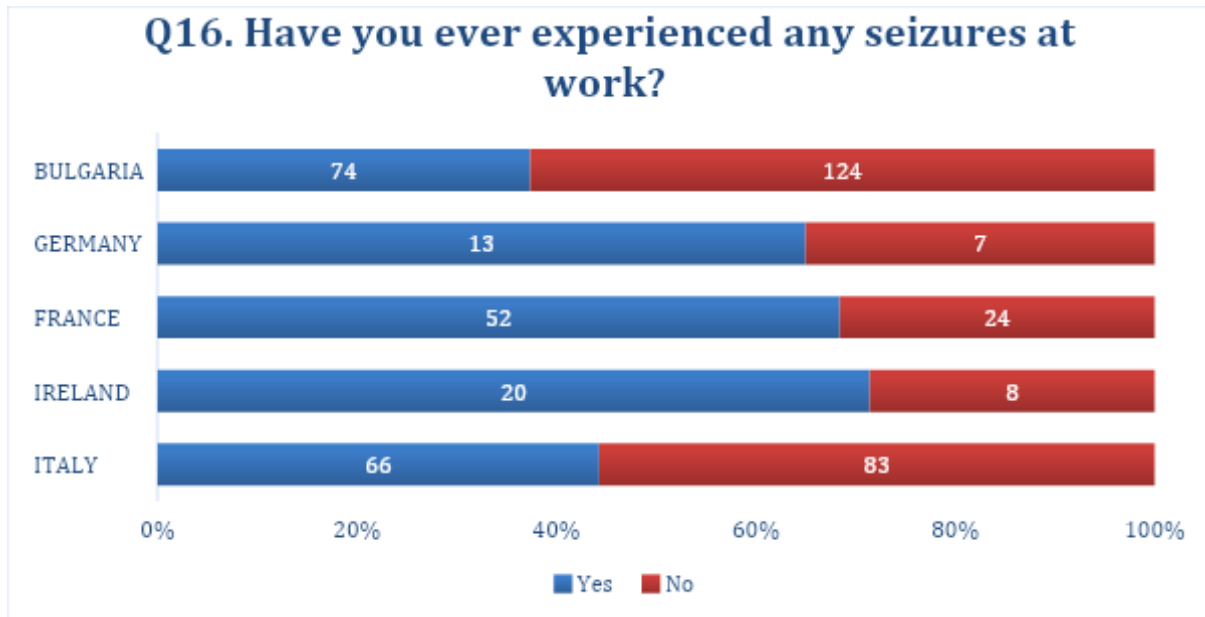


Figure 13 Rate of PwE who have experienced seizures in workplace

In Italy and Bulgaria, a greater proportion of respondents did not experience any seizure at work, on the opposite in Germany, France and Ireland most of respondents experienced seizures at work.

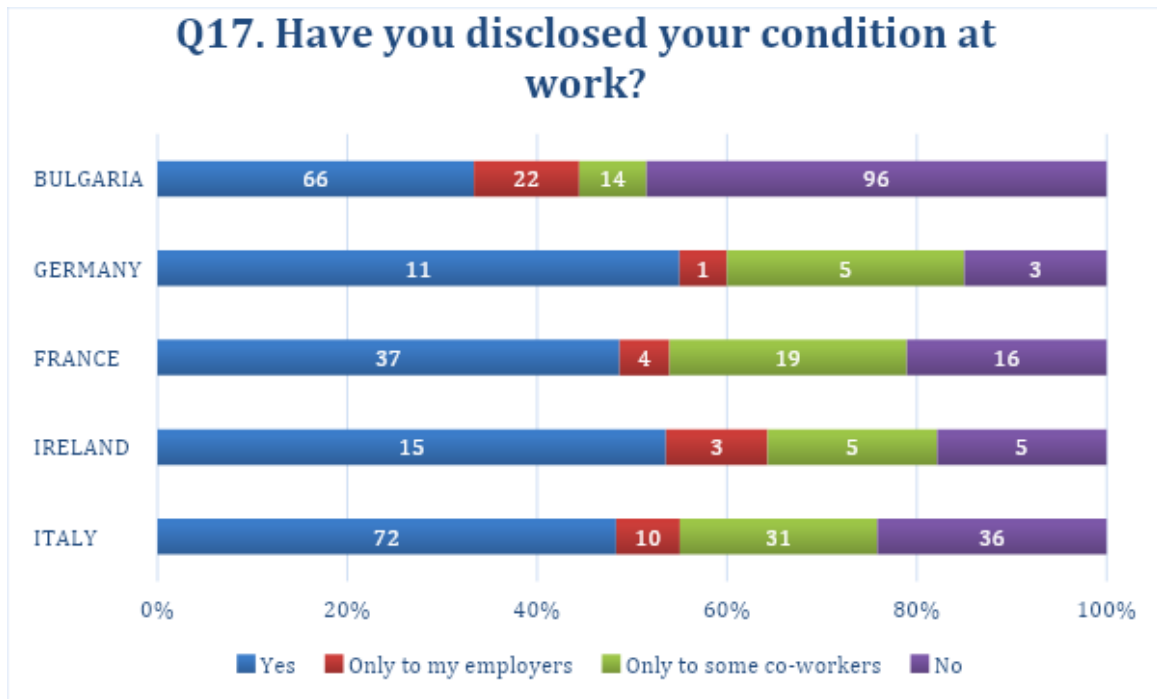


Figure 14 Rate of PwE who disclosed epilepsy in workplace

We also explored disclosure: in Italy 24,2% did not disclose their condition at work; in Ireland 17,9%; in France 21%; in Germany 15% and in Bulgaria 48,5%.

The bar plots below show answers regarding difficulties experienced at work because of epilepsy.



Figure 15 Difficulties experienced in workplace among PwE

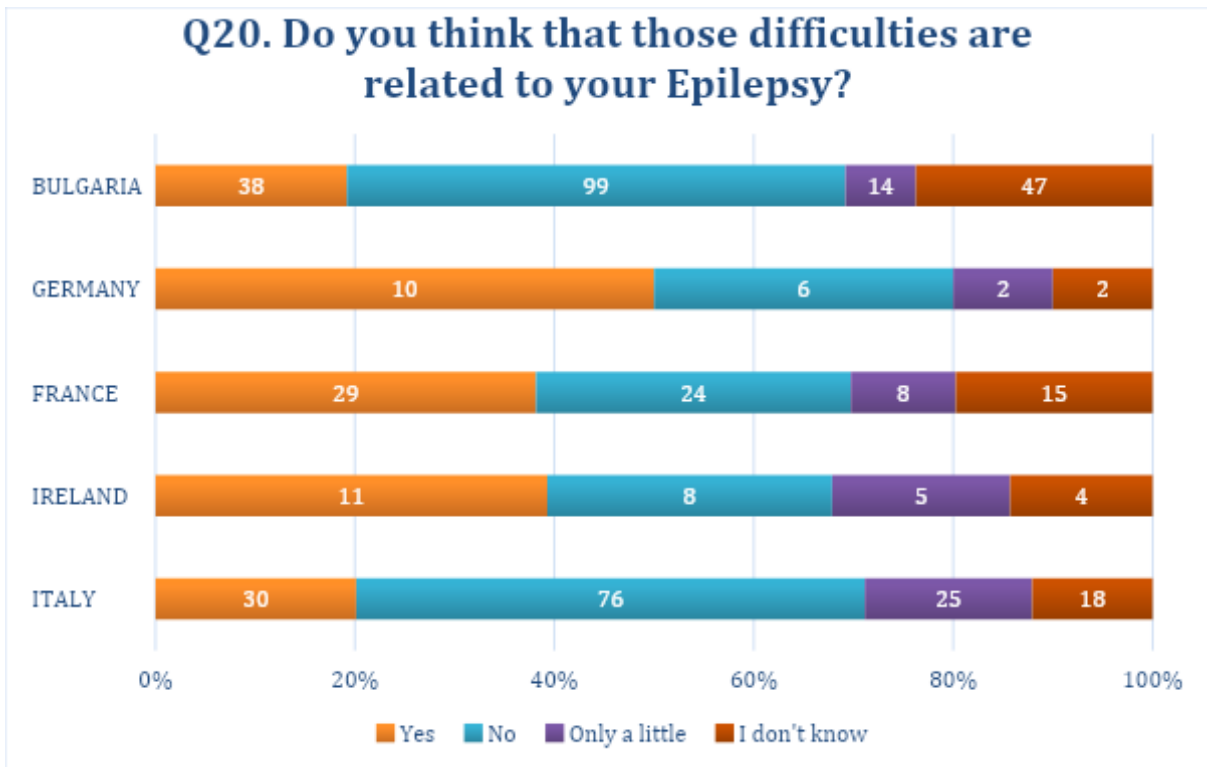


Figure 16 Question about whether difficulties in workplace are related to epilepsy

Finally, we asked about challenges and stigma in workplace:

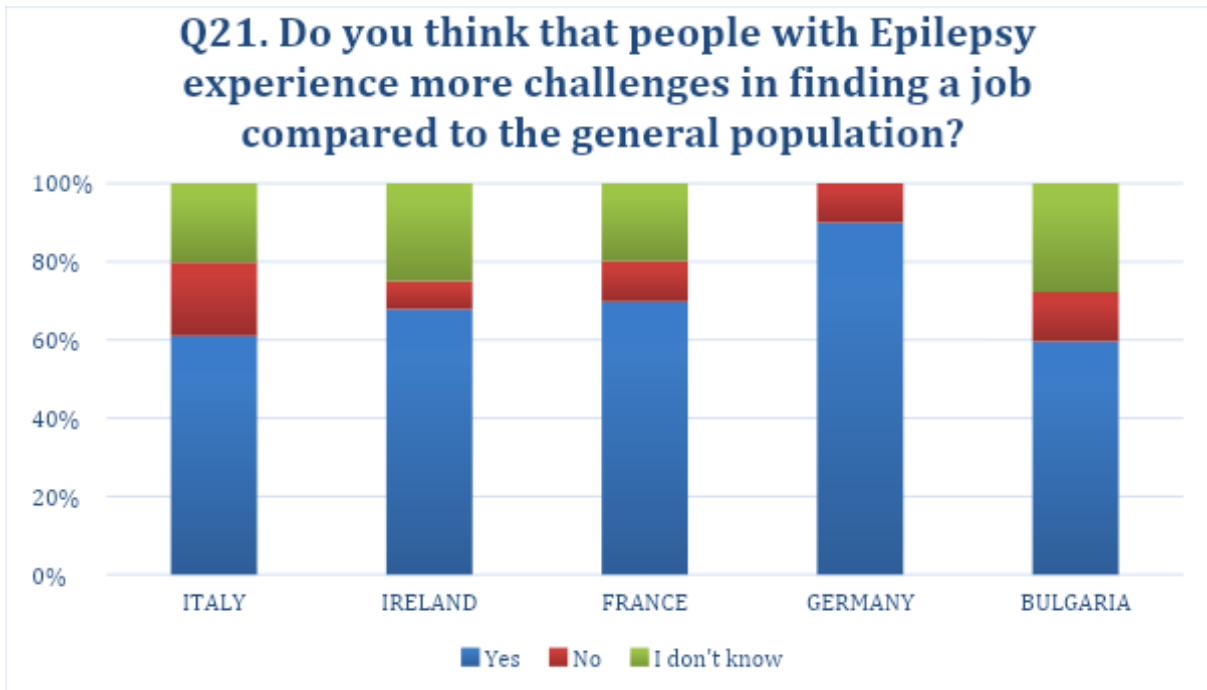


Figure 17 Question about challenges in finding a job for PwE

Most of the respondents agreed that finding and retaining a job is more challenging for PwE.

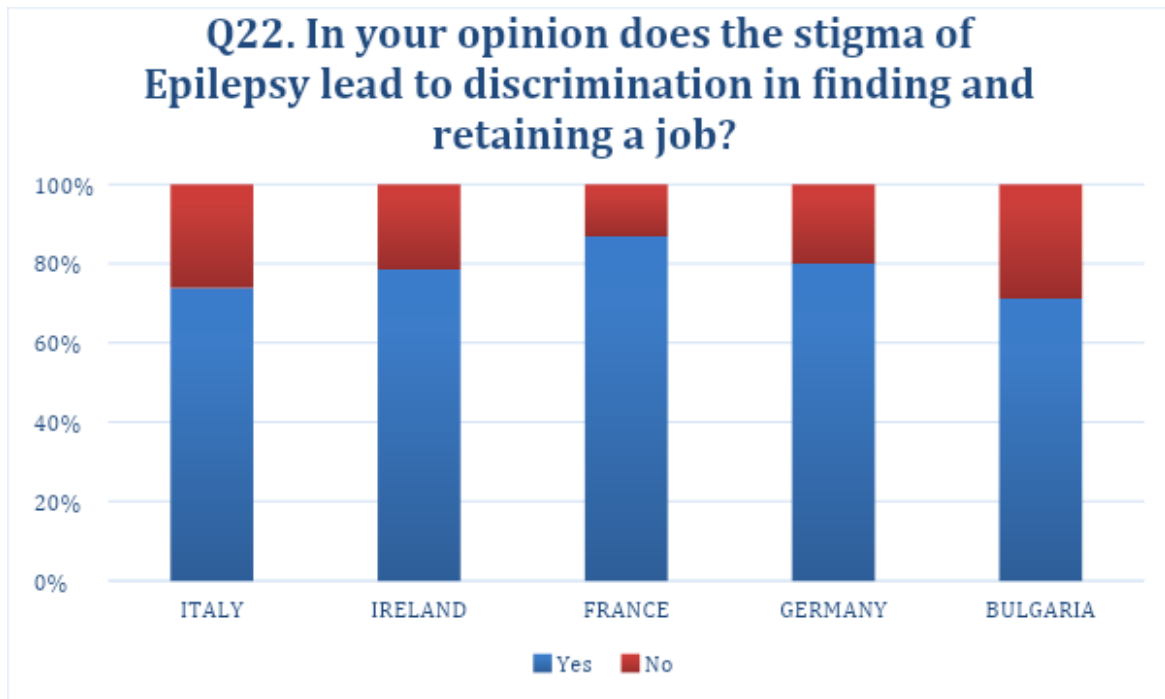


Figure 18 How does stigma affect job research and retaining among PwE

About 70% of PwE from Italy and Bulgaria and 80% in Ireland, France and Germany thought that stigma prompts discrimination in finding and retaining a job.

4.3.3 HEI surveys

We collected a total of 291 answers from HEI. In the first section we asked questions about demographic factors such as age and sex (see figures below).

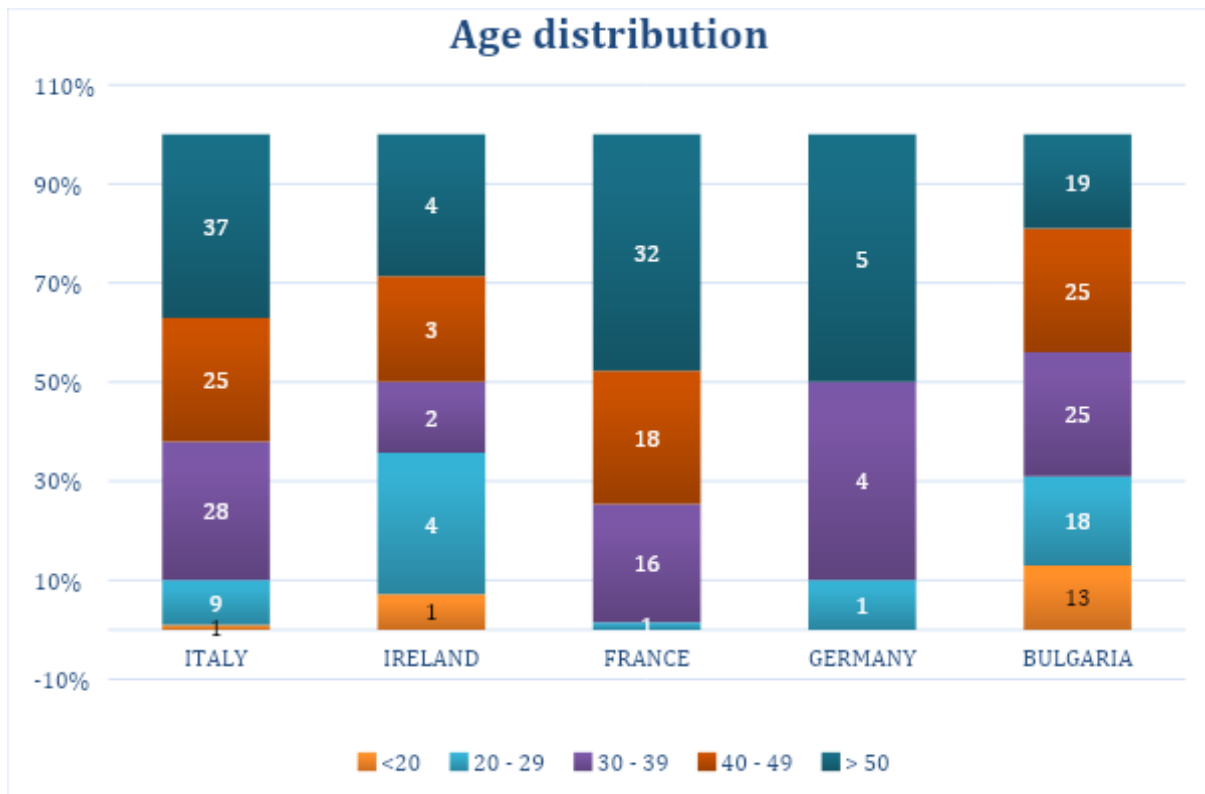


Figure 19 Age distribution of HEI respondents

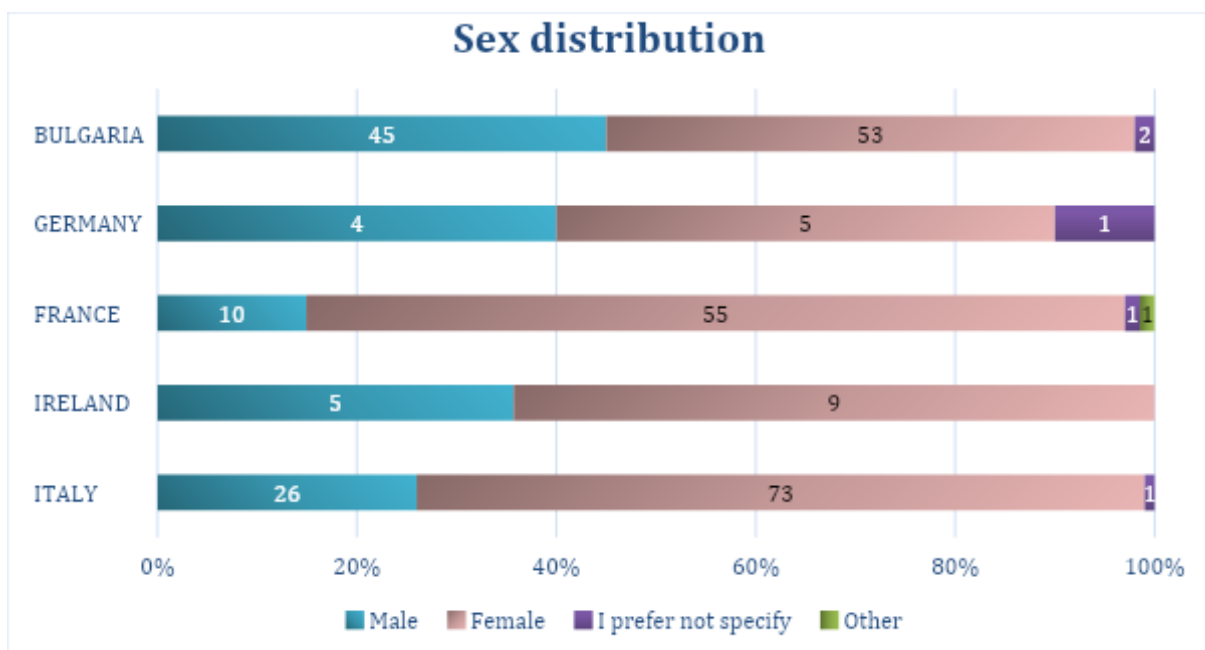


Figure 20 Sex distribution of HEI respondents

Answers	ITALY	IRELAND	FRANCE	GERMANY	BULGARIA
---------	-------	---------	--------	---------	----------

Male	26,00%	26	35,71%	5	14,93%	10	40,00%	4	45,00%	45
Female	73,00%	73	64,29%	9	82,09%	55	50,00%	5	53,00%	53
I prefer not to specify	1,00%	1	0,00%	0	1,49%	1	10,00%	1	2,00%	2
Other	0,00%	0	0,00%	0	1,49%	1	0,00%	0		0
	Answered	100	Answered	14	Answered	67	Answered	10	Answered	100

