# Inclusion of People with Epilepsy in France – Epilepsy Power Research Project Findings

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## Abstract

The unemployment rate of people with epilepsy (PWE) is twice that of the general population and those who are employed often occupy positions requiring lower qualifications and skill sets, which affects their financial status and general well-being. The stigma associated with epilepsy often causes more suffering to PWE than the seizures themselves and despite advances in epilepsy clinical management and legislation put in place to include people with disabilities (including PWE), studies show that PWE are still being discriminated against by employers. Job restrictions imposed on PwE are based on prejudices and misconceptions, which can be overcome through training programs aimed at recruiters and Higher Education Institutions (HEI). Awareness aimed at 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. This European project includes 5 countries. We began with a survey to obtain information on the experience and knowledge of epilepsy from two populations, HEIs and PWE. We then created two sets of learning modules, one aimed at PWE and the other for HEIs and employers. Each partner country held a collaborative lab consisting of 15 stakeholders (experts on epilepsy, employers and PWE). We present the results obtained from France, which show that there is a general consensus that more training is required in order to lift the misconceptions which lead to stigmatization and discrimination. We outline the best practices identified from the collaborative lab held in Paris in February 2024.

## Introduction

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. The side effects of drugs, psychiatric comorbidities, and cognitive deficits, increase the burden of epilepsy (Bautista et al., 2014; Beghi, 2020). Despite adequate seizure control, the unemployment rate of PwE is high and this is due to a combination of internal factors (like seizures and cognitive deficits) and external factors (like stigma and employers’ attitudes). False beliefs, misconceptions and employers' concerns also contribute to unemployment in PwE (Collings & Chappell, 1994; Gloag, 1985; Jacoby et al., 2005).

Many studies have been conducted in the last few decades on the level of knowledge, attitudes and practices toward epilepsy (Rafael et al., 2010). Studies show that PWE are continuously experiencing discrimination by employers with more than 50% of recruiters claiming that employing a PWE would be “somewhat of an issue” (Jacoby et al., 2005). A survey from the U.K. showed that only 58% of employers said they had jobs suitable for PWE while 80% claimed to have jobs suitable for people with other conditions including diabetes and heart disease. The misconceptions of employers from this survey included fear that insurance policy rates would go up by employing a PWE, or that despite having a valid driving license a PWE should not be allowed to operate heavy machinery (McLellan, 1987; John & McLellan, 1988).

Many employers refuse to hire PWE because they mistakenly believe that they are more susceptible to work-related injuries and absenteeism from work. Nishida et al. (2020) recently demonstrated that the risk of seizure-related accidents is comparable to that of injury not related to seizures. Even though absenteeism and accidents are not recorded to be higher in PWE, their salaries are lower than those of their colleagues (Lassouw et al., 1997). Since epilepsy is an invisible disability, half of the PWE conceal their disease to employers, because of fear or stigma (Jacoby et al., 2005).

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, 1982). Unemployment can contribute to emotional and behavioral problems in people with epilepsy (Taylor et al., 2011). The best way to reduce the unemployment rate of PWE is through spreading awareness and providing training programs, thereby eliminating misconceptions and ignorance in the workplace. PWE can also benefit from training in order to better equip them to identify the appropriate career paths to take according to their condition and give them the job-hunting skills required to land these jobs.

EpilepsyPOWER\*, a project co-funded by the European Union and Erasmus+, is a cooperation partnership in adult education which aims 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 valorization of their abilities; support universities, companies, micro and small enterprises in inclusion improvement. The core organizations involved in it bring experience from Italy, Bulgaria, Germany, Ireland and France.

## Methods

In accordance to the guidelines of this project, a number of stages are to take place. The first was a systemic literature review on the situation of PWE concerning inclusion in higher education and the workplace. The second step was a survey sent out throughout the partner countries to gain insight into the current state of knowledge among target populations. There were two versions of this survey, one aimed at HEIs and the other at PWE. Stage three was the development of learning modules which will be made available on an online, free-access, website containing 14 modules, two learning paths with 7 modules each, one aimed at PWE and the other at employers/companies. The fourth stage of this project was a collaborative lab where professionals and stakeholders concerning epilepsy were brought together to discuss the issues concerning PWE and their employment. Following these collaborative labs, best practices were identified and the learning modules were then enhanced with the feedback provided preparing for the fifth and final stage, which is the development and launch of the online training platform.