Table 4 Sex distribution answers among HEI respondents

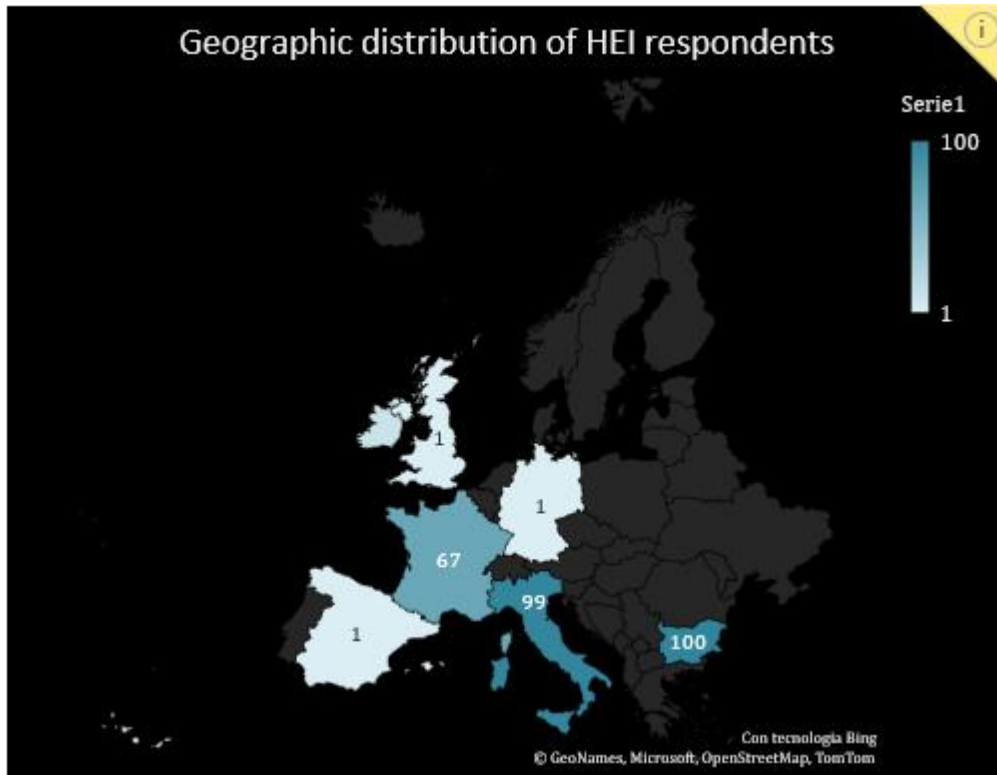


Figure 21 Geographic distribution of HEI respondents

In the previous figure you can see the geographic distribution of respondents.

We asked to higher educational institution workers what kind of disease epilepsy is and if it is treatable:

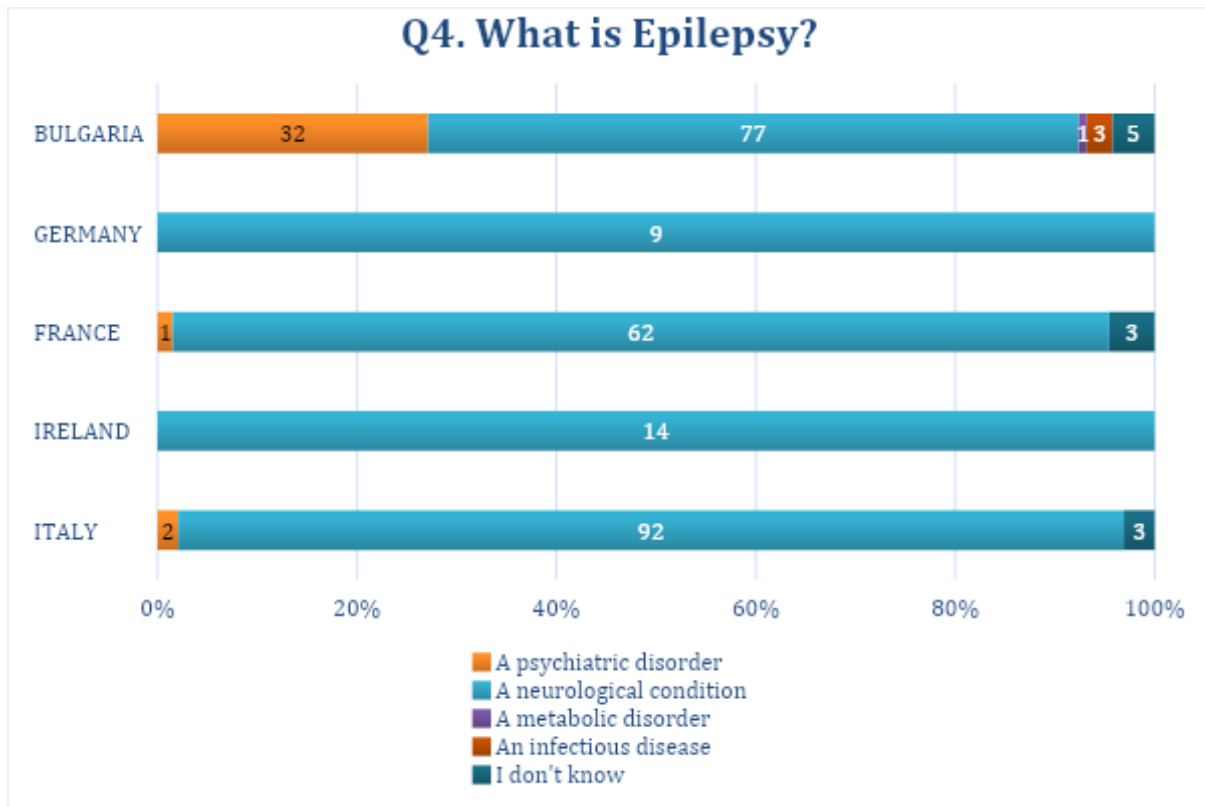


Figure 22 HEI opinions about nature of epilepsy.

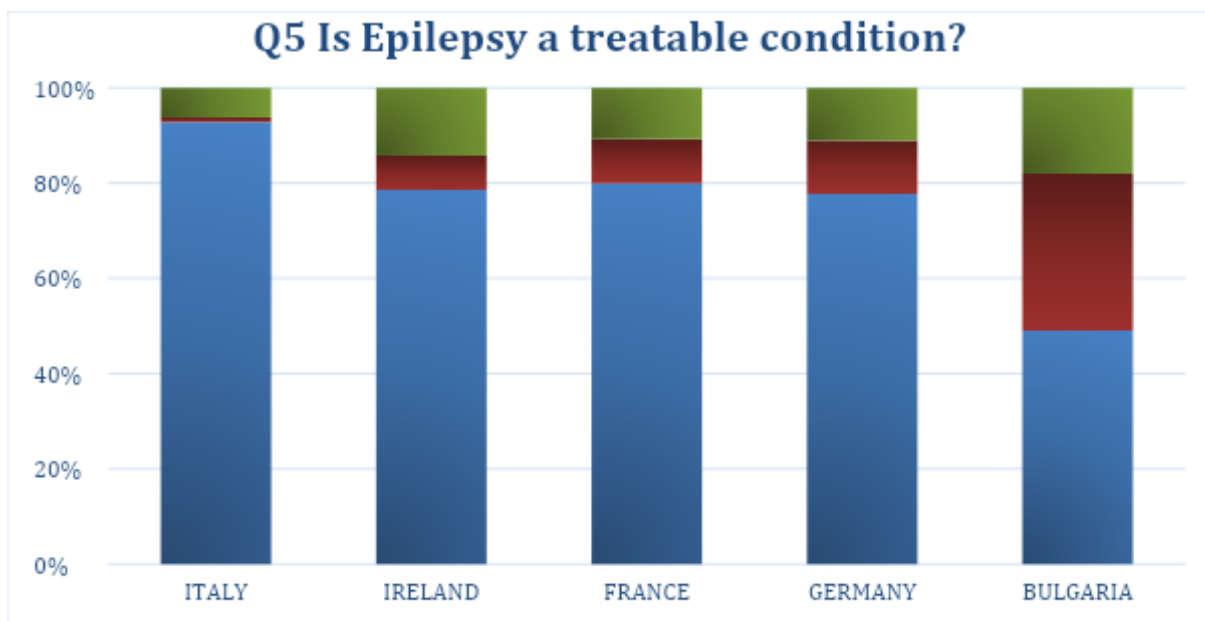


Figure 23 Answers regarding possibility to treat epilepsy from HEI perspective.

Most respondents answered that epilepsy is a neurological condition in all countries and they all agreed that it is treatable in most cases.

Then we asked about opportunities and unemployment among PwE:



Figure 24 Answers regarding job opportunities in PwE from HEI's perspective.

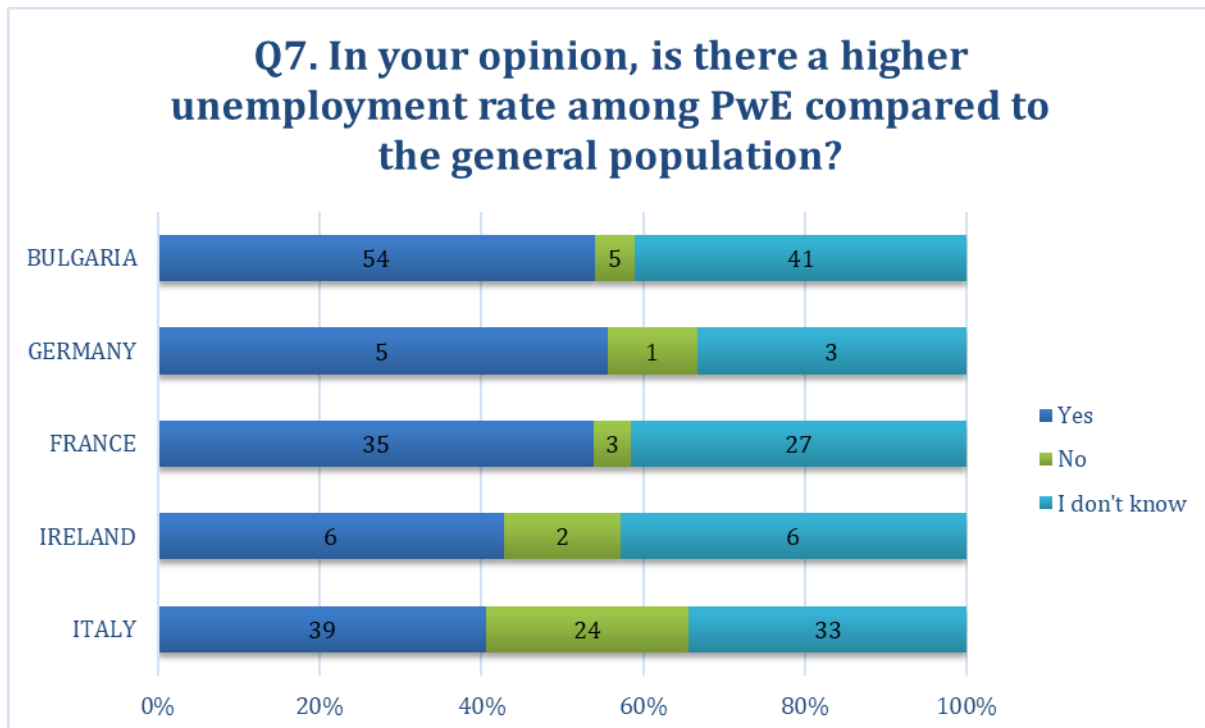


Figure 25 Question about level of unemployment among PwE from HEI's perspective

Most of the respondents thought that unemployment rate is higher in PwE compared to general population.

Q8. Do you think that people with Epilepsy have a higher absenteeism compared to general population?

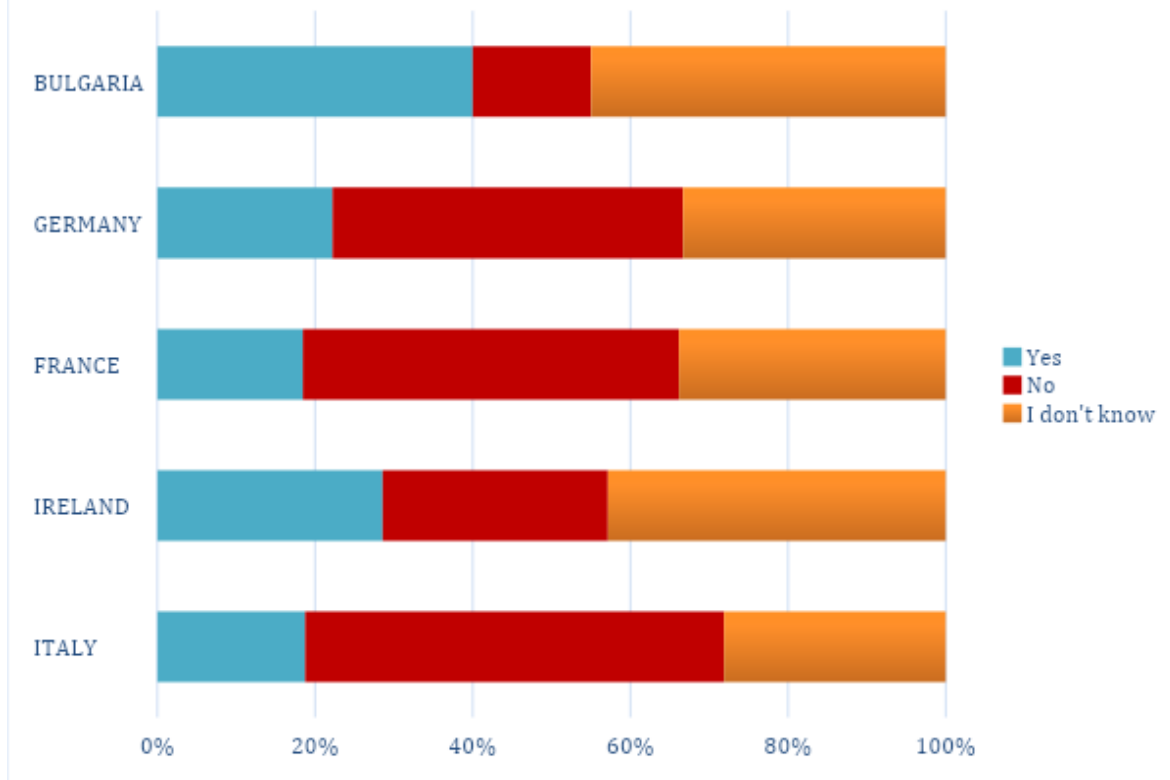


Figure 26 Level of absenteeism among PwE from HEI's perspective

On the contrary, most of the respondents thought that the rate of absenteeism is not higher among PwE.

We have also asked if HEI have known anyone affected by epilepsy and have ever worked with them.

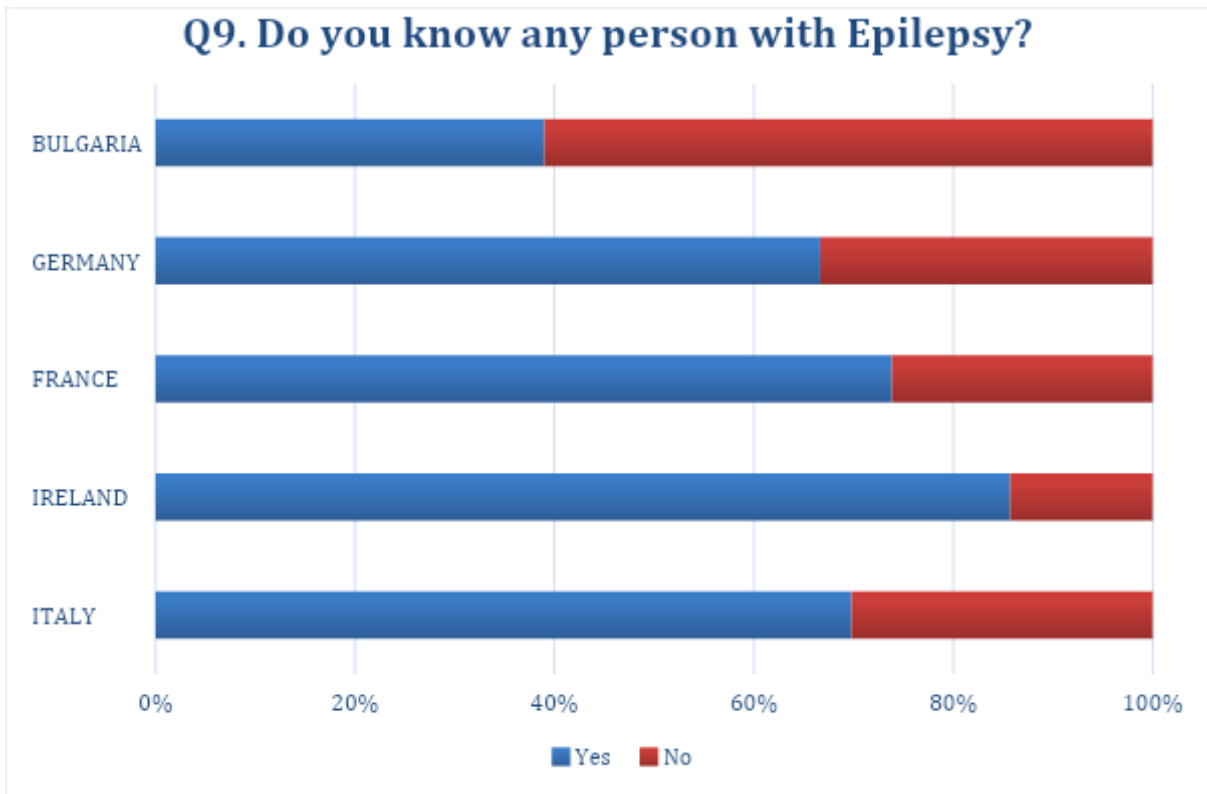


Figure 27 Question about knowing a person with epilepsy.