*Surveys*

In connection with the results from the literature search and the lack of sufficient information by official sources on crucial aspects regarding the employment of PwE, two surveys were conducted aimed at two target groups. We used SurveyMonkey to develop the anonymous surveys. Each survey was created in English and then translated to the partner languages: Italian, French, German, and Bulgarian.

1. The first survey was aimed at **People With Epilepsy** and contained questions about demographics (age, sex and residing country), clinical data (number of anti-seizure medications (ASMs), seizure frequency, type of seizures), educational and job attainment, issues in workplace (disclosure, stigma, level of satisfaction).

2. The survey for **Higher Education Institutions** was aimed at staff and end users: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, employees, recruiters, HR experts and recruitment agencies. It was composed of questions about demographics (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.

*Collaborative Lab*

The purpose of the collaborative lab was to bring together several stakeholders who are in contact with People with Epilepsy (PwE) in order to discuss the issues related to their ability to incorporate the work world. 15 people met in person during a 5-hour workshop to discuss a number of identified issues and report their expertise, allowing us to improve the training modules according to the feedback received.

Participants were identified through the networks of the partner organization as well as through internet searches based on the list of previously identified organizations working with PwE. Potential participants were contacted by email, messages on LinkedIn and forms on websites as well as by telephone. Invitations were sent out to people all over France who corresponded with the criteria required for the collaborative lab meeting as follows:

* 2 representatives of the national hosting partner (our team members)
* 4 PwE
* 2 PwE’s caregivers
* 1 representative of PwE associations,
* 1 neurologist expert in epilepsy,
* 3 representatives of HEIs,
* 2 representatives of companies/other organizations

A Google Form was sent out to the participants to fill out before the collaborative lab. The questions were organized in two main parts. The first part started with an inquiry on the project’s proposed ten issues by assessing respondents’ level of agreement with how severe the issue is, and the second part to suggest other issues which may influence the inclusion of people with epilepsy in the workplace. The ten key employment issues identified are the following:

Before employment:

1. Seizure control.
2. Driving restrictions.
3. Disclosure of the illness (to the employer and then to colleagues).

After employment:

1. Seizures in the workplace (first aid instructions for staff in higher education institutions and work organizations and description of the consequences for people with epilepsy).
2. Workplace safety and layout (lighting, reading, startle, noise, heights and machinery).
3. Shift patterns (night and morning).
4. Absence/authorization for medical examinations.
5. Sick leave
6. Stress and mental health (cognitive effects of epilepsy and medication, co-morbidities)
7. Training and employment programs

The Collaborative Lab Workshop was organized to facilitate a comprehensive exploration of epilepsy-related workplace challenges and solutions. The agenda was structured as follows:

1. **Welcoming and Presentation of the Project**

This initial segment introduced participants to the workshop's objectives, providing a foundational overview and setting the context for the day's activities. The project was explained in detail.

1. **Activity 1: Reflecting on the 10 Issues**

This activity involved a detailed presentation and subsequent discussion of ten pre-identified issues concerning epilepsy in the workplace. Participants engaged in a critical examination of these concerns, leveraging diverse perspectives to deepen collective understanding.

1. **Activity 2: Reflecting on Best Practices**

The focus then shifted towards identifying and deliberating on best practices. This segment aimed at fostering a dialogue on practical and effective strategies to mitigate the identified challenges.

## Results

*Survey 1: PWE*

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) but for this paper we will focus on the results from France.