In all Countries more than 2/3 of respondents knew a person with epilepsy, except in Bulgaria.

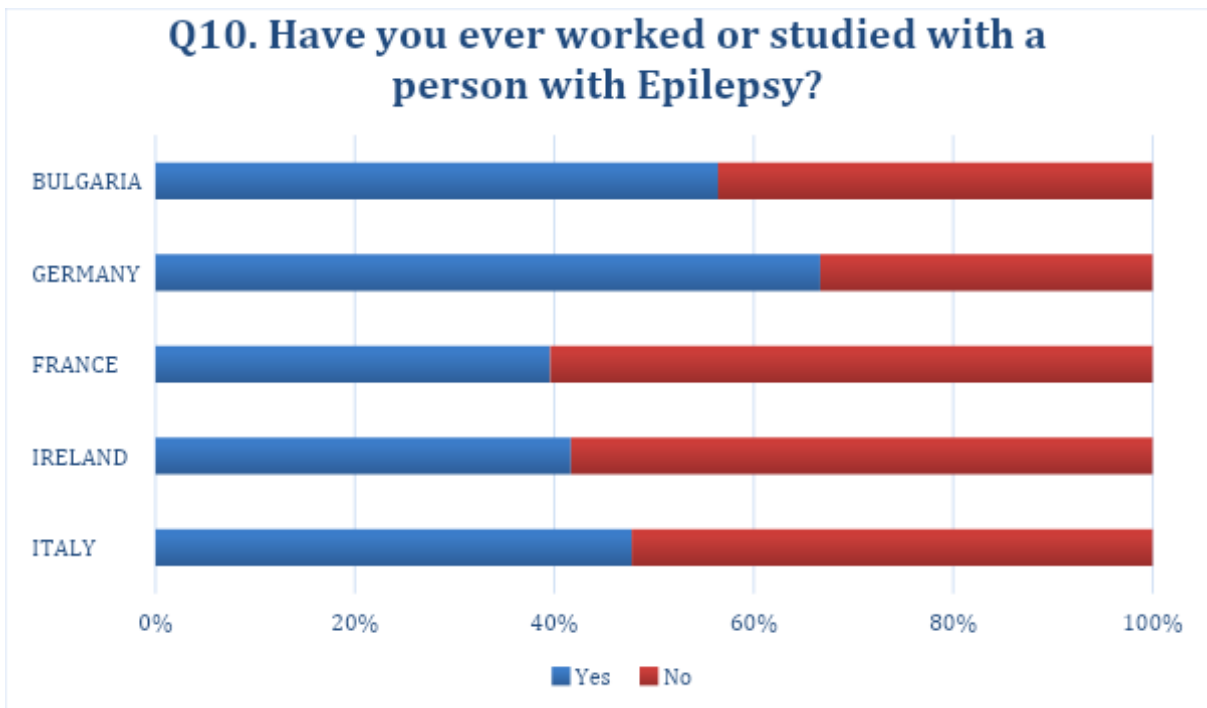


Figure 28 Number of people among HEI who have ever worked/studied with a person with epilepsy

Finally, we have asked if they have ever seen a person experiencing a seizure and if they know how to give medical aid.

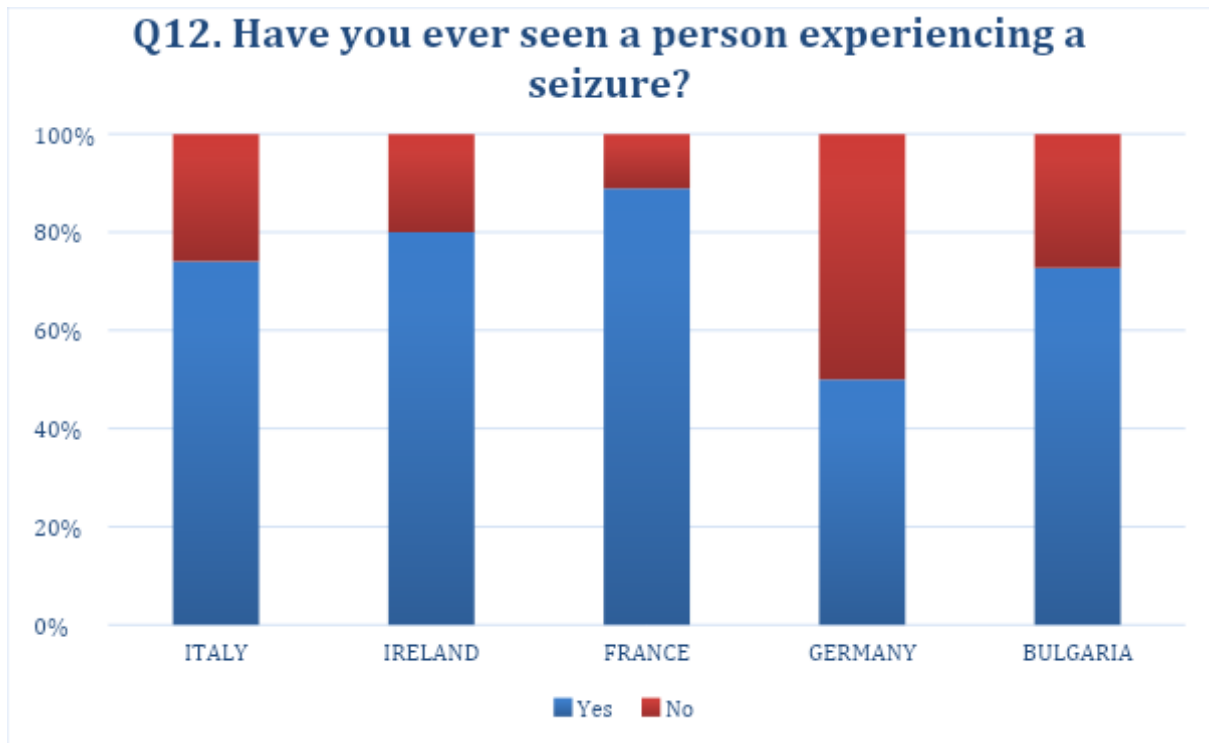


Figure 29 Number of people among HEI who have ever seen a seizure in person

Most respondents of all Countries have seen a seizure in person, but in some cases (Germany and Bulgaria) the major percentage of respondents did not know how to give medical aid to a person experiencing a seizure.

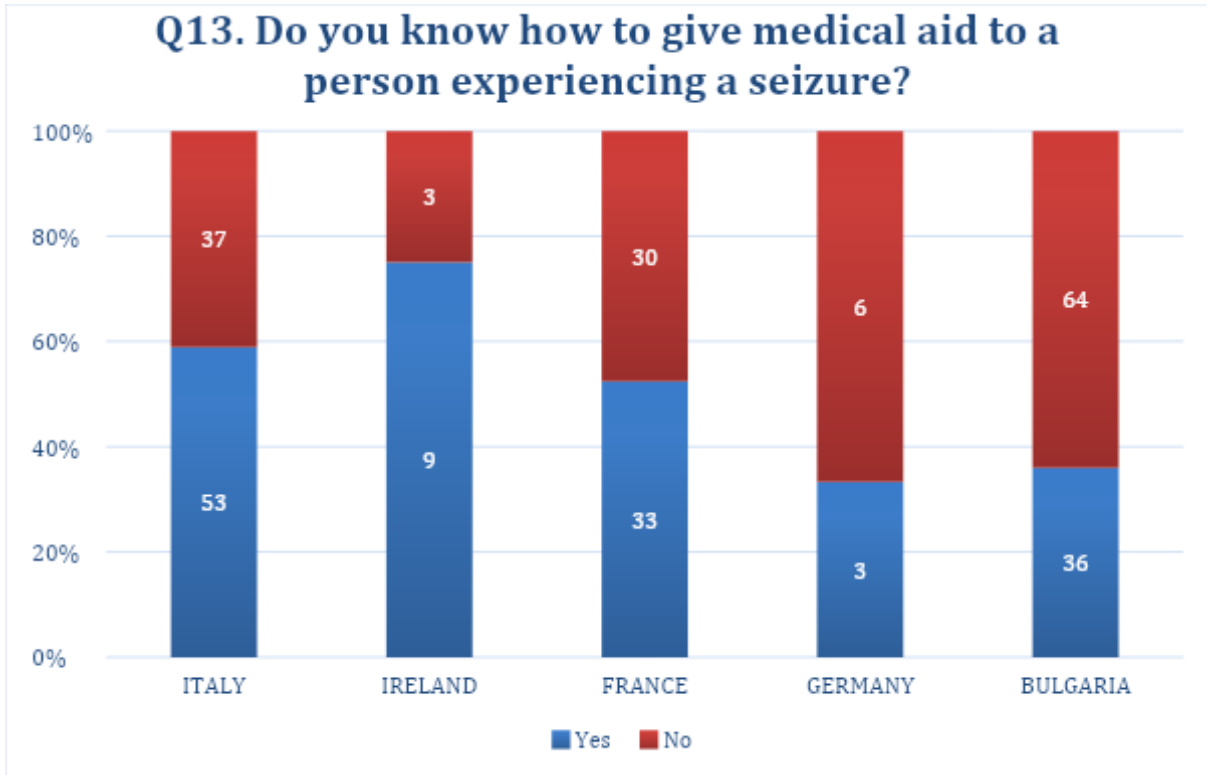


Figure 30 Level of knowledge about how to give medical aid during a seizure

Finally, from the Institutions point of view we asked if they receive some money support to employ PwE and most of the respondents declared that they do not receive any economic aid, in all countries.

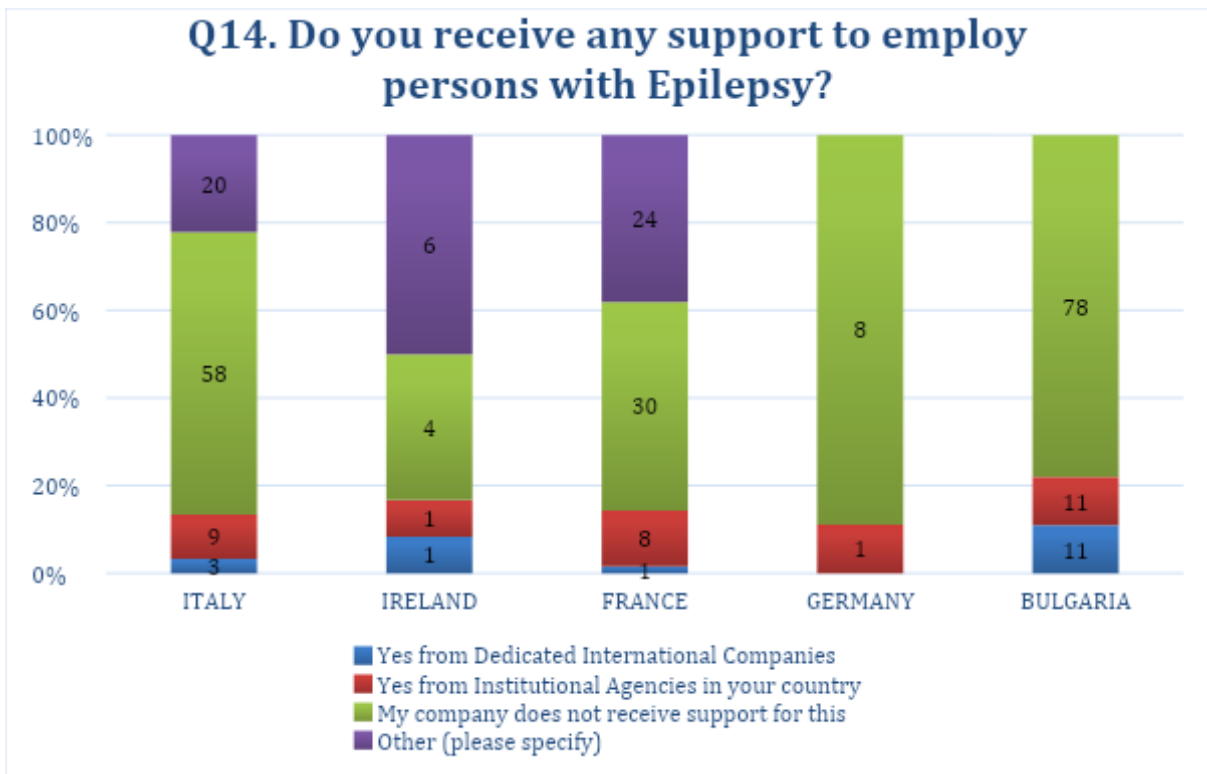


Figure 31 Question about economic support received to hire PwE

5. STATE OF THE ART OF THE INCLUSION SYSTEMS IN COMPANIES IN EACH PARTNER COUNTRY

5.1 Italy

5.1.1 Current situation

As in other Countries of Europe, unemployment of PwE in Italy is higher compared to the general population. We do not have specific studies, focused only on the Italian situation.

We can analyse studies from multicentric experience, such as The RESt-1 Group study in 2000 which reported an unemployment rate of 18% compared to 13% of the general population in 7 European countries (Beghi et al., 2000).

After some years, Cornaggia published a prospective cohort study about the accidents at work among people with epilepsy, reporting a rate of unemployment of 13.3% compared to 9.6% of controls in a European multicentric study including Italy (Cornaggia et al., 2006).

5.1.2 National Legislation

Actually, in Italy there is no specific legislation about epilepsy.

Law 104/1992 regulates general disability and “handicap”: within the 3rd article of this law, “handicap” is defined as “a physic, psychic and sensorial impairment, stable or progressive, causing difficulties in learning, relationships and work integration and causing social disadvantage and exclusion of the person”. This law provides some economic, work, fiscal and social advantages for people with disabilities balanced on handicap severity:

- Paid work leave: caregivers of people with disability have the right to take work-leave 3 days per month or 18 hours per month.
- Work location: caregivers of people with disability have the right to choose (whenever possible) work location near to the person affected.
- Nocturnal shifts: according to the law 104/1992, people with disability are not obliged to attend night shifts.
- Specific job placement, when disability level is 46% or more.

Law 68/1999 is a law promoting the integration of disabled people in the workplace throughout specific work locations. It is dedicated to:

- People with physic, psychic and sensorial impairment prompting a reduction of work capability major than 45%;

- People with a 33%-degree invalidity.

Another pivotal law is Decreto Legislativo 9 July 2003, in the 3rd article this law specifies that employers should adopt “reasonable accommodation” in order to facilitate employees. Accommodations must be effective and practical in order to promote access in workplace and professional training, duties and functions and shifts should be subdivided to facilitate workers with disability, avoiding excessive expenses and disadvantages for other workers.

Recently, because of the Coronavirus emergency, the Law 22 May 2017 has promoted “agile” work, favouring PwE and balancing institutions’ needs.

As for law drafts, we have two consider two drafts:

- Disegno di Legge 354: it is specific for PwE and it promotes their social integration and quality of life. It comprehends some articles about driving restrictions and transfer to and from the workplace.
- Disegno di Legge 1219: it provides an article in order to promote programs for inclusion of PwE in workplaces, enhancing their capability and eligibility to work (regardless disease severity and disability) and avoiding any form of discrimination; furthermore, it extends benefits from Law 104 to people with epilepsy not having a disability.

5.2 Bulgaria

5.2.1 Current situation

Ways of provision for people with disabilities

According to the United Nations Standard Rules, persons with disabilities should receive the necessary assistance and support in mainstream settings and in mainstream education, health, employment and social service settings. Persons with disabilities must be enabled to exercise their human rights and, particularly in the area of employment, must be provided with equal opportunities for productive and gainful work.

The European Union's policy on equal opportunities for people with disabilities implies measures to remove barriers to their full integration, including through employment.

The National Association of Employers of People with Disabilities works to create conditions for the full integration of people with disabilities into the economic and social life of the country.

The main objective of the Association is to provide conditions for the employment of people with disabilities of working age and to improve their quality of life as a condition for free and full inclusion in the social life of the country.

When establishing jobs for this target group, employers are faced with issues involving knowledge of the programmes, benefits and preferences, of the obligations under the current legislation in the country, and of various social skills for working with people with disabilities.

Employment policies for people with disabilities at European Union level.

According to research by the European Commission, one in six EU citizens is a person with a disability, or more than 50 million of the EU's total population. Poverty rates for people with disabilities have been found to be 70% higher than average, mainly due to limited access to employment.

Fundamental documents of the European Union and the international community, which treat the equal rights of persons with disabilities, including in relation to their employment, are:

- The EU Charter of Fundamental Rights;
- The United Nations Standard Rules on Equality and Equal Opportunities for Persons with Disabilities;
- The United Nations Convention on the Rights of Persons with Disabilities.

The European Parliament's Working Group on Public Services engages on services of general interest - a package of state aid measures such as public service compensation; public procurement, concessions and public-private partnerships, territorial union, fundamental rights and the implementation of the Member States' Directive on the application of services.

In 2010, the European Disability Strategy 2010-2020 "A Barrier-Free Europe" was adopted by the European Commission, together with an action plan for its implementation. The main focus of the strategy is the elimination of identified barriers in member states and the commission has identified eight main areas for action, one of which is the employment of people with disabilities.

The real picture of employment of people with disabilities in Bulgaria.

People with disabilities remain one of the most at-risk target groups on the labour market.

According to data from almost all available sources of information, around 10-15% of people with disabilities of working age are in employment.

According to the 2011 Population Census, 465 228 (or 7.2%) of the country's citizens are persons with disabilities. Only about 12% of them aged 18 to 65 works. These data illustrate the fact that employment among them is about 4-5 times lower than employment among persons without disabilities.