The respondents’ age distribution was as follows:

|  |  |
| --- | --- |
| Age | Number of respondents |
| < 20 | 22 |
| 20 - 29 | 32 |
| 30 - 39 | 27 |
| 40 - 49 | 21 |
| > 50 | 21 |

38 (30.89%) respondents were male, 83 (67.48%) were female, two respondents preferred not to say or chose “other”. The mean age of onset was about 16. When asked about anti-seizure medication 6 responded that they do not take any, 28 take one medication, 48 take two and 35 people were on three or more medications to control their seizures. 51 respondents were seizure-free while 66 were not. The mean number of seizures reported by this group in the last three months amounts to 44.63, including focal and generalized seizures. 75% of the respondents said they were employed (full or part-time, or studying) with an unemployment rate calculated at 8.5%. About half the respondents reported a salary of less than 15 000€ annually but the majority claimed that they were very satisfied or mostly satisfied with their jobs. Two thirds have experienced a seizure at work but 21% have not disclosed their condition at work. 40% have experienced difficulties with co-workers or their employer and 29% believe that these difficulties are related to their epilepsy. Around 70% believe that it is more challenging to find a job when you have epilepsy and almost 90% believe that the stigma of epilepsy can lead to discrimination in landing or maintaining a job.

*Survey 2: HEI*

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) and, again, for this paper we will focus on the results from France.

The respondents’ age distribution was as follows:

|  |  |
| --- | --- |
| Age | Number of respondents |
| < 20 | 0 |
| 20 - 29 | 1 |
| 30 - 39 | 16 |
| 40 - 49 | 18 |
| > 50 | 32 |

10 (14.93%) respondents were male, 55 (82.09%) were female, two respondents preferred not to say or chose “other”. 93.93% of the respondents claimed that epilepsy is a neurological condition and 80% agreed that it is a treatable condition. 35 of the 66 respondents believe that job opportunities for PWE are not limited or simply require accommodations. More than half the respondents believe that there is a higher unemployment rate among PWE compared to the general population and just under 20% claimed that there is a higher absenteeism in that population. More than two-thirds of the HEIs surveyed claimed to know a PWE and 40% have worked or studied with someone with epilepsy. 90% have witnessed a seizure but only half claimed to know how to give medical aid to a person experiencing a seizure. Just under half of the respondents claim to not receive any support when employing a PWE.

*Collaborative Lab*

***Activity 1 - Reflecting on the 10 issues***

Participants were asked to analyze the 10 identified issues individually and then discuss their answers in small groups. Participants were organized into three tables of four and were asked to write a summary of the major points arising from the discussion onto a paperboard.

The questions asked were:

1. **Do you think there are any other relevant issues concerning the professional inclusion of people with epilepsy that you haven't found in the list?**
2. **In your opinion, having identified all these issues regarding employability, which would be the most relevant?**

* **for people with epilepsy**
* **employers and people working in educational organizations?**

Each group was then asked to present their findings to the other groups and further discussions arose from this. After discussing the 10 suggested issues, the group listed the following items as essential and/or missing from the above:

**Table 1:**

* Flexible work & remote work
* General first aid and epilepsy training
* Treating side effects
* Driver’s license or dangerous occupations --> need to see occupational or educational physician first

**Table 2:**

* Spreading awareness, information sharing
* Occupational and educational physicians
* Posters with first aid measures
* Learning about cognitive difficulties
* Better understanding of attitudes, abilities and needs
* Driver's license
* First aid
* Adapted schedule
* Diversity of jobs, fields or geographical location

**Table 3:**

* What training do occupational physicians have?
* What training sessions, financing bodies or stakeholders are available?
* Self-censuring
* Training of managers to reassure them
* What impact does schooling have on a person’s social life and job insertion?
* Appropriate training and awareness is necessary
* Safety at work
* Disclosure, acquisition of formal legal status as a person with disability
* Self confidence
* What to do when a seizure takes place
* Work conditions, commute
* Work hours
* Stress and mental health

These discussions not only addressed the initial ten issues but also expanded the conversation to include additional relevant factors. The emerging themes can be grouped into several key areas, reflecting both the breadth and depth of the participants' insights (table 1).

|  |  |  |
| --- | --- | --- |
| ***Emerging themes*** | ***Key Points*** | ***Relation to Initial Issues*** |
| **Workplace Flexibility and Accessibility** | Flexible work arrangements, remote work options, adapted schedules, diversity of jobs and locations. | Directly addresses the need for seizure control and stress management, suggesting practical adjustments for individuals' needs. |
| ***Education and Awareness*** | General first aid and epilepsy training, spreading awareness, information sharing, learning about cognitive difficulties. | Enhances understanding and preparedness for seizures at work, contributing to a safer and more inclusive environment. |
| ***Health, Safety, and Legal Considerations*** | Treating side effects, driver’s license and dangerous occupations considerations, safety at work, formal legal status as a person with a disability. | Tackles the physical and legal aspects of epilepsy, emphasizing health management and legal protections. |
| ***Professional Development and Support*** | Occupational and educational physician involvement, training sessions, financing bodies, stakeholders, training of managers, appropriate training and awareness. | Focuses on professional support and development opportunities, enhancing employability and workplace inclusion. |
| ***Psychosocial Factors*** | Better understanding of attitudes, abilities, and needs, self-censuring, impact on social life and job insertion, self-confidence, stress and mental health. | Highlights the psychological and social dimensions of epilepsy, including the impact on mental health, self-perception, and social integration. |

*Table 1: Key emerging thematic areas.*

The additional items identified by the participants hint toward the need of a comprehensive approach that goes beyond immediate medical management to consider broader social, legal, and psychological factors. By grouping these insights into thematic areas, it emerges how addressing epilepsy in the workplace requires a multifaceted strategy that encompasses flexible work policies, education and awareness initiatives, health and safety measures, professional development, and psychosocial support:

* **Workplace Flexibility and Accessibility:** through the adoption of flexible work arrangements and remote work options. The discussion around adapted schedules and the diversity of jobs and locations directly addressed the unpredictability of epilepsy, suggesting that such accommodations are essential for managing seizure control and reducing stress. These adjustments are not just about creating a supportive work environment but also about recognizing and accommodating the unique needs of individuals with epilepsy, thereby enabling them to thrive professionally.
* **Education and Awareness:** with a focus on both general first aid and epilepsy training, along with spreading awareness and sharing information. Participants clearly identified the critical need for a well-informed workplace. Understanding phisical and cognitive difficulties associated with epilepsy is vital for creating an inclusive environment. This theme suggests that increasing awareness and knowledge about epilepsy among all employees can significantly contribute to a safer and more supportive work setting, thereby enhancing the employability of individuals with epilepsy.
* **Health, Safety, and Legal Considerations**: addressing the physical and legal aspects of epilepsy encompassing health management and legal protections. The discussion on treating side effects, considerations for driver’s licenses and dangerous occupations, and ensuring safety at work highlights the importance of legal status and workplace safety. This theme points to the need for workplaces to navigate the legal and safety implications of epilepsy thoughtfully, ensuring that individuals with epilepsy are not only protected by law but also supported in managing their condition effectively.
* **Professional Development and Support:** with emphasis on the involvement of occupational and educational physicians, along with the need for training sessions and the support of financing bodies and stakeholders. Training managers and providing appropriate training and awareness can enhance the workplace inclusion of individuals with epilepsy. This theme suggests that professional support mechanisms are crucial for fostering an environment where individuals with epilepsy can pursue their career goals without hindrance.
* **Psychosocial Factors**: drawing attention to the need for addressing stigma, mental health challenges, and the impact of epilepsy on social life and job insertion. The focus on understanding attitudes, abilities, and needs, along with fostering self-confidence and managing stress, points to the broader implications of epilepsy beyond the workplace. This theme underscores the importance of considering the emotional and social well-being of individuals with epilepsy in professional inclusion efforts.