Such statistics make issues related to the social inclusion through employment of people with disabilities a primary task of the country's social policy in the field of disability.

There are several reasons for the lack of or very limited access to work for this category of persons:

- One of the most acute problems is that of architectural barriers and accessible housing and settlement environments.
- Employers are not hiring people with disabilities, and there is a lack of interest from the private sector in the resources that people with disabilities offer.
- The qualifications of people with disabilities. More than 40% of them have primary education and below. This prevents them from even being included in retraining courses through the Employment Agency due to educational requirements.

In this regard, when entering the labour market, people with disabilities face many social barriers that severely narrow their opportunities - the accessible environment; access to adequate education; lack of training and support services; lack of a system for vocational orientation and professional activation; employers' attitudes; the so-called "benefits trap", etc. It is the needs of people with disabilities to remove existing barriers in society that are the biggest challenge, both for themselves and employers with disabilities, and for social policy in general.

In order to achieve adequate and effective social inclusion through employment, the necessary national and local social policy actions can be broadly reduced to two main areas:

Firstly, actions directly targeted at the person with a disability and his or her immediate social environment.

Second, actions to form the physical and social environment in which people with disabilities live.

In line with the United Nations Convention on the Rights of Persons with Disabilities, it is important to create the conditions for the implementation of the so-called social model, i.e. the identification and removal of existing social barriers, rather than the various limitations and deficits of the person with a disability and attempts to overcome, reduce and eliminate them, should be the focus of policies, including social inclusion through employment, as their dominant feature. This also means creating guarantees for the rights of persons with disabilities at all levels.

The main objective of the Long-term Strategy for Employment of People with Disabilities is to provide conditions for the effective exercise of the right to free choice of employment of people with disabilities of working age and to improve their quality of life as a condition for free and full inclusion in the social life of the country.

Specific activities and measures are outlined which need to be implemented in order to ensure conditions for a decent working life for people with disabilities:

- Providing appropriate forms of qualification and retraining.
- Providing appropriate forms of employment.

In order to expand the opportunities and ensure the continued employment of people with permanent disabilities of working age, it is necessary to implement a variety of forms of employment. It is the right of the person to choose the form of employment:

- Protected employment. Protected employment for people with permanent disabilities is not regulated in Bulgarian legislation.
- Specialised enterprises and cooperatives for people with disabilities. They employ mixed collectives, enterprises participate in the market on an equal footing with companies that do not employ people with disabilities, which makes them uncompetitive.
- Open labour market.
- Home-based and distance forms of employment. In view of the economic crisis leading to a significant increase in unemployment in general, it is necessary to implement more flexible and diverse forms of employment for people with disabilities by employers. This would also be in line with the more effective implementation of European legislation on the employment of people with disabilities and their equality, as well as with the good practices of the European Union Member States.
- Home-based and distance forms of employment are very suitable for people of working age with a high degree of reduced working capacity. Distance employment, in today's society of rapidly developing information technology, is a very promising form of work, particularly suitable for people with severe disabilities. These forms of employment avoid the need to overcome architectural barriers, specialised transport, etc.
- Social entrepreneurship. This form of employment is applied in many EU Member States. It should be promoted, developed and secured by both the state and local authorities. The latter has real leverage to promote micro-enterprises of people with disabilities by easing the range of permitting and coordination regimes in place locally. In this country, social enterprises are supported by "Human Resources Development, priority 5 "Social inclusion and promotion of the social economy".
- Development of independent business of persons with disabilities through self-employment.

Open labour market. People with disabilities must be given the opportunity to work within an open labour market. This is one of the most important factors for their integration and autonomy and is set as a key objective in the Long-term Strategy for the Employment of People with Disabilities 2011-2020. This will be achieved by enabling people with disabilities to access appropriate forms of vocational training and employment.

The open labour market as a form of employment implies the fastest social inclusion of people with permanent disabilities but is the most difficult to implement in a crisis. On the other hand, employers face a number of barriers that restrict them from being flexible in hiring and firing

people with disabilities. It is still difficult to grasp the fact that a person's loss of capacity to work relates to a particular type of work depending on the type and degree of their disability, not to their capacity to work at all.

In this regard, it is necessary to draw public attention to the provision of opportunities for people with disabilities to be equal participants in the free labour market and to the creation of a support mechanism in providing opportunities for people with disabilities to be integrated into the free labour market. This can be created through vocational training and long-term strategies; specialised mediation and assistance; and the provision of opportunities for people with disabilities to enter the free labour market through support from professionals, employers and other actors in the process.

An individual approach is needed to provide services to people with disabilities according to the type and degree of disability, the degree of permanently reduced working capacity and depending on their individual needs for participation in employment and vocational (re)qualification, for access to integrated education and training or so-called supported employment services.

Self-employment of people with disabilities.

This form of employment is implemented in many EU member states. It should be encouraged, developed and secured by both the state and local authorities. The state has real policy levers to promote micro-enterprises for people with disabilities by simplifying the range of permitting and coordination regimes in place locally.

Social entrepreneurship is an economic activity aimed entirely at creating and developing its own business.

Since 2006, the social enterprise has been developing a social enterprise. The Agency for Persons with Disabilities has been implementing a programme for funding projects for the start-up and development of self-employment by people with permanent disabilities. The interest in this programme has been extremely high, but due to limited financial resources only 129 projects have been funded in the period 2006-2013. AHU has monitored the implementation of the projects for about three years and found that they are 95% successfully implemented. The non-implementation of the remaining 5% is due to objective reasons (drastic deterioration of the health condition or death of the financed beneficiary). This form of employment of people with permanent disabilities is highly successful, sustainable, contributing to their self-esteem, self-expression and satisfaction with the results achieved. The business development of these beneficiaries enables them to become entrepreneurs and employers of others.

The Labour Code (LC), Article 315, regulates the obligations of every employer with more than 50 employees to determine annually jobs suitable for employment of persons with

reduced working capacity from 4 to 10 percent of the total number of employees, depending on the sector.

However, employers, as well as state and municipal institutions, have been particularly unwilling to hire persons with disabilities. This forms public attitudes that there is no requirement to employ a certain percentage of people with disabilities.

The Labour Code also stipulates that employees with 50 percent or more loss of working capacity are entitled to basic paid annual leave of not less than 26 working days.

An important guarantee of the right to work of persons with disabilities is also the relative prohibition of dismissal of employees suffering from diseases specified in a regulation of the Council of Ministers and of persons with disabilities (Article 333, paragraph 1, item 3 and paragraph 2 of the Labour Code) - eligibility for dismissal on certain grounds is possible only after prior authorization by the labour inspectorate and after taking the opinion of the TELK.

The EU anti-discrimination directives are reflected in the Protection against Discrimination Act. It specifically lists the grounds on which all direct and indirect discrimination is prohibited - sex, race, disability, etc. The Commission for Protection against Discrimination monitors the implementation of and compliance with the Protection against Discrimination Act and other laws governing equality of treatment.

One of the most significant duties of an employer is to adapt the workplace to the needs of the disabled person - to provide access to the workplace, appropriate equipment and working hours, subject to occupational safety requirements, that compensate for the person's disability and enable them to work.

Specialised working environment

To date, 124 specialised enterprises and cooperatives have been registered in the register of specialised enterprises and cooperatives of people with disabilities, maintained by the Agency for People with Disabilities. They employ persons with permanent disabilities in an integrated working environment together with persons without disabilities. These enterprises participate in the market on an equal level with companies that do not employ people with disabilities, making them uncompetitive. Without state support they could not survive on the free market, yet they are an essential form of providing more permanent employment for the target group. Specialised enterprises and cooperatives are: micro, small and medium-sized enterprises for people with disabilities; municipal enterprises for people with disabilities; cooperatives for people with disabilities; specialised enterprises for the blind and partially sighted; specialised enterprises for people with hearing impairments; and occupational therapy facilities providing employment through occupational therapy.

The establishment of specialised enterprises shall be carried out under the Commercial Act or the Cooperatives Act.

Municipal councils may establish specialised enterprises:

- through commercial companies with municipal participation in the capital, registered under the Commercial Law;
- through municipal enterprises established under Article 53 of the Municipal Property Law.

Within the framework of the regulated State assistance, specialised enterprises could occupy certain commercial areas, which is a fact for some of them at present. Municipal specialised undertakings could carry out municipal activities that are now outsourced. This practice could also be successfully applied by large manufacturing and trading corporations, thus combining economic and social effects.

There are many activities and programmes that employers can take advantage of in the process of creating jobs for people with disabilities or in the process of providing employment to persons with disabilities already in employment.

5.2.2 National Legislation

- I. **All the laws/policies regulating** the inclusion of people with disabilities in employment and **in HEI**.

Internal rules on the conditions and procedure for granting access to public information

LAW on protection against discrimination

Personal Assistance Act

Medical Devices Act

Law on family allowances for children

Social Services Act

Social Assistance Act

Disabled Persons Act

Order No 01 - 364 of 22.05.2019 List of medical devices intended for people with disabilities

Order No 01 - 365 of 22.05.2019 Maximum amounts of targeted aid for the manufacture, purchase and/or repair of aids, devices, equipment and medical devices for people with disabilities

Order No 01-366 of 22.05.2019 List of aids and equipment for people with disabilities

Order No. 09-296 of 24.08.2007 of the Minister of Health on determining the list of medical devices that may be sold in establishments other than those referred to in Article 83, paragraph 1 of the Medical Devices Act.

Convention on the Rights of Persons with Disabilities

METHODOLOGY for carrying out individual assessment of support needs for people with disabilities

REGULATION on medical expertise

DIRECTIVE No. 02-20-2 of 26.01.2021 on determining the requirements for accessibility and universal design of the elements of the accessible environment in the urban area and of buildings and facilities.

DIRECTIVE No 06-51 of 27.08.2021 on the conditions and procedure for providing free of charge interpretation services in Bulgarian sign language.

DIRECTIVE No. 07-6 of 20.06.2019 on the procedure for control over the use of funds from reimbursed social security contributions of employers, respectively appointing authorities, specialized enterprises and cooperatives of people with disabilities and labour-medical bases
Ordinance No. 07-8 of 24.07.2019 on the conditions and procedures for the implementation and control of activities on the provision and repair of aids, devices, equipment and medical devices for people with disabilities.

NATIONAL STRATEGY FOR PERSONS WITH DISABILITIES 2021-2030.

National programme "Assistants for people with disabilities".

NATIONAL PROGRAMME FOR ACCESSIBLE HOUSING AND PERSONAL MOBILITY UNDER ARTICLE 56, PARAGRAPH 1 OF THE NATIONAL LAW.

NATIONAL PROGRAMME FOR THE EMPLOYMENT OF PEOPLE WITH DISABILITIES PURSUANT TO ARTICLE 44(1) OF THE DISABILITY ACT.

REGULATIONS on the activities and organisation of the National Council for Disabled Persons, the procedure for recognition of national representation of organisations of and for disabled persons and monitoring of compliance with the criteria for national representation

REGULATORY GUIDE for the implementation of the Social Services Act.

REGULATORY GUIDE for the implementation of the Social Assistance Act.

REGULATIONS for the implementation of the Disability Act.

PROCEDURES AND CONDITIONS FOR SUBMITTING SIGNALS, SUGGESTIONS AND COMPLAINTS TO THE DISABILITY AGENCY.

REGULATORY REGULATIONS of the Agency for Persons with Disabilities.

This is the link where you can find all the laws/policies in Bulgarian language

<https://ahu.mlsp.government.bg/portal/page/3>

5.3 Ireland

5.3.1 Current situation

There are no current specific accreditations or awards in Ireland nor is there a legislative code of practice specific to employing persons with disabilities. (*National Disability Authority, January 2016.*) In addition, there are no specific provisions regarding epilepsy in Irish Employment and Education Legislation. This means that epilepsy should be covered under more general disability and equality laws, but proving epilepsy is a disability can be challenging due to the nature of the condition and its heterogeneous presentations in those affected. Therefore, proceedings/requests involving people with epilepsy are often considered on a case-by-case basis, often outside of a judicial setting. Therefore, it is important to raise awareness of the impact of epilepsy in workplaces and educational institutions. Below is a list of legislative provisions that may be relevant.

5.3.2 National Legislation

Irish Employment and Education Legislation: Disability and Equality

<https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html>

<https://www.oireachtas.ie/en/bills/bill/2003/34/>

<https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-for-employers/what-does-the-law-say/eea-summary/>

<https://www.irishstatutebook.ie/eli/2018/act/14/enacted/en/html>

<https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-for-employers/what-does-the-law-say/eea-summary/>

<https://www.justice.ie/en/JELR/Pages/WP17000244>

<https://www.ahead.ie/equalstatusacts>

<https://www.ihrec.ie/>

<https://www.ahead.ie/disabilityact>

<https://www.ahead.ie/employmentequalityacts>

<https://www.ahead.ie/specialneedsact>

https://www.citizensinformation.ie/en/employment/equality_in_work/equality_in_the_workplace.html

https://www.citizensinformation.ie/en/employment/employment_and_disability/working_with_a_disability.html

<https://www.employersforchange.ie/Reasonable-Accommodation>

<https://www.irishstatutebook.ie/eli/2005/act/10/enacted/en/html>

<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:EN:HTML>
<https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html>
<https://www.ahead.ie/graduate>
https://www.citizensinformation.ie/en/employment/enforcement_and_redress/equality_tribunal.html#I910ea
https://www.workplacerelations.ie/en/what_you_should_know/equal-status-and-employment-equality/employment-equality/employment-equality/
<https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-in-the-provision-of-good-and-services/what-does-the-law-say/education/>
https://www.childrensrights.ie/sites/default/files/submissions_reports/files/Child_Law_Audit_chapter1.pdf
https://www.citizensinformation.ie/en/education/the_irish_education_system/special_education.html
<https://nda.ie/disability-overview/key-policy-documents/report-of-the-commission-on-the-status-of-people-with-disabilities/a-strategy-for-equality/a-strategy-for-equality-report-of-the-commission-on-the-status-of-people-with-disabilities/education/>
https://www.citizensinformation.ie/en/education/the_irish_education_system/special_education.html

5.4 Germany

5.4.1 Current situation

Inclusion and Employment in the European Union: Legal framework

By 2020, 20% of the entire EU population have some form of disability. Building on *the Charter of Fundamental Rights of the EU*, the EU and its member states are committed to improving the social and economic situation of persons with disabilities.

The first important legal milestone internationally is the signing of *the UN Convention on the Rights of Persons with Disabilities* (UNCRPD) in 2007. UNCRPD is the first international, legally binding instrument setting minimum standards for rights of people with disabilities. The Convention came into force on 3 May 2008, and by April 2022 it has 184 states worldwide plus the EU. UNCRPD is also the first human rights convention to which the EU has become a party, and it entered into force on 22 January 2011. By ratifying the UNCRPD in 2010, the EU made the commitment to guarantee the fundamental rights of people with disabilities.

Based on the Convention, the EU drafted and signed *the European Disability Strategy 2010 – 2020*, which reflects the main elements of the UN Convention.

The action plan covers eight areas: accessibility, participation, equality, employment, education, social protection and inclusion, and health and external action. As regards employment, the strategy stresses the need to increase the participation of persons with disabilities in the labour market, where they are currently under-represented. The strategy's fourth objective is to 'enable many more people with disabilities to earn their living on the open labour market' by means of:

- analysing the labour market situation of people with disabilities;
- fighting those disability benefit cultures that discourage people with disabilities from entering the labour market;
- helping their integration in the labour market with the use of the European Social Fund (ESF);
- developing active labour market policies;
- making workplaces more accessible;
- developing services for job placement, support structures and on-the-job training.

Following *the European Disability Strategy 2010 – 2020*, the European Commission adopted *the Strategy for the rights of persons with disabilities 2021 – 2030* in March 2021, which aims to empower persons with disabilities so that they can participate fully in society and economy. Some of the key priorities of the strategy include that all persons with disabilities in Europe shall:

- have equal opportunities, equal access to participate in society and economy;
- are able to decide where, how and with whom they live;
- move freely in the EU regardless of their support needs;
- and no longer experience discrimination.

This new and strengthened Strategy includes 7 flagship initiatives and 64 concrete actions. It takes account of the diversity of disability comprising long-term physical, mental, intellectual or sensory impairments (in line with Article 1 of the [UNCPRD](#)), which are often invisible. The new strategy therefore contains an ambitious set of actions and flagship initiatives in various domains and has numerous priorities, such as having a decent quality of life and to live independently as it focuses notably on the deinstitutionalisation process, social protection and non-discrimination at work.



Figure 32 Strategy for the Rights of Persons with Disabilities in Europe from 2021 to 2030.

(<https://ec.europa.eu/social/main.jsp?catId=1484&langId=en>)

The 2021-2030 Strategy is also closely monitored by the EU. [The first update report](#) was published on 25 May 2022, and it stated that “out of seven flagship initiatives of the Strategy, two have already been delivered:

- establishing the **Disability Platform**, where EU countries, civil society and institutions work together on making the goals of the Strategy a reality
- a **renewed Human Resources (HR) Strategy** for the European Commission, with actions to promote diversity and inclusion of persons with disabilities

More flagship initiatives will be adopted in the coming months and years:

- a **package to improve the labour market outcomes of persons with disabilities** (second half of 2022);
- a European resource centre **AccessibleEU** (2022). AccessibleEU will provide information and good practices on accessibility across sectors;
- a proposal for a **European Disability Card** that would apply to all EU countries (by the end of 2023). The card will make it easier for persons with disabilities to get the proper support when they travel or move to another country in the European Union;
- guidance recommending improvements on **independent living** and inclusion in the community (2023);

- Framework for Social Services of Excellence to improve the quality of **community-based services** for persons with disabilities (2024).

The same report also provided the current statistics, that across the EU, only half (50.8%) of persons with disabilities are **employed** compared to 3 in 4 (75%) persons without disabilities. The monitoring table will be updated on an annual basis and the next update is scheduled in January 2023.

5.4.2 National Legislation

Inclusion and employment in Germany

Besides ratifying the UNCRPD, Germany has a history of legislation to secure the rights of people with disabilities. After the Second World War, “Severely Damaged Act” was introduced in 1953, mainly focused on injured veterans. It proposed a quota system, which set the model for the employment of persons with disabilities for the decades to come. The “Severely Damaged Act” was replaced in 1974 by “Severely Handicapped Persons Act”, which regulates the quota system systematically and expands the definition of disability. The definition was further expanded in 2001 through the Social Code (Sozialgesetzbuch), which is a comprehensive legislation on rehabilitation and participation of persons with disabilities. It consolidates the previous laws over this issue, and it is still the most important legal framework when it comes to employment of persons with disabilities.