***Activity 2: Encountered Experiences in the Workplace – Reflecting on Best Practices***

The tables were reorganized to get participants working with others in the room. This was done on a voluntary basis with no obligation to change groups. Each person was asked to respond to the following question:

**“Which of the problems studied in Activity 1 have you encountered/detected in your organization/company? (insert reference number(s), e.g., 1, 5, 7 and 10) and give details.”**

Each member of the group presented one issue to their group members and the following question was discussed:

**“Based on the problems you've encountered, what actions would you suggest? What should be done to get things moving?”**

After discussion, each member wrote one suggestion on the problem sheet. The problem sheets from all three groups were then laid out on a long table and everyone went around reading each problem and three possible solutions. Participants were asked to vote for the best solution per problem page by placing dots on the solutions. One to three dots were permitted per solution with zero dots being the less favorite option and three dots being the best option.

The following table provides an overview on the identified best practices:

|  |  |
| --- | --- |
| **Best practice category** | **Key points and recommendations** |
| **Seizure Control** | - Staff training on seizure response protocols.  - Proactive communication and protocol establishment.  - Workspace layout restructuring for safety.  - Stress management and reasonable work hours to prevent seizures. |
| **Driving Restrictions** | - Utilization of taxis financed under disability agreements for commuting.  - Consideration of seizure-alert dogs or electronic devices for safety.  - Evaluation of driving capabilities on a case-by-case basis. |
| **Disclosure** | - Mandatory training on first aid and seizure management.  - Development of internal regulations for seizure response.  - Encouragement of open communication about epilepsy to facilitate accommodations. |
| **Seizure at Work** | - Early training for understanding epilepsy, integrated with practical exercises.  - Emphasis on removing stigma for better workplace inclusion. |
| **Workplace Safety and Accommodations** | - Introduction of epilepsy-friendly workplace labels.  - Sharing real-world examples from inclusive employers.  - Highlighting the importance of medical advice and transparency. |
| **Work Shifts** | - Flexibility in work hours and schedules to accommodate personal health needs.  - Tailoring work arrangements to minimize stress and seizure risks. |
| **Time Off for Medical Appointments** | - Support and understanding from employers for necessary medical appointments.  - Ensuring job security and flexibility for health maintenance. |
| **Sickness Absence** | - Clear policies on sickness absence due to epilepsy.  - Supportive measures to reintegrate employees post-absence. |
| **Stress and Mental Health** | - Training on managing stress and understanding its effects on epilepsy.  - Promotion of mental health support and resources. |
| **Job Training and Inclusion Programs** | - Development of job training and inclusion programs tailored to individuals with epilepsy.  - Collaboration with epilepsy associations for program development. |

*Table 2: Summary of the identified best practices*

## Discussion

*Legal Framework*

In France, the legislation guarantees an equivalent access to education and employment for People with Disability (PWD). 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 PWD in society.

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.”

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 to declare one’s disability but this administrative recognition gives access to financial aids and to “the obligation to employ disabled workers” (BOE in French). This obligation applies to both private and public sector companies, with 20 employees or more, and sets the percentage of their jobs filled by disabled workers at 6%. 2.7 million people have a recognition of disabled worker status in France. They represent 6.5% of the population aged 15-64 (AGEFIPH website).

Companies are required to declare the number of jobs held by disabled workers and a financial contribution is set when they fall below the 6% threshold. This contribution is used to fund initiatives which help PWD to prepare for, access or maintain a job and progress in their careers. This compensation is accessible to companies and PWD.

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 favor 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.

(defenseur des droits website)

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. Maintaining a disabled worker in a position that is not adapted to his or her needs could endanger the worker or create a risk to his or her health and safety. In this case, the employer would be failing in their obligation in terms of safety at work.

The latest law of 2018 emphasizes 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. All higher education institutions are required to adapt their courses to the particular needs of students with disabilities and to appoint a disability officer. 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 appropriate study conditions through concrete aids discussed 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, administratively, as a disabled person.

*Survey and Collaborative Lab*

The survey results and the collaborative lab discussions point to the fact that PWE are still being stigmatized and discriminated against in the workplace due to lack of understanding and information. The discussions during the collaborative lab unveiled an emerging perspective which both aligns with the initial ten issues discussed but also expands the scope to include critical areas that were not previously identified. In particular, the emphasis on education, awareness, and legal considerations reflect a need for systemic changes that can foster a more inclusive and supportive work environment. The focus on psychosocial factors highlights the importance of addressing the stigma and mental health challenges associated with epilepsy, suggesting that professional inclusion efforts must also consider the emotional and social well-being of individuals.