The Social Code further establishes the quota system, which contains the obligation of all employers to employ severely disabled persons. In a workplace with 20 or more employees, the proportion of severely disabled employees must be at least 5% of the workforce. In a workplace with less than 40 employees, the employer must employ at least one severely disabled employee (or equivalent). In a workplace with 40 – 60 employees, the employer must employ at least two severely disabled persons. In case of non-compliance with the quota, the employer must pay financial compensation to the administrative authority.

“Inklusionsbetriebe” (commonly translated as “social firms”) are established in Germany to support people with disabilities with better access to the job market. Originally created in Italy in the 1970s, social firms provide people with disabilities safe and healthy working conditions with additional vocational training. In Germany social firms receive financial support for equipping their facilities based on the needs of their employees, and the proportion of people with disabilities must be between 30 – 50% of all the employees.

Based on the Social Code of Germany, every employer who employs at least one severely disabled employee, is obliged to appoint an inclusion officer (Inklusions Beauftragter). The key task of the inclusion officer is to represent the employees with disabilities, advocating their rights as well as improving the working condition at the workplace. The absence of an inclusion officer can result in a fine up to 10,000 Euro. For bigger companies with at least 5 employees with disabilities, a representative body (Schwerbehindertenvertretung) can be elected on the initiative of at least 3 employees with disabilities. This representative body operates similarly as a work council, and it must be consulted (in addition to the work council) before the dismissal of an employee with disability.

Furthermore, the Social Code also regulates that the workspace must be adapted to the specific needs of employees with disabilities. They are also granted an additional leave of five working days per year (prorated in case of part-time work) and have the possibility to ask to be exempted from overtime work.

In 2019, about 7.9 million people were living with a severe disability in Germany, representing 9.5% of the population. About 40% of the people with severe disabilities, roughly 3.2 million, were at working age between 25 and 64 years old. And among these 3.2 million people with severe disabilities who are at working age, only 46.9% of them have a job, in contrast to 75.2% of the general population.

Compared to the statistics at the European level, where 50.8% of people with disabilities are **employed** compared to 3 in 4 (75%) persons without disabilities, Germany is lagging behind. This points to the enormous space for improvement in the current German labour market, as well as the problematic system of education and training that lay the ground for this disappointing outcome. With the EpilepsyPOWER project, we hope to do our humble part to make a contribution in this field.

Inclusion and HEI in Germany

As a result of the federal structure within Germany, the policies concerning HEI remain the capacities of each federal state (*Bundesland*). This means that the concrete policies supporting students with disabilities at HEI vary from state to state. In most federal states, students with disability or chronic illness are able to require “inclusion assistance” (*Eingliederungshilfe*) through the social service providers, based on Article 53 and 54 of the Social Code XII (§§ 53 and 54 SGB XII). The inclusion assistance aims to protect students with disabilities, and to reduce the potential impact resulting from the disabilities, which includes supporting education for future occupation.

In practice, HEI institutions in Germany commonly offer “study assistance” (*Studienassistenz*) to students with disabilities. Study assistance is intended to provide the necessary support during studies due to disability or illness. It is usually provided by students from the same semester in the same major. These study assistants can take notes during classes or help with the preparation and revision of the course material, for example. If necessary, the disability officers at the universities can help with the selection of suitable study assistance.

5.5 France

5.5.1 Current situation

Access to employment for people with disabilities remains difficult. Employment is the first area in which discrimination based on disability occurs.

Among the population of people with disabilities, not all of them apply for administrative recognition as disabled workers (RQTH).

For people who apply for and obtain recognition as disabled workers, we find that:

- Unemployment rate of disabled workers is twice that of the non-disabled population.
- Longer duration of unemployment
- But the employment rate is increasing.

Despite a restrictive legal framework obliging companies in the private and public sectors to hire or keep disabled workers in employment, the 6% employment obligation is not reached by companies.

Access to employment for disabled workers (definition below) remains difficult.

- For data on the evolution of the employment obligation for disabled workers.
<https://dares.travail-emploi.gouv.fr/donnees/lobligation-demploi-des-travailleurs-handicapes-oeth>

· All the latest information on this document:

https://www.agefiph.fr/sites/default/files/medias/fichiers/2021-10/Agefiph-TB-1sem21_BD.pdf

5.5.2 National Legislation

· Inclusion of people with disabilities in employment:

In France, the legislation guarantees an equivalent access to education and employment.

The International Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly on December 13, 2006, and ratified by France in 2010, has been transposed into national legislation through several laws.

The aim of the current legislation on the subject of disability, since 2005, is the inclusion of people with disabilities in society.

<https://www.vie-publique.fr/eclairage/19409-chronologie-evolution-du-regard-sur-les-personnes-handicapees>.

The law gives the following definition of disability:

“For the purposes of this Act, a disability is any limitation of activity or restriction of participation in society suffered by a person in his or her environment because of a substantial, lasting or permanent impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling health condition.”

Disability is linked to a context, a situation. It's different from impairment, which is due to health problems.

Handicap situations, in the workplace, arise from the mismatch between the work situation and the abilities of the person concerned. A deficiency does not necessarily lead to a situation of handicap or, a fortiori, to administrative recognition of disability, so that a deficiency will constitute a disability in some situations but not in others.

This point is important to understand the mechanism of recognition of disability in France.

To have a disability does not necessarily lead to a situation of handicap in the workplace and recognition as a disabled worker.

Workers are recognized as disabled by an official commission (CDAPH). This recognition of disabled workers is intended for “all persons whose possibilities of obtaining or keeping a job are effectively reduced following the alteration of one or more physical, sensory, mental or psychological functions”. It is the result of a voluntary approach by the person with a disability. There is no obligation for him or her but this administrative recognition gives access to financial aids and to “the obligation to employ disabled workers” (BOE in French). 2,7 million people have a recognition of disabled workers. They represent 6.5% of the population aged 15-64 (2020 –AGEFIPH – see above link to the document).

This obligation applies to both private and public sector companies, with at least 20 employees, and sets the percentage of their jobs filled by handicapped workers at 6%.

Companies declare the number of jobs held by disabled workers. When they fall below the 6% threshold, they must pay a financial contribution. This contribution will be used to finance aids to compensate for the disability in the preparation, access, maintenance and development of employment, both for disabled workers and for companies. Companies can also reduce their financial contribution by subcontracting through adapted companies. These companies employ disabled workers who are unable to enter the regular work environment.

The latest law of 2018 emphasises direct employment and implements measures to promote access to employment via internships, apprenticeships, but also the gradual transition between the sheltered workplace and work in companies.

There is the principle of non-discrimination, which prohibits denying access to training or employment on the basis of health or disability, among different patterns.

Since 2005, all employers (private and public), regardless of their workforce, have an obligation to make "reasonable accommodation" for disabled workers. The objective is to guarantee equal treatment of disabled workers in all work and employment situations.

"The obligation of reasonable accommodation does not aim to favour the disabled person over another, because of his or her disability, but rather to compensate for the inequality induced by the disability, in a concrete situation, by implementing the necessary adjustments to enable

him or her to be on an equal footing with others. This conception of equality, called "real" as opposed to "formal" equality".

<https://www.defenseurdesdroits.fr/fr/guides/guide-amenagement-raisonnable>.

This translates into concrete measures adapted to individual needs in a concrete work situation that the employer is obliged to take to enable a disabled worker to access, perform or progress in a job. The obligation of reasonable accommodation is not aimed at disabled persons considered in the abstract, but at THE disabled person, in his or her work environment. As soon as his or her disability justifies it, equal treatment will result in active and continuous adaptation of the work situation to the needs of the disabled person.

The adjective "reasonable" is important in the obligation of reasonable accommodation. The employer no longer has this obligation when the accommodation required by the disabled worker objectively represents a disproportionate burden for the company. Moreover, the employer could be held liable. By maintaining a disabled worker in a position that is not adapted to his or her needs, this would be tantamount to endangering the worker and creating a risk to his or her health and safety. In this case, the employer would be failing in its obligation of result in terms of safety at work.

According to the Human Rights Defender (Défenseur des Droits), "Although it has been included in national legislation since the law of February 11, 2005, the obligation of reasonable accommodation, provided for by the Convention, remains largely unknown to employers and, more generally, to those involved in professional integration and is therefore little respected in practice." (Guide: Emploi des personnes en situation de handicap et aménagement raisonnable. L'obligation d'aménagement raisonnable comme garantie de l'égalité de traitement dans l'emploi. Défenseur des Droits. Décembre 2017. <https://www.defenseurdesdroits.fr/fr/guides/guide-amenagement-raisonnable>)

Inclusion of people with disabilities in employment and in HEI

The principle of inclusion of people with disabilities also applies to education.

Since 2005, several laws have provided for various measures to enable children and adolescents with disabilities to attend school in a mainstream environment.

In 2005-2006, 151,500 children and adolescents with disabilities were enrolled in mainstream schools. There were approximately 360,000 at the start of the 2019-2020 school year.

As seen in the first part, this has had an impact on higher education.

All higher education institutions are required to adapt their courses to the particular needs of students with disabilities and to appoint a disability advisor. This person is the dedicated contact for adapting the chosen course to the student's needs. The disability can be compensated for in order to offer good study conditions through concrete aids studied with the disability advisor before registration. Each disabled student has a right to examination accommodations.

Measures exist to help cover the additional costs related to disability in terms of housing and travel.

This legal framework applies of course to people with epilepsy, as soon as they are recognized, on the administrative level, as a disabled person.

6. “Study on the recent research and advances on the impact of epilepsy in the workplace” in each partner country

6.1 Italy

6.1.1 Projects and initiatives

As regards Projects, we should mention two Italian projects promoted by LICE (Italian Chapter of ILAE). The first one is a Position paper about employability of PwE. The second one is a narrative medicine project.

Position Paper

FIE Federazione Italiana Epilessie, LICE, ISTUD, BIAL and Health Ministry all together promoted creation of a position paper about employability in PwE between March and July 2020. Its main aims are:

1. to develop specific programmes to include PwE in workplace;
2. to make counselling and support PwE in order to get the right job;
3. to increase their job opportunities.

In this paper, they have evidenced the crucial role of schools in increasing knowledge about epilepsy and developing educational programs. Indeed, providing information about disease helps to reduce misconceptions and strengthen work inclusion. Secondary objectives of this project included reducing stigma and helping PwE with disclosure's issues.²

Narrative Medicine Project

The narrative medicine project was promoted by LICE and FIE and it focused on narration of epilepsy in the workplace.³

This project was made up of a comprehensive survey about demographic and clinical factors (e.g., seizure frequency), experience in the workplace (seizures in workplace, disclosure, etc.) and the specific request to provide a narration about epilepsy in the workplace. About 147 PwE were included, 71% females and 29% males. They were divided in two populations: people who have received epilepsy diagnosis in school period 67% and people receiving epilepsy diagnosis in work period 33%. Mean age of the population considered was 41 years old.

² https://www.lice.it/pdf/Position_Paper_Epilessia_e_Occupazione.pdf

³ https://www.lice.it/pdf/REPORT_progetto_Storie_di_Epilessia_e_Lavoro.pdf

As regards school achievement: 43% of the population completed University/Master; 42% High school; 15% primary school.

As regards employment: 60% were employed; 24% unemployed; 16% underemployed.

As regards clinical features: 30% were Drug resistant; 34% were seizure free.

In this project they have the possibility to explore PwE expectations and perceptions about how epilepsy impacts on job attainment.

As regards disclosure during job interviews:

- among people with epilepsy diagnosis during school period: 27% did not disclose Epilepsy; 16% disclosed Epilepsy; 57% of the population did not answer.
- Among people with epilepsy diagnosis during work period: 56% have disclosed epilepsy.

Globally, people with drug resistant epilepsy tend to disclose more about their disease, maybe because of the inevitability of disease manifestations.

Most important, 14% of this population have reported refusal to hire by employers when disclosing Epilepsy during interviews.

Among most narrations, driving licence appears to be a recurrent theme, as it is part of independence instruments for PwE in daily life.

Most of the respondents (90%) declared to be satisfied with the actual job position and have good relationships with colleagues and employers (82%).

6.2 Bulgaria

6.2.1 Projects and initiatives

Introduction: Disability rights policy is concerned with the universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need to ensure that persons with disabilities enjoy their full rights without discrimination of any kind, applying an integrated method in its management. This policy applies a personality-oriented approach, which is also based on human rights and aims at ensuring the full participation of persons with disabilities in society.

Projects and programmes

NATIONAL MEASURES AND PROGRAMMES

Incentives for employers to hire persons with permanent disabilities

Encouraging employers to employ the unemployed with permanent disabilities in temporary, seasonal or part-time work

Encouraging employers to employ the unemployed with permanent disabilities in temporary, seasonal or part-time work	
Main objective	Employment of unemployed persons with permanent disabilities in temporary, seasonal or part-time work for up to 6 months.
Target group	<ul style="list-style-type: none"> • Unemployed persons with permanent disabilities.
Employer grants	<p>For each unemployed person employed for the time he/she has been in work, funds from the national budget are provided for:</p> <ul style="list-style-type: none"> - wages, in the amount of: <ul style="list-style-type: none"> - BGN 310 for persons with secondary education and below; - BGN 350 for persons with higher education; - additional remuneration at the minimum rates established in the Labour Code; - remuneration for basic paid annual leave under Article 155 or Article 319 of the Labour Code; - social security contributions at the employer's expense to the Social Security Funds, on the gross wages received, including accrued and unpaid gross wages, or on the gross wages not accrued, as well as to the funds for Supplementary Compulsory Pension Insurance and the National Health Insurance Fund; - the cash remuneration referred to in Article 40 para 5 of the CCS.
Grant period	Not more than 6 months
Rights, obligations and employer's penalties	<ul style="list-style-type: none"> - create temporary, seasonal or hourly employment; - conclude an employment contract with the unemployed person for up to 6 months; - in the event of non-fulfilment of the contract, refund the funds received in accordance with the contract
The procedure	An employer willing to use the preference must go through the following steps:

	<p>- to submit to the Directorate of the Labour Office an application form for vacancies and the necessary documents for the use of the incentive;</p> <p>After approval by the Cooperation Council:</p> <ul style="list-style-type: none"> • enter into a contract in an approved form with the Directorate of the Labour Office for the provision of funds from the National Budget;
--	---

Encouraging employers to hire unemployed persons with permanent disabilities or military disabilities

Encouraging employers to hire unemployed persons with permanent disabilities or military disabilities	
Main objective	Providing employment to unemployed persons with permanent disabilities for a period of 12 months.
Target group	<ul style="list-style-type: none"> • Unemployed persons with permanent disabilities, including war invalids.
Employer grants	<p>For each unemployed person employed for the time he/she has been in work, funds from the national budget are provided for:</p> <ul style="list-style-type: none"> - wages, in the amount of: <ul style="list-style-type: none"> - BGN 310 for persons with secondary education and below; - BGN 350 for persons with higher education; - additional remuneration at the minimum rates established in the Labour Code; - remuneration for basic paid annual leave under Article 155 or Article 319 of the Labour Code; - social security contributions at the employer's expense to the Social Security Funds, on the gross wages received, including accrued and unpaid gross wages, or on the gross wages not accrued, as well as to the funds for Supplementary Compulsory Pension Insurance and the National Health Insurance Fund; - the cash remuneration referred to in Article 40 para 5 of the CCS.
Grant period	Not more than 6 months

Rights, obligations and employer's penalties	<ul style="list-style-type: none"> • create jobs and keep them for at least 12 months; • conclude an employment contract with the unemployed person for a period of not less than 12 months; • may successively employ more than one unemployed person in the advertised job • in the event of non-fulfilment of the contract, refund the funds received in accordance with the contract.
The procedure	<p>An employer willing to use the preference must go through the following steps:</p> <ul style="list-style-type: none"> - to submit to the Directorate of the Labour Office an application form for vacancies and the necessary documents for the use of the incentive; <p>After approval by the Cooperation Council:</p> <ul style="list-style-type: none"> • enter into a contract in an approved form with the Directorate of the Labour Office for the provision of funds from the National Budget;

<p>Encouraging employers to hire the unemployed under the age of 29 with permanent disabilities , people with military disabilities, and young people from social institutions who have completed their education</p>	
Main objective	Ensuring the employment of unemployed young people for a period of 12 months.
Target group	<ul style="list-style-type: none"> - Unemployed persons up to age 29 with a permanent disability or military disability; - Young people from social care institutions who have completed their education.
Employer grants	<p>For each unemployed person employed for the time he/she has been in work, funds from the national budget are provided for:</p> <ul style="list-style-type: none"> - wages, in the amount of: <ul style="list-style-type: none"> - BGN 310 for persons with secondary education and below; - BGN 350 for persons with higher education; - additional remuneration at the minimum rates established in the Labour Code;

	<ul style="list-style-type: none"> - remuneration for basic paid annual leave under Article 155 or Article 319 of the Labour Code; - social security contributions at the employer's expense to the Social Security Funds, on the gross wages received, including accrued and unpaid gross wages, or on the gross wages not accrued, as well as to the funds for Supplementary Compulsory Pension Insurance and the National Health Insurance Fund; - the cash remuneration referred to in Article 40 para 5 of the CCS.
Grant period	Not more than 6 months
Rights, obligations and employer's penalties	<ul style="list-style-type: none"> • create jobs and keep them for at least 12 months; • conclude an employment contract with the unemployed person for a period of not less than 12 months; • may successively employ more than one unemployed person in the advertised job • in the event of non-fulfilment of the contract, refund the funds received in accordance with the contract.
The procedure	<p>An employer willing to use the preference must go through the following steps:</p> <ul style="list-style-type: none"> - to submit to the Directorate of the Labour Office an application form for vacancies and the necessary documents for the use of the incentive; <p>After approval by the Cooperation Council:</p> <ul style="list-style-type: none"> • enter into a contract in an approved form with the Directorate of the Labour Office for the provision of funds from the National Budget;

Programmes and projects to support people with disabilities:

- National Employment and Training Programme for People with Permanent Disabilities
- National programme "Assistants for people with disabilities"
- Association of Parents of Children with Epilepsy member of the World Bureau of Epilepsy and the National Council for People with Disabilities
- PROJECT "COMPLEX FOR ELDERLY AND DISABLED PEOPLE IN THE MUNICIPALITY OF VRATSA"
- PROJECT "SOCIAL INCLUSION OF PERSONS WITH MENTAL DISORDERS AND INTELLECTUAL DISABILITIES"

ACTIVITIES OF THE DISABILITY AGENCY

The provision of employment, vocational rehabilitation and full social inclusion for people with disabilities represent a significant part of the activities of the Agency for Persons with Disabilities, which is primarily a support to achieve independent and self-reliant living for these beneficiaries. And in 2021 the Agency for Persons with Disabilities continued its work in this direction. Specifically, the activity is expressed in various programmes and measures implemented by the Agency. Funding of projects under the programmes is carried out on the basis of Methodologies approved by the Minister of Labour and Social Policy or the Executive Director of the Agency for Persons with Disabilities. These documents, which have the force of legal acts, are binding on all stakeholders in the procedures for the recruitment and financing of projects and contain: the object, scope and conditions for applying; the documents required and specific requirements for applying; the procedure and criteria for evaluating and ranking project proposals; the purpose and amount of the financial resources; the procedure and conditions for the implementation of the activities to be carried out; the mechanism and time limit for financing and the monitoring and control of the financed projects; the procedure for In 2021, the competitive procedures for the solicitation and financing of projects were conducted on the basis of the following normative documents:

- *Link to the document and annexes of the National Programme for Employment of Persons with Disabilities - <https://ahu.mlsp.government.bg/portal/page/83>*
- *Link To The Document And annexes For Employers Under Article 49 Of The Disability Employment Act - <https://ahu.mlsp.government.bg/portal/page/84>*
- *Link To The Document And Annexes Of The Programme For Starting And Developing Self-Employment Of People With Disabilities - <https://ahu.mlsp.government.bg/portal/page/87>*
- *Link To The Document And Annexes Of The Programme For Rehabilitation And Integration Of People With Disabilities- <https://ahu.mlsp.government.bg/portal/page/86>*
- *Link To The Document And Annexes Of The Programme For Building An Accessible Environment For People With Disabilities - <https://ahu.mlsp.government.bg/portal/page/85>*
- *Link To The Document And Annexes Of The Programme For The Establishment Of Protected Employment Centres - <https://ahu.mlsp.government.bg/portal/page/90>*

6.3 Ireland

6.3.1 Projects and initiatives

Introduction: The below results are based on the work of Epilepsy Ireland; listing their activities (advocacy and awareness-raising, information provision, capacity-building, evidence generation and research) in the areas of employment and education. From the results below, it is clear that much content exists at the national level but a pan-European approach could add value.

Epilepsy Ireland is an organisation whose vision is to achieve a society where no person's life is limited by epilepsy.

In pursuance of this vision, much of their work is around providing information and support to people with epilepsy on the wider societal impact of epilepsy – which, of course, includes a focus on educational and employment issues.

To this end, Epilepsy Ireland have developed information packs on education and employment for people with epilepsy, employers and educators. See below:

[Epilepsy in the Workplace - A Information Resource for Employers](#)

[Education Information Pack - An Epilepsy Resource for Pre-Schools, Schools and Colleges](#)

These resource packs are also supplemented by training/workshops to employers on the subject of Epilepsy and Employment, delivered in-house to companies by Epilepsy Ireland.

They also run workshops for people with epilepsy on topics related to education and employment. In fact, one of Epilepsy Ireland's most unique pillars of activity is its Training For Success (TFS) programme: a one-year, free, QQI level 5 course for people with epilepsy, aiming to overcome the barriers created by epilepsy to equitable educational and employment opportunities.

It is the only course of its kind in Europe and is only available at Atlantic Technological University, Sligo.

Throughout the year, the students learn more about how to self-manage their epilepsy while also being presented with opportunities to develop vital skills that are required for entering the workforce or pursuing further education.

Modules on the course include Research & Study Skills; Communications; Health and Safety at Work; Customer Service and more.

Participating students may be eligible for a training allowance payment or be able to retain their existing social welfare payment. There are no educational requirements for entry on the course, but prospective students must be capable of independent living, as they will have the full on-campus, university experience.

85% of students who have completed the course, have gone on to further education or employment.

Once in further education or employment, people with epilepsy then face the issue of disclosing their condition.

Epilepsy Ireland has produced a [How2Tell Booklet](#) – designed for people with epilepsy who want to learn how to tell others about their epilepsy. It covers topics like: Why Tell, Who to Tell, When to Tell and How to Tell. This is important for those in education and employment so that they are empowered to tell their teachers and classmates, or employers and colleagues, about their epilepsy. Disclosure can lead to improved safety, strengthened relationships, development of a support network, provision of support and reduction in alarm.

Following disclosure, it is important that employers and educators are open-minded in seeing the potential of the person with epilepsy, and not just focusing on the disability.

With this in mind, Epilepsy Ireland & Headway (an organisation serving people with brain injury), developed the *I See Beyond* campaign, which challenged audiences to ‘see beyond’ the disability and consider what the person living with the condition might be going through. This campaign targeted both employees and employers. See below:

<http://iseebeyond.ie/about-us/>

<http://iseebeyond.ie/employee/>

<http://iseebeyond.ie/employers/>

Almost 18 months after an initial survey to assess attitudes in the workplace to hidden disability, and a year after the campaign was launched, a national survey conducted by Amárach Research showed its positive impact. This included:

- 85% rise in awareness towards hidden disabilities in Irish workplaces and places of education, since 2016
- 78% of people surveyed would hire someone with a hidden disability if they were an employer
- An increase of 36% of people who feel comfortable telling their employer they have a hidden disability.

Aside from the development of such resources, Epilepsy Ireland has also been active in advocating for rights of people with epilepsy in educational settings and in the workplace. This had included submissions to the Department of Education on Reasonable Accommodations for State Exams, but also submissions to companies to secure reasonable accommodations at work for people with epilepsy.

[Submissions available on request]

Such advocacy, awareness-raising, capacity-building and resource-development needs to be evidence-based. Therefore, Epilepsy Ireland has also conducted its own research on the societal impact of epilepsy. It is part of Ireland's Medical Charities Research Group.

Currently, they are working with partners to analyse the societal impact of driving restrictions on both newly diagnosed and established patients with epilepsy: <https://www.epilepsy.ie/content/analysis-current-implementation-and-societal-impact-group-1-and-group-2-driving-restrictions>

The paper is currently being finalised and not yet published, but this builds on existing evidence which shows that driving restrictions can impact the ability of a person with epilepsy to secure and retain employment. More information can be found here:

<https://www.epilepsy.ie/content/driving>

https://www.researchgate.net/publication/272578279_A_Survey_Examining_the_Impact_of_Driving_Cessation_on_People_with_Epilepsy_in_Ireland

Additionally, there is much research (ongoing and previous) focussing on the educational journey of young people with epilepsy – exploring their lived experiences, in terms of challenges, supports and outcomes.

Much of this research suggests that young people with epilepsy are increasingly being integrated into mainstream schooling but are not being provided with specific/adequate learning supports/reasonable accommodations to optimise their prospects. Much of this can be connected to the fact that epilepsy is often not explicitly named as a disability in legislation related to workplace/educational settings for people with disabilities. Stigma associated with epilepsy is also still prevalent.

There is a clear need for more general awareness raising teacher training and support structures. See below:

Students with epilepsy, their experiences in school and with State exams

<https://www.ucc.ie/en/media/research/carl/SarahCookeCARLreport2017EpilepsyIreland.pdf>

Current Research - PENNI - Project on educational and neuropsychological outcomes of children with neurological disorders in Ireland

<https://www.epilepsy.ie/content/research-request-can-you-help-ucd-school-psychology>

6.4 Germany

6.4.1 Projects and initiatives

Projects at the European level

1. Facilitating Inclusion in Epilepsy: a pictorial guide

Funding program: Erasmus plus

Project Reference: 2017-1-MT01-KA204-026946

EU Grant: 59.789,00 €

Start date and end date: 01-11-2017 – 31-10-2019

Project website: <http://epipicto.eu/>

Partners:

- Caritas Malta Epilepsy Association (Lead)
- Austria Epilepsie Dachverband Österreich
- Epilepsy Connections (Scotland/UK)
- Netherlands Stichting Epilepsie Instellingen Nederland
- Deutschlands Interessenvereinigung für Anfalls Kranke in Köln e.V.

Awarded with “Good practice”

This Erasmus+ project thus had the aim to develop a pictorial guide for adult persons with epilepsy (PwE) and their carers who are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe and persons with low literacy levels and low health literacy.

The output from this project is the EPIPICTO pictorial guide was the first such guide developed for use with adult PwE and thus contributed to the social inclusion of these persons by providing them with tailored information using a pictorial guide to overcome language barriers and literacy issues and thus helped them to better manage their epilepsy. It also provided more knowledge about epilepsy; improved the health-seeking behaviour of PwE; contributed to an improved quality of life for PwE; contributed towards a reduction of stigma based on misinformation and ignorance.

0. An European pilot network of reference centres in refractory epilepsy and epilepsy surgery

Funding program: 2nd Health Program (2008 – 2013)

Project Reference: JA2015 - GPSD [705038]

EU Grant: 1.429.420,00 €

Start date and end date: 01-01-2014 – 01-01-2017

Project website:

https://webgate.ec.europa.eu/chafea_pdb/health/projects/20131203/summary

Partners:

- Universite Claude Bernard Lyon (Lead)
- University College London
- Aristotle University Of Thessaloniki
- Christian Doppler Klinik - Universitätsklinik Für Neurologie
- University Hospital “Saint Ivan Rilski”
- University Clinical Hospital “Sestre Milosrdnice”
- Göteborgs Universitet
- Universitaetsklinikum Bonn

- Diakonie Kork Epilepsiezentrum
- Azienda Ospedaliera Niguarda Ca'granda
- Universitair Medisch Centrum Utrecht
- Oslo University Hospital
- Univerzita Karlova V Praze

E-PILEPSY aims at achieving significant and sustained progress in the quality and harmonisation of healthcare provision delivered to children and adults with refractory epilepsy across Europe.

More specifically, we wish to trigger accelerated development of epilepsy surgery, the one treatment option offering reasonable chances for definite cure, by promoting cooperation between highly specialised neurology, clinical neurophysiology and neurosurgery centres in all EU regions.

We will reduce current inequalities between EU countries in all aspects related to refractory epilepsy (expertise, quality of care, policies), increase and facilitate access to epilepsy surgery by working with all stakeholders (patients, professionals, policymakers), and optimise presurgical diagnostic procedures to offer a greater chance of postoperative seizure freedom at reduced risk of surgery related complication and morbidity.

Projects at the national level

1. TEA – Teilhabe – Epilepsie – Arbeit

Funded by the Federal Ministry of Labour and Social Affairs & Diaconia of Munich

The project aims to support people with epilepsy at the workplace. They offer individual consultation for employers and employees, workplace inspection, and organise events and training programs. They are active across the country; all the service is completely free.

The project lasted 3 years and ended on 31 October 2021

Project website: <https://www.epilepsie-arbeit.de/>

0. “Brücken bauen” – building bridges

Funded by the Federal Ministry of Labour and Social Affairs

Implemented by

Berufsbildungswerke (vocational training centers) Waiblingen und CJD Offenburg, and Epilepsiezentrum (Center for Epilepsy) Kork

The cooperation project aims to support the sustainable integration of young people with epilepsy into the world of work. The three institutions have the task of looking for ways to accompany young people with epilepsy into permanent employment. The project ended at the end of December 2012.

6.5 France

6.5.1 Projects and initiatives

Inclusion in HEI

Recent information in the attached document in HEI in general:
https://publication.enseignementsup-recherche.gouv.fr/eesr/FR/T243/les_etudiants_en_situation_de_handicap_dans_l_enseignement_superieur/

2020: 39 786 students with disabilities (1,82 % of the student population). x 5 since 2005.

Slower progression in the pathways compared to students in the general population, but a trend towards narrowing the gaps over the last 5 years.

Access to higher education for students with disabilities has increased, on average, by 13.5 percent each year since the start of the 2006 school year. According to a study by DARES of 2015, 49% of people with disabilities have no diploma or only the BEPC (end of the collège), compared to the 28% of the general population, 25% have a degree, a professional diploma or more, compared to the 49% of the general population.

The increase in enrolment is especially evident in universities, mainly at the bachelor's level, with few students with disabilities going on to the master's level. (Rapport du Défenseur des

droits sur la mise en œuvre de la Convention relative aux droits des personnes handicapées (CDAPH) - 2020.

<https://www.defenseurdesdroits.fr/fr/rapports/2020/07/la-mise-en-oeuvre-de-la-convention-relative-aux-droits-des-personnes-handicapees>)

In 2020, 87.7% of students with disabilities will benefit from a personalised support plan for their studies, which may include human assistance, technical assistance, and course adjustments.

Finally, 95.3% of students with disabilities benefit from special arrangements for exams.

· Recent information in the attached document in HEI/ “Grandes Ecoles” in particular:
<https://www.cge.asso.fr/publications/2020-01-16-barometre-handicap-2019/>

7. ANALYSIS OF PROJECT TARGET GROUPS OF LEARNING FEATURES AND NEEDS

The EpilepsyPower project aims to improve the inclusion of people with epilepsy (PwE) in the working system, increasing awareness of higher students and firms about the issue through the provision of targeted training and by supporting PwE in their process toward employment. The main goal is to spread a culture and a practice for the implementation of inclusion systems for PwE, based on the enhancement of knowledge and the abatement of the stigmatisation burdening PwE.

For this project, we have identified two project target groups:

- Higher Educational Institutions: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, adult people employed in organisations, recruiters, HR experts and recruitment agencies.
- People with Epilepsy.

PwE have higher rates of unemployment and underemployment. In addition, PwE often have greater difficulty keeping their jobs. Half of PwE workers do not disclose their epilepsy to potential employers when applying for jobs. Many employers refuse to hire workers with epilepsy because they wrongly believe they are more susceptible to accidents and absenteeism from work. Job restrictions imposed on PwEs, in most cases, are unfair and based on prejudices and stereotypes. The reduced employability of PwE is also sustained by the limited access of PwE to the driving licence. However, PwE are often burdened by impaired cognitive performance due to the medical condition and medications and fewer educational opportunities. This leads to lower job skills and, thus, in reduced opportunities to access any employment.

Another issue that PwE has to face is stigma: working and social marginalisation are the main determinants of the impaired quality of life and mood disorders in PwE.

To overcome these issues the project will pursue the two specific goals: - increasing the awareness of high education students and entrepreneurs on epilepsy to fight superstition, stigma and prejudice on PwE and assuring them a safe and comfortable workplace environment; - improving their job skills and their awareness for a self-assessment of the individual medical risk to focus their job research on the most suitable choice. An operational framework and learning methodology have been conducted according two specific learning paths, one for the following target groups:

- 1) PwE;
- 2) HEI's staff and end-users: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, adult

people employed in organisations, recruiters, HR experts and recruitment agencies.

The aim of the project is to develop a methodological document and to create:

- Integrated online platform for digital integrated learning, multilevel cooperation and resources sharing;
- Collaborative laboratories for best practices;
- Learning contents and classroom guidelines;
- Online tool and epilepsy label.

Also, we will develop two specific multimedia learning paths (curricula) to improve specific and transversal skills for target groups: people with epilepsy (PwE), HEI's staff and end-users: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, adult people employed in organizations, recruiters, HR experts and recruitment agencies.

Specifically, the **first one** will be focused specifically on PwE aimed to improve their knowledge and to prepare them to work in a better comfortable workplace. It will provide online training on many different sectors. For example, co-workers and employers sometimes make work difficult for young PwE for the following reasons: discrimination in the workplace, emergency events management, bullying by management, including ridicule and verbal abuse, or often, lack of communication and support. The first will be focused specifically on people with epilepsy (PwE) aimed to improve their knowledge and to prepare them to work in a better and more suitable workplace. It will provide online training on many different sectors. For example, co-workers and employers sometimes make work difficult for young PwE for the following reasons: discrimination in the workplace, emergency events management, bullying by management, including ridicule and verbal abuse, or often, lack of communication and support.

The **second learning path** will be focused on HEI's staff and end-users. The learning modules will increase the general knowledge on epilepsy with a particular focus on medical aspects and their social impacts in the workplace to remove false beliefs, prejudices and stereotypes on epilepsy. They will illustrate best practices to facilitate a safe and productive integration of people with epilepsy in the workplace. The learning process will take advantage of a rewarding process leading the entrepreneur to an **“epilepsy-friendly” company certification**. These contents will also include multimedia tutorials correctly adapted and customised on the specific needs that will be indicated from companies and associations to host young workers with epilepsy.

The two learning paths will be composed by 14 modules in total and will be adapted to the

specificness of Partners countries. At the end an assessment online tool for individual people and for organisations that aim to obtain the EpilepsyPOWER label (and so to achieve the Epilepsy Friendly mark) will be freely available by the online platform.

EpilepsyPOWER operational framework and learning methodology document will be based on a focused user-oriented approach respecting fundamental teaching principles:

1. to customise the training process, allowing learning to be adapted to the emergent opportunities, characteristics and interests of each individual, so that the learner himself become the manager of the learning process, thanks to a modular structure of the training tools;
2. to enrich the planned learning programs with any valuable contribution from each Partner;
3. to promote the ability to apply the proposed contents, so that learners involved in the training process can achieve immediate results in their practices;
4. to carry out a critical analysis to respond to emerging needs, including results from previous literature and legal aspects. in all Partners' countries.

8. TWO KEY PERFORMANCE INDICATORS (KPI)

We have identified two key performance indicators for employment in PwE: stigma and seizure severity.

Stigma

For people suffering from chronic diseases, a wide range of elements making them “different” from healthy people could represent a source of stigma. Furthermore, social disapproval, ostracism and stereotypes all contribute to increasing this feeling and elements of difference can represent a source of stigma.

Goffmann theorised the stigma as an attribute which potentially discredits an individual and his social identity (DeFleur, 1964.).

Epilepsy can be hidden: if no seizure manifests at work, PwE can work normally, especially if they are well controlled and have normal intelligence (as in most of the cases). Despite that, private and national institutions systematically pose restrictions and discriminate against PwE. Thus, stigma spread not only among PwE, but it also affects family members and friends of PwE. (Thomas & Nair, 2011)

Stigma is strictly rooted in PwE life, it impairs their perception of things and quality of life. Discrimination from colleagues and employees leads to increased stigma and self-denial, moving forward lower attainment in job (Chaplin et al., 1998; Floyd et al., 1993; Scambler & Hopkins, 1980; Thompson & Oxley, 1988).

In order to design a suitable environment for PwE, employers and colleagues should be informed.

Attitudes of employers and **stigma** belong to external factors contributing to unemployment. Indeed misconceptions, false myths surrounding PwE prompts discrimination from employers and self-denial of employees in the workplace. **Employers’ attitudes** and **unsupportive familiar environment** can hamper gaining a good employment position, thus one of the tools to fight stigma is to increase knowledge among employers (Elwes et al., 1991; Geerlings et al., 2015; Jacoby et al., 2005; Thompson & Oxley, 1988).

Seizure severity

Seizures impair daily life, in particular seizures with impairment of awareness and generalised tonic-clonic seizures. Higher frequency of seizures prompts lower quality of life, increased hospitalisation and mortality.

Although there is no consensus about how to measure seizure severity, an attempt was made in 2002, when Cramer validated the Seizure Severity Questionnaire, made up of questions about warning symptoms, ictal symptoms and post-ictal physical, emotional and cognitive effects.

Apart from clinical consequences of seizures, we know from the literature that seizure control is strictly connected to social outcomes. Indeed, the most important determinants of good employment are seizure freedom and seizure remission. Multiple studies reported **seizure severity** as the main explanation for the unemployment situation in PwE. From early 80's the correlation between active epilepsy and poor employment was clear (Scambler & Hopkins, 1980)

Active epilepsy seems to impair employment in well-controlled PwE (Jacoby, 1992). Indeed, refractory epilepsy impairs long-term social outcomes including employment (Marinas).

Seizure frequency is also linked to unemployment and underemployment ((Chaplin et al., 1998; Geerlings et al., 2015; Herodes et al., n.d.; Jacoby, 1995; Majkowska-Zwolińska et al., 2012; Rätsepp et al., 2000; Reinholdson et al., 2020; Scambler & Hopkins, 1980).

On the contrary, seizure remission and having no history of status epilepticus are positive factors in people with childhood onset epilepsy (Sillanpää & Schmidt, 2010).

Thus, we can conclude that seizure control (gained with drug therapy or surgery) is the most important factor to obtain, in order to favour social inclusion and job attainment.

9. SUCCESSFULLY INCLUSION CASES FOR EACH PARTNER COUNTRY

We reported some case reports of successful employment of PwE in the partner countries.

Italy

Case N.1

CARLA

A married woman aged 45 years old with a bachelor's degree. She started to have epilepsy at 19 years old. She takes 1 drug to control seizures,

We asked her to describe her job and her level of satisfaction:

"Today I am an entrepreneur. I lead a multifunctional agricultural company with a restaurant. Furthermore, I have a small artistic workshop where I paint with oil colours on canvas and pyrography on wood. I am fully satisfied with my job and my earning salary."

We have also asked her:

- Did you struggle with any issue when searching for a job? No, I did not.
- Have you disclosed your epilepsy to your employer? I do not have an employer.
- Have you disclosed your epilepsy to your co-workers? No, I have not.
- Are you happy with your job? If not, which are the aspects bothering you? Yes, I am fully satisfied with my job.
- Are you happy with your salary? Yes, I am fully satisfied with my salary.

Case N.2

MARCO

Marco is a married man with a University Degree. He is employed in a big company. He takes two anti-seizure medications, and he has had a focal seizure in the last 3 months. He suffers from epilepsy since he was 16 years old.

We asked how his experience in workplace was:

- Did you struggle with any issue when searching for a job? Initially, employers refused my applications, because of the disease, then I met an experienced employer who helped me in reaching my actual position.
- Have you disclosed your epilepsy to your employer? Yes, I had to be honest.
- Have you disclosed your epilepsy to your co-workers? No, I worry they could not accept me.

- Are you happy with your job? If not, which are the aspects bothering you? Yes, I am happy with my job now.
- Are you happy with your salary? Yes, I think I have reached the right attainment.
- Please, give us a brief description of your job experience (positive and negative aspects).
“Today I work for a big company, with a stable contract for 27 years and I have the right job for my academic attainment. Now I have reached the right attainment for my education, and I am fully satisfied with my job now.”

Bulgaria

Case N.1

- Name: without surname **Mariela**
- Age: **57**
- Gender: **Female**
- Marital status: **Married with 1 child**
- Educational level: **Secondary special education**
- Age of onset of epilepsy: **15 years old**
- Are you seizure free? If not, how many seizures have you had in the last 3 months? **1**
How many convulsive seizures? **I don't have one.**
- Do you take anti-seizure medications? If yes, how many? **Yes, 1 per day.**
- Did you struggle with any issue when searching for a job? **No**
- Kind of a job. **Accountant**
- Have you disclosed your epilepsy to your employer? **Yes**
- Have you disclosed your epilepsy to your co-workers? **No, But I have had seizures during working hours**
- Are you happy with your job? If not, which are the aspects bothering you? **Yes**
- Are you happy with your salary? **Yes**
- Please, give us a brief description of your job experience (positive and negative aspects).
I have had no problems at work, I started working after completing my Secondary Education and I have been working as an accountant ever since.

Case N.2

- Name: without surname **Ivan**
- Age: **32**
- Gender: **Male**

- Marital status: **Single**
- Educational level: **Bachelor degree**
- Age of onset of epilepsy: **10 years old**
- Are you seizure free? If not, how many seizures have you had in the last 3 months? **I have almost every week**
How many convulsive seizures? **4**
- Do you take anti-seizure medications? If yes, how many? **Yes, 4 per day.**
- Did you struggle with any issue when searching for a job? **No**
- Kind of a job. **Online shop**
- Have you disclosed your epilepsy to your employer? **No**
- Have you disclosed your epilepsy to your co-workers? **No. Working from home allows me to keep this confidential.**
- Are you happy with your job? If not, which are the aspects bothering you? **Yes**
- Are you happy with your salary? **No (never enough)**
- Please, give us a brief description of your job experience (positive and negative aspects).
I have had no problems at work, I started working after finishing my degree. I'm always looking for work from home, so people don't know about my condition.

Ireland

Case N.1

- Name: without surname - LORRAINE
- Age: 36
- Gender: Female
- Marital status: widow
- Educational level: Masters Level
- Age of onset of epilepsy: 8 years old diagnosed officially
- Are you seizure free? If not, how many seizures have you had in the last 3 months? How many convulsive seizures?
- Do you take anti-seizure medications? Yes, 3 and the CPD oil
- Did you struggle with any issue when searching for a job? Yes
- Kind of job- Legal work
- Have you disclosed your epilepsy to your employer? Yes
- Have you disclosed your epilepsy to your co-workers? Yes

- Are you happy with your job? If not, which are the aspects bothering you? I am self-employed and do work for individuals, companies, and organisations.

- Are you happy with your salary? Yes

- Please, give us a brief description of your job experience (positive and negative aspects)

- As an employee in the past I was not supported in employment therefore I made a decision to focus on being self-employed so that I could manage my epilepsy as well.

- The first time I shared my epilepsy in a national newspaper article which resulted in some colleagues telling me I made a huge mistake. Looking back now, the article was nearly 10 years ago.

<https://www.independent.ie/lifestyle/health/health-case-study-living-with-epilepsy-29983730.html>

- That I was placing a label on myself as a practising barrister. For me the positives were there as well with co-workers and colleagues telling me of their family experiences.

- The reactions were mixed and some of the comments were a little hurtful at the time. But you realise when you get to a certain point that your epilepsy is part of you and if you don't accept it then you are not accepting yourself. I spoke about living with epilepsy for myself and others.

Case N.2

- Name: William

- Age: 50

- Gender: Male

- Marital status: Married

- Educational level: Masters

- Age of onset of epilepsy: 10

- Are you seizure free? If not, how many seizures have you had in the last 3 months? How many convulsive seizures? 0 (Seizures irregularly now, every 2-3 years)

- Do you take anti-seizure medications? If yes, how many? 1

- Did you struggle with any issue when searching for a job? No. My epilepsy settled down when I was in college. I did well, studied hard there and got a job soon after I left with my current employer where I have worked for nearly 30 years now. I even went back to college later on to get a Master's degree by night. I wasn't cured, I still got seizures at the same frequency and had to surrender my driving licence off and on.

- Kind of job. Desk based with travel.

- Have you disclosed your epilepsy to your employer? Yes

- Have you disclosed your epilepsy to your co-workers? Yes (but not initially)

- Are you happy with your job? If not, which are the aspects bothering you? Yes

- Are you happy with your salary? Yes
- Please, give us a brief description of your job experience (positive and negative aspects).
My employer has been fantastic to me, making sure that I was fully supported if I needed to work from home on an odd day or sorting arrangements if I needed to travel about for my work which I frequently did. I never wanted for anything, and even in later years I gained the confidence to open up to my colleagues about my epilepsy, which was well received, and I thank them for the support they showed me. A major challenge is losing the driving licence after a seizure.

Germany

Case N.1

- Name:
 - o Laura
- Age:
 - o 26
- Gender:
 - o female
- Marital status:
 - o unmarried
- Educational level:
 - o A-levels and completed vocational training.
- Age of onset of epilepsy:
 - o 15
- Are you seizure free? If not, how many seizures have you had in the last 3 months? How many convulsive seizures?
 - o approx. 5 absences in the last three months. The last seizure was in 2013
- Do you take anti-seizure medications? If yes, how many?
 - o 2 medicines, approx. 1400 mg per day
- Did you struggle with any issue when searching for a job?
 - o I was not allowed to do a job with shift work, otherwise no restrictions.
- Kind of a job.
 - o Physiotherapist
- Have you disclosed your epilepsy to your employer?
 - o No, so far I have not had any good experiences with it.

- Have you disclosed your epilepsy to your co-workers?
 - o No.
- Are you happy with your job? If not, which are the aspects bothering you?
 - o No, my job doesn't fill me up and isn't as much fun as I thought it would be.
- Are you happy with your salary?
 - o The salary is ok, but it could always be more :)
- Please, give us a brief description of your job experience (positive and negative aspects).
 - o The job is physically very demanding, but relatively poorly paid.
 - o To work with people is fun but not always easy, in the short therapy time you can only achieve your goals for the patient to a limited extent.
 - o I didn't tell them about my epilepsy, because in the past they didn't take it into account, and it was perceived rather negatively.

France

Case N.1

- Name: Patrick
- Age: 45
- Gender: Man
- Marital status: Divorced with children
- Educational level: Master 2
- Age of onset of epilepsy: Diagnosed at 15 years old - Certainly before, perhaps since birth.
- Are you seizure free? No

If not, how many seizures have you had in the last 3 months? Type of crisis: "absences".
Difficult to detect. 6 or 7 / days on average but variable. Sometimes, it can be 30 attacks.

- How many convulsive seizures? None
- Do you take anti-seizure medications? Yes

If yes, how many? 2

- Did you struggle with any issue when searching for a job? No, not during the job search. I have always found a job, even after changing jobs.
- Kind of a job. Operational pilot / IT project manager. Job specifics: professional missions carried out at clients' sites.
- Have you disclosed your epilepsy to your employer? Now I do, but it was in spite of myself, on the occasion of an article on epilepsy that I had published with my name. This

information came into the professional sphere. Previously, I had carefully avoided revealing it, either in the private or professional sphere, except in cases of trust.

- Have you disclosed your epilepsy to your co-workers? It may happen that I reveal it to some people, on the occasion of more personal discussions. I may have to explain my associative responsibilities. In the past, I have always avoided revealing it.
- Are you happy with your job? No. That's not what I wanted to do. Epilepsy was a contraindication to the job I dreamed of with my friends (aeroplane pilot in the army).

If not, which are the aspects bothering you? I chose this professional orientation by having a certain taste for computers, through video games. There are less risks to work in front of a screen. But the work is boring and not motivating. I have a job that is purely "food" for me.

- Are you happy with your salary? Yes, the salary was in line with the position I held, but I voluntarily limited myself in the possibilities of professional evolution that I could have had because of my medical treatment, the fatigue and the stress inherent to professional missions.

Please, give us a brief description of your job experience (positive and negative aspects).

It's not the job I would have liked to do. But a job in IT, in front of a screen was more suitable, according to my personal reflections, with my absences.

I never had a trained person to discuss the consequences of the disability and possibly open me up to other professional sectors during my university orientation.

I have had 4 different employers in the IT sector. I had to carry out numerous missions for different clients. Sometimes, the mission had to be shortened because of fatigue.

I have only had an RQTH (administrative recognition as disabled worker) for 2 years. I never wanted to apply for it before. The time it takes to adapt to one's illness varies from person to person and can sometimes be long. The medical profession I met was never helpful in accepting the disease. There were no discussion groups.

My job is food, but it allows me to live correctly and to have a place in society. I have a function.

On the negative side, there are no real accommodations possible with absences. It is difficult to arrive with health problems at an end client. Many people I have met do not declare their disability.

A professional assessment to look for other ways would have been a plus.

The limitations and restrictions I have imposed on myself in my work mainly concern interactions and presentations with clients.

On the other hand, I am very involved in my volunteer activities, with strong responsibilities. I lead conferences, I answer interviews. I even did a television interview. In this context, I have a lot of interactions.

I don't have an explanation for this gap between my professional activity and my associative activity. My epilepsy is one of the factors of legitimacy in the role I play in the association.

Case N.2

- Name: without surname GREG

- Age: 38

- Gender: MALE

- Marital status: MARRIED

- Educational level: BACHELOR'S

- Age of onset of epilepsy: 30

- Are you seizure free? YES

If not, how many seizures have you had in the last 3 months? How many convulsive seizures?

- Do you take anti-seizure medications? YES

If yes, how many? YES. 1 MEDICATION, 800 MG/DAY

- Did you struggle with any issue when searching for a job? No

- Kind of job. Teacher at different structures (language school, universities)

- Have you disclosed your epilepsy to your employer? As needed (for example, i was not able to drive for an extended period of time after a seizure or changing treatments and informed the employer.)

- Have you disclosed your epilepsy to your co-workers? Only in passing, not as a medical or safety concern. Overall, I would feel comfortable, if needed.

- Are you happy with your job? If not, which are the aspects bothering you? Overall, yes. Thankfully, epilepsy plays practically no role in my professional life.

- Are you happy with your salary? Yes.

- Please, give us a brief description of your job experience (positive and negative aspects). As related to epilepsy or similar issues that people may have, a more active role on the part of employer (thinking of the public and private universities where i teach) could improve the feeling of safety and inclusion, for example, if i were concerned about my epilepsy and wanted professional guidance (ways to talk about it with students/colleagues, rights as employee, available resources, etc), i have no idea who, if anyone, i could ask.

Case N.3

- Name: Mel
- Age: 25
- Gender: Female
- Marital status: Single
- Educational level: Undergraduate
- Age of onset of epilepsy: 13 years old
- Are you seizure free? Yes
- *If not, how many seizures have you had in the last 3 months? How many convulsive seizures?*
- Do you take anti-seizure medications? YES

If yes, how many? 2

- Did you struggle with any issue when searching for a job?

I worked before I I went back to school. I have struggled. It's hard to find people who can understand the accommodations you need. For example, regularity of working hours: it was particularly difficult for me to work two days in a row when I finished late at night and had to start again the next morning. My employer fired me because of my epilepsy.

- Kind of job: Administrative management in the Theatre industry.
- Have you disclosed your epilepsy to your employer? During this previous experience no. But, in my current job (internship), I did.
- Have you disclosed your epilepsy to your co-workers? No
- Are you happy with your job? If not, which are the aspects bothering you?

Yes. Currently, I work in a consulting company. They take care of employees. They adapt work to your needs (tasks, work duration, lots of flexibility...). My manager and HR teams are open to talk about accommodations I can need. I work at home.

- Are you happy with your salary? Yes
- Please, give us a brief description of your job experience (positive and negative aspects).

In the United States, I attended various schools, both public and private. I had difficulty getting accommodations. I obtained my degree at 25 years old. I decided to continue my studies in France. Medication is easier to obtain in France. The state of your health is important in the decision you make. It's a positive experience. The first year went very well.

I met the disability advisor when I arrived. I was able to share my needs with her. I encountered difficulties that were not originally envisioned when the school decided to do the 1st semester exams online. The use of an e-platform for online exams wasn't adapted for me. I can't obtain some accommodations. During the 2nd semester, I obtained different conditions for my exam. The school and I also learned a lot from these exchanges.

10. BIBLIOGRAPHY

- Bautista, R. E. D., Shapovalov, D., Saada, F., & Pizzi, M. A. (2014). The societal integration of individuals with epilepsy: Perspectives for the 21st century. In *Epilepsy and Behavior* (Vol. 35, pp. 42–49). Academic Press Inc. <https://doi.org/10.1016/j.yebeh.2014.04.006>
- Beghi, E. (2016). Addressing the burden of epilepsy: Many unmet needs. *Pharmacological Research*, *107*, 79–84. <https://doi.org/10.1016/j.phrs.2016.03.003>
- Beghi, E. (2020). The Epidemiology of Epilepsy. *Neuroepidemiology*, *54*(2), 185–191. <https://doi.org/10.1159/000503831>
- Beghi, E., Cornaggia, C. M., Hauser, W. A., Loeber, J. N., Thorbecke, R., Sonnen, A. E. H., Severi, S., Zolo, P., Specchio, L. M., Specchio, N., Boati, E., Defanti, C. A., Pinto, P., Breviario, E., Pasolini, M. P., Antonini, L., Aguglia, U., Russo, C., Gambardella, A., ... Mikhailov, V. (2000). Social aspects of epilepsy in adults in seven European countries. The RESt-1 Group. *Epilepsia*, *41*(8), 998–1004. <https://doi.org/10.1111/J.1528-1157.2000.TB00285.X>
- Callaghan N, C. M. G. T. (1992). Epilepsy and employment, marital, education and social status. *Irish Medical Journal*, *1*, 17–19.
- Carreño, M., Becerra, J. L., Castillo, J., Maestro, I., Donaire, A., Fernández, S., Bargalló, N., Setoain, X., Pintor, L., Bailles, E., Rumi, J., Boget, T., Vernet, O., & Fumanal, S. (2011). Seizure frequency and social outcome in drug resistant epilepsy patients who do not undergo epilepsy surgery. *Seizure*, *20*(7), 580–582. <https://doi.org/10.1016/j.seizure.2011.04.010>
- Carreño, M., Donaire, A., & Sánchez-Carpintero, R. (2008). Cognitive disorders associated with epilepsy: Diagnosis and treatment. *Neurologist*, *14*(6 SUPPL. 1), 26–34. <https://doi.org/10.1097/01.nrl.0000340789.15295.8f>
- Carroll, D. (1992). Employment among young people with epilepsy. In *Seizure* (Vol. 1).
- Chaplin, J. E., Lasso, Y., Shorvon, S. D., & Floyd, M. (n.d.). *GENERAL PRACTICE National general practice study of epilepsy: the social and psychological effects of a recent diagnosis of epilepsy*.
- Chaplin, J. E., Wester, A., & Tomson, T. (1998). Factors associated with the employment problems of people with established epilepsy. In *Seizure* (Vol. 7).
- Collings, J. A., & Chappell, B. (1994). Correlates of employment history and employability in a British epilepsy sample. In *Seizure* (Vol. 3).
- Cooper, M. (1995). Epilepsy and employment-employers' attitudes. In *Seizure* (Vol. 4).
- Cornaggia, C. M., Beghi, M., Moltrasio, L., & Beghi, E. (2006). Accidents at work among people with epilepsy. Results of a European prospective cohort study. *Seizure*, *15*(5), 313–319. <https://doi.org/10.1016/j.seizure.2006.03.001>

- De Boer, H. M. (2005). Overview and Perspectives of Employment in People with Epilepsy. In *Epilepsia* (Vol. 46).
- DeFleur, M. L. (1964). Stigma: Notes on the Management of Spoiled Identity. By Erving Goffman. Englewood Cliffs, New Jersey: Prentice-Hall, 1963. 147 pp. Cloth, \$4.50; paper, \$1.95. *Social Forces*, 43(1), 127–128. <https://doi.org/10.1093/SF/43.1.127>
- Dorota, T., Witkowska, M., & Michalak, M. (2014). Attitudes of employees of service and trading companies towards people with epilepsy and their professional activity in Poland. *Seizure*, 23(3), 178–183. <https://doi.org/10.1016/j.seizure.2013.11.008>
- Dupont, S., Tanguy, M. L., Clemenceau, S., Adam, C., Hazemann, P., & Baulac, M. (2006). Long-term prognosis and psychosocial outcomes after surgery for MTLE. *Epilepsia*, 47(12), 2115–2124. <https://doi.org/10.1111/j.1528-1167.2006.00852.x>
- Edelvik, A., Flink, R., & Malmgren, K. (2015). *Prospective and longitudinal long-term employment outcomes after resective epilepsy surgery From the Department of Clinical Neuroscience and Rehabilitation (A*.
- Elwes, R. D. C., Marshall, J., Beattie, A., Newman, P. K., & Beattie, T. A. (1991). Epilepsy and employment. A community-based survey in an area of high unemployment. In *Journal of Neurology, Neurosurgery, and Psychiatry* (Vol. 54). <http://jnnp.bmj.com/>
- Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., Engel, J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D. C., Lee, B. I., Mathern, G. W., Moshé, S. L., Perucca, E., Scheffer, I. E., Tomson, T., Watanabe, M., & Wiebe, S. (2014). ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia*, 55(4), 475–482. <https://doi.org/10.1111/EPI.12550/SUPPINFO>
- Fisher, R. S., Cross, J. H., French, J. A., Higurashi, N., Hirsch, E., Jansen, F. E., Lagae, L., Moshé, S. L., Peltola, J., Roulet Perez, E., Scheffer, I. E., & Zuberi, S. M. (2017). Operational classification of seizure types by the International League Against Epilepsy: Position Paper of the ILAE Commission for Classification and Terminology. *Epilepsia*, 58(4), 522–530. <https://doi.org/10.1111/EPI.13670>
- Fisher, R. S., Van Emde Boas, W., Blume, W., Elger, C., Genton, P., Lee, P., & Engel, J. (2005). Epileptic seizures and epilepsy: Definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*, 46(4), 470–472. <https://doi.org/10.1111/J.0013-9580.2005.66104.X>
- Floyd, M., Chaplin, J., & Lislef, J. (1993). Pre-employment screening of NHS employees with epilepsy. In *Occup. Med* (Vol. 43). <http://occmed.oxfordjournals.org/>
- Forsgren, L., Beghi, E., Öun, A., & Sillanpää, M. (2005). The epidemiology of epilepsy in Europe - a systematic review. *European Journal of Neurology*, 12(4), 245–253. <https://doi.org/10.1111/J.1468-1331.2004.00992.X>

- Geerlings, R. P. J., Aldenkamp, A. P., Gottmer-Welschen, L. M. C., de With, P. H. N., Zinger, S., van Staa, A. L., & de Louw, A. J. A. (2015). Developing from child to adult: Risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. *Epilepsy and Behavior, 51*, 182–190. <https://doi.org/10.1016/j.yebeh.2015.07.035>
- Geerts, A., Brouwer, O., Van Donselaar, C., Stroink, H., Peters, B., Peeters, E., & Arts, W. F. (2011). Health perception and socioeconomic status following childhood-onset epilepsy: The Dutch study of epilepsy in childhood. *Epilepsia, 52*(12), 2192–2202. <https://doi.org/10.1111/j.1528-1167.2011.03294.x>
- Glauser, T., Ben-Menachem, E., Bourgeois, B., Cnaan, A., Guerreiro, C., Kälviäinen, R., Mattson, R., French, J. A., Perucca, E., & Tomson, T. (2013). Updated ILAE evidence review of antiepileptic drug efficacy and effectiveness as initial monotherapy for epileptic seizures and syndromes. *Epilepsia, 54*(3), 551–563. <https://doi.org/10.1111/EPI.12074>
- Gloag, D. (1985). Epilepsy and employment. *British Medical Journal (Clinical Research Ed.)*, 291(6487), 2. <https://doi.org/10.1136/BMJ.291.6487.2>
- Gordon, N., & Russell, S. (1958). The problem of unemployment among epileptics. *The Journal of Mental Science, 104*(434), 103–114. <https://doi.org/10.1192/BJP.104.434.103>
- Graham Jones, J. (1965). EMPLOYMENT OF EPILEPTICS. *The Lancet, 286*(7410), 486–489. [https://doi.org/10.1016/S0140-6736\(65\)91441-8](https://doi.org/10.1016/S0140-6736(65)91441-8)
- Haag, A., Strzelczyk, A., Bauer, S., Kühne, S., Hamer, H. M., & Rosenow, F. (2010). Quality of life and employment status are correlated with antiepileptic monotherapy versus polytherapy and not with use of “newer” versus “classic” drugs: Results of the “Compliant 2006” survey in 907 patients. *Epilepsy and Behavior, 19*(4), 618–622. <https://doi.org/10.1016/j.yebeh.2010.09.037>
- Herodes, M., Õun, A., Haldre, S., & Kaasik, A.-E. (n.d.). *Epilepsy in Estonia: A Quality-of-Life Study*.
- Jacoby, A. (1992). Epilepsy and the Quality of Everyday Life Findings from a Study of People with Well-Controlled Epilepsy (Vol. 34, Issue 6).
- Jacoby, A. (1995). EPILEPSY RESEARCH Impact of epilepsy on employment status: Findings from a UK study of people with well-controlled epilepsy. In *Epilepsy Research* (Vol. 21).
- Jacoby, A., Baker, G. A., Steen, N., Potts, P., David, ", & Chadwick, W. (1996). The Clinical Course of Epilepsy and Its Psychosocial Correlates: Findings from a U.K. Community Study. In *Epilepsia* (Vol. 37, Issue 2).
- Jacoby, A., Gorry, J., & Baker, G. A. (2005). Employers’ Attitudes to Employment of People with Epilepsy: Still the Same Old Story? In *Epilepsia* (Vol. 46, Issue 12).
- Jahoda, & Marie. (1982). Employment and Unemployment. *Cambridge Books*. <https://ideas.repec.org/b/cup/cbooks/9780521285865.html>
- Jennum, P., Debes, N. M. M., Ibsen, R., & Kjellberg, J. (2021). Long-term employment, education, and healthcare costs of childhood and adolescent onset of epilepsy. *Epilepsy and Behavior, 114*. <https://doi.org/10.1016/j.yebeh.2020.107256>

- Jennum, P., Gyllenborg, J., & Kjellberg, J. (2011). The social and economic consequences of epilepsy: A controlled national study. *Epilepsia*, *52*(5), 949–956. <https://doi.org/10.1111/j.1528-1167.2010.02946.x>
- John, C., & McLellan, D. L. (1988). Employers' attitudes to epilepsy. In *British Journal of Industrial Medicine* (Vol. 45). <http://oem.bmj.com/>
- Keezer, M. R., Sisodiya, S. M., & Sander, J. W. (2016). Comorbidities of epilepsy: current concepts and future perspectives. *The Lancet. Neurology*, *15*(1), 106–115. [https://doi.org/10.1016/S1474-4422\(15\)00225-2](https://doi.org/10.1016/S1474-4422(15)00225-2)
- Kerr, M. P. (2012). The impact of epilepsy on patients' lives. *Acta Neurologica Scandinavica. Supplementum*, *126*(194), 1–9. <https://doi.org/10.1111/ANE.12014>
- Koponen, A., Seppälä, U., Eriksson, K., Nieminen, P., Uutela, A., Sillanpää, M., Hyvärinen, L., & Kälviäinen, R. (2007). Social functioning and psychological well-being of 347 young adults with epilepsy only - Population-based, controlled study from Finland. *Epilepsia*, *48*(5), 907–912. <https://doi.org/10.1111/j.1528-1167.2007.01017.x>
- Korchounov, A., Tabatadze, T., Spivak, D., & Rössy, W. (2012). Epilepsy-related employment prevalence and retirement incidence in the German working population: 1994-2009. *Epilepsy and Behavior*, *23*(2), 162–167. <https://doi.org/10.1016/j.yebeh.2011.09.017>
- Lassouw, G., Lefferst, P., De Krom, M., & Troost, J. (1997). Epilepsy in a Dutch working population: are employees diagnosed with epilepsy disadvantaged? In *Seizure* (Vol. 6).
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ (Clinical Research Ed.)*, *339*. <https://doi.org/10.1136/BMJ.B2700>
- Majkowska-Zwolińska, B., Jedrzejczak, J., & Owczarek, K. (2012). Employment in people with epilepsy from the perspectives of patients, neurologists, and the general population. *Epilepsy and Behavior*, *25*(4), 489–494. <https://doi.org/10.1016/j.yebeh.2012.10.001>
- Marinas, A., Elices, E., Gil-Nagel, A., Salas-Puig, J., Sánchez, J. C., Carreño, M., Villanueva, V., Rosendo, J., Porcel, J., & Serratosa, J. M. (2011). Socio-occupational and employment profile of patients with epilepsy. *Epilepsy and Behavior*, *21*(3), 223–227. <https://doi.org/10.1016/j.yebeh.2011.01.025>
- McLellan, D. L. (1987). Epilepsy and Employment*. In *J. Soc. Occup. Med* (Vol. 37). <http://occmed.oxfordjournals.org/>
- Mireia, G., Lara, G. L., Marta, J., Marina, H. S., Alejandra, F., Jordi, C., Luis, B. J., & Laia, G. L. (2021). Clinical factors associated with work disability in epilepsy: A cross-sectional study at a tertiary referral hospital. *Epilepsy and Behavior*, *124*. <https://doi.org/10.1016/j.yebeh.2021.108310>

- Nishida, T., Terada, K., Ikeda, H., & Inoue, Y. (2020). Seizures, accidental injuries at work, and reasons for resignation in people with epilepsy. *Epilepsy & Behavior: E&B*, 111. <https://doi.org/10.1016/J.YEBEH.2020.107237>
- Olsson, I., & Campenhausen, G. (1993). Social Adjustment in Young Adults with Absence Epilepsies. In *Epilepsia* (Vol. 34, Issue 5).
- Partanen, E., Laari, S., Kantele, O., Kämppi, L., & Nybo, T. (2022). Associations between cognition and employment outcomes after epilepsy surgery. *Epilepsy and Behavior*, 131. <https://doi.org/10.1016/j.yebbeh.2022.108709>
- Peña, P., Sancho, J., Rufo, M., Martínez, S., & Rejas, J. (2009). Driving cost factors in adult outpatients with refractory epilepsy: A daily clinical practice in clinics of neurology in Spain. *Epilepsy Research*, 83(2–3), 133–143. <https://doi.org/10.1016/j.epilepsyres.2008.10.004>
- Pond, D. A., & Bidwell, B. H. (n.d.). *A Survey of Epilepsy in Fourteen General Practices 11. Social and Psychological Aspects*.
- POND, D. A., & BIDWELL, B. H. (1960). A survey of epilepsy in fourteen general practices. II. Social and psychological aspects. *Epilepsia*, 1(1–5), 285–299. <https://doi.org/10.1111/J.1528-1157.1959.TB04266.X>
- Rätsepp, M., Õun, A., Haldre, S., & Kaasik, A. E. (2000). Felt stigma and impact of epilepsy on employment status among Estonian people: Exploratory study. *Seizure*, 9(6), 394–401. <https://doi.org/10.1053/seiz.2000.0439>
- Reinholdson, J., Olsson, I., Edelvik Tranberg, A., & Malmgren, K. (2020). Long-term employment outcomes after epilepsy surgery in childhood. *Neurology*, 94(2), E205–E216. <https://doi.org/10.1212/WNL.00000000000008681>
- Scambler, G., & Hopkins, A. (1980). Social class, epileptic activity, and disadvantage at work. In *Journal of Epidemiology and Community Health* (Vol. 34).
- Schneider-Von Podewils, F., Gasse, C., Geithner, J., Wang, Z. I., Bombach, P., Berneiser, J., Herzer, R., Kessler, C., & Runge, U. (2014). Clinical predictors of the long-term social outcome and quality of life in juvenile myoclonic epilepsy: 20-65 years of follow-up. *Epilepsia*, 55(2), 322–330. <https://doi.org/10.1111/epi.12491>
- Schulz, J., Beicher, A., Mayer, G., Oertel, W. H., Knake, S., Rosenow, F., & Strzelczyk, A. (2013). Counseling and social work for persons with epilepsy: Observational study on demand and issues in Hessen, Germany. *Epilepsy and Behavior*, 28(3), 358–362. <https://doi.org/10.1016/j.yebbeh.2013.05.027>
- Shackleton, D., Kasteleijn-Nolst Trenité, D., de Craen, A., Vandenbroucke, J., & Westendorp, R. (2003). *Living with epilepsy Long-term prognosis and psychosocial outcomes*. www.neurology.org

- Shackleton, D. P., Kasteleijn-Nolst Trenité, D. G. A., De Craen, A. J. M., Vandenbroucke, J. P., & Westendorp, R. G. J. (2003). Living with epilepsy. *Neurology*, *61*(1), 64–70. <https://doi.org/10.1212/01.WNL.0000073543.63457.0A>
- Sillanpää, M., & Schmidt, D. (2010). Long-term employment of adults with childhood-onset epilepsy: A prospective population-based study. *Epilepsia*, *51*(6), 1053–1060. <https://doi.org/10.1111/j.1528-1167.2009.02505.x>
- Smeets, V. M. J., van Lierop, B. A. G., Vanhoutvin, J. P. G., Aldenkamp, A. P., & Nijhuis, F. J. N. (2007). Epilepsy and employment: Literature review. In *Epilepsy and Behavior* (Vol. 10, Issue 3, pp. 354–362). <https://doi.org/10.1016/j.yebeh.2007.02.006>
- SOREL, L. (1972). The epileptic worker in the construction industry. *Epilepsia*, *13*(1), 57–62. <https://doi.org/10.1111/J.1528-1157.1972.TB04550.X>
- Taylor, R. S., Sander, J. W., Taylor, R. J., & Baker, G. A. (2011). Predictors of health-related quality of life and costs in adults with epilepsy: A systematic review. *Epilepsia*, *52*(12), 2168–2180. <https://doi.org/10.1111/J.1528-1167.2011.03213.X>
- Thomas, S. V., & Nair, A. (2011). Confronting the stigma of epilepsy. *Annals of Indian Academy of Neurology*, *14*(3), 158. <https://doi.org/10.4103/0972-2327.85873>
- Thompson, P. J., & Oxley, J. (1988). Socioeconomic Accompaniments of Severe Epilepsy. *Epilepsia*, *29*, S9–S18. <https://doi.org/10.1111/j.1528-1157.1988.tb05791.x>
- Walther, K., Dogan Onugoren, M., Buchfelder, M., Gollwitzer, S., Graf, W., Kasper, B. S., Kriwy, P., Kurzbuch, K., Lang, J., Rössler, K., Schwab, S., Schwarz, M., Stefan, H., & Hamer, H. M. (2018). Psychosocial outcome in epilepsy after extratemporal surgery. *Epilepsy and Behavior*, *81*, 94–100. <https://doi.org/10.1016/j.yebeh.2018.01.038>
- Wedlund, E. W., Nilsson, L., Erdner, A., & Tomson, T. (2012). Long-term follow-up after comprehensive rehabilitation of persons with epilepsy, with emphasis on participation in employment or education. *Epilepsy and Behavior*, *25*(2), 219–223. <https://doi.org/10.1016/j.yebeh.2012.06.029>
- Wo, M. C. M., Lim, K. S., Choo, W. Y., & Tan, C. T. (2015). Employability in people with epilepsy: A systematic review. *Epilepsy Research*, *116*, 67–78. <https://doi.org/10.1016/j.eplepsyres.2015.06.016>

Other references:

Book Nine of the Social Code in Germany: [https://www.gesetze-im-](https://www.gesetze-im-internet.de/sgb_9_2018/index.html#BJNR323410016BJNE021400000)

[internet.de/sgb_9_2018/index.html#BJNR323410016BJNE021400000](https://www.gesetze-im-internet.de/sgb_9_2018/index.html#BJNR323410016BJNE021400000)

Efimov, I., Lengen, J.C., Kordsmeyer, AC. et al. Capturing and analysing the working conditions of employees with disabilities in German social firms using focus groups.

BMC Public Health 22, 413 2022. <https://doi.org/10.1186/s12889-022-12689-w>

<https://www.ibe-epilepsy.org/downloads/Employment%20Guidelines.pdf>

https://www.lice.it/pdf/Position_Paper_Epilessia_e_Occupazione.pdf

https://www.lice.it/pdf/REPORT_progetto_Storie_di_Epilessia_e_Lavoro.pdf

Info pamphlet of the German association of epilepsy (Deutsche Epilepsievereinigung):

https://www.epilepsie-vereinigung.de/wp-content/uploads/2016/05/Epi_Epilepsie-und-Studium_0516-low.pdf

Marie Lecerf, Members' Research Service, European Union, May 2020: Briefing of the European Parliament: Employment and disability in the European Union:

[https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/651932/EPRS_BRI\(2020\)651932_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2020/651932/EPRS_BRI(2020)651932_EN.pdf) (accessed on 14 June 2022)

Robin van Kessel, Ines Siepman, Luis Capucha, Apostolos Kavaliotis Paschalis, Carol Brayne, Simon Baron-Cohen, Katarzyna Czabanowska, Andres Roman-Urrestarazu, Education and austerity in the European Union from an autism perspective: Policy mapping in Ireland, Portugal, Italy, and Greece, European Policy Analysis, 10.1002/epa2.1121, 7, 2, (508-520), 2021:

<https://onlinelibrary.wiley.com/doi/full/10.1002/aur.2315>

Website of the EU, Check progress on the strategy for the Rights of Persons with Disabilities:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=1484&furtherNews=yes&newsId=10274> (accessed on 14 June 2022)

Website of the EU, Persons with disabilities: <https://ec.europa.eu/social/main.jsp?catId=1137> (accessed on 15 June 2022)

Website of the EU, Union of equality: Strategy for the rights of persons with disabilities 2021 – 2030: <https://ec.europa.eu/social/main.jsp?catId=1484&langId=en> (accessed on 15 June 2022)