The surveys and discussions unveiled six major best practices which can help improve the inclusion of PWE.

## Spread Awareness

Epilepsy remains a mystery for many people with all the myths surrounding it not helping its case. It is important to share information through all levels of the organization, especially when there is a PwE on the team. This can be done by sharing videos through the internal communication system, placing documents like brochures or posters in visible areas within the premises or sending out links to documentation to staff members.

The stigma associated with epilepsy makes it difficult for PwE to find employment because employers fear that hiring a PwE will inevitably lead to burdens associated with seizures. Employers and colleagues might think that a PwE will have frequent seizures and that accommodating for this population will necessitate mobilizing a large amount of time and energy, as well as a large financial investment. Educating recruiters will lower discrimination and educating staff will remove the stigma associated with epilepsy.

## Provide Training

The inclusion of PWD is not easy since accommodation may need to be put in place for this population. Generally, people tend to offer help to colleagues with disabilities but do not always know how they can help. It can be difficult to know whether offering help can come across as patronizing to a person who tries to remain autonomous to avoid being ostracized by coworkers. PwE face increasing discrimination due to the lack of knowledge by the general population on what needs to be done when dealing with a PwE.

Training is the obvious solution to this issue yet it is not often provided in companies. Training sessions can be provided by competent bodies like associations specializing in epilepsy or developed by internal (or external) training staff. These sessions should include not only how to include a PwE but also what to do in the case of a seizure and how to develop a personalized action plan. This training should educate employees on the importance of inclusivity and equip them with practical skills to support their colleagues. This includes learning to recognize the signs of a seizure, understanding the proper steps to ensure safety during an episode, and familiarizing themselves with post-seizure protocols. Additionally, training can help dismantle misconceptions and encourage a supportive dialogue within the team, fostering an environment where PwE feel secure and valued.

## Accommodate for PwE

Often, a PwE does not need accommodations at work. When there is a specific need, in most cases, a doctor will provide a list of accommodations to create an environment that will be safe and comfortable for the PwE. The employer needs to meet with the employee to discuss the specifics and to ensure that nothing is overlooked. In some cases the accommodation will be minor, like adapting the work schedule to allow time for rest leading to decreased risk of seizures. Regular meetings need to be scheduled to verify that everything is in order and that no further adjustments need to be made.

## Implement a Buddy System

It is not always easy for a PwE to disclose their condition and even when they do disclose to their employer, they might not want the entire staff to know. It is a good idea, in this case, that the PwE confides in someone in their team in order to be sure that the correct actions are taken in the case of a seizure. It is reassuring for the person to know that they are supported and safe. This peace of mind can make all the difference in creating a workplace that encompasses the same sense of security that one might find at home.

## Draft Documentation

Disability inclusion documentation is obligatory in many countries but often lacks specific information about epilepsy. A quick modification of texts to add a few lines about this condition might make all the difference to a PwE. Companies that have at least one member of staff with epilepsy may benefit from creating specific documents, procedures, guidelines or recommendations along the lines of epilepsy. There are a lot of existing documents available on websites of associations specializing in epilepsy that could be used or slightly modified and integrated into the company policies.

## Create an Epilepsy-Friendly Environment

The recommended practices above will inevitably lead to an epilepsy-friendly environment. A culture of understanding and empathy will emerge once these guidelines are implemented leading to better health and safety for PwE and thereby fostering cohesion within the team. An epilepsy-friendly environment also means celebrating diversity and the unique contributions of all employees. This can be achieved through internal campaigns, highlighting success stories, and recognizing the strengths that PwE bring to the team.

Additionally, forming partnerships with epilepsy advocacy groups can provide valuable resources for both employers and employees, such as access to educational materials, seminars, and expert consultations. These partnerships can help maintain an informed and current approach to supporting PwE and can serve as a model for how companies can accommodate other disabilities.

An “Epilepsy Friendly” label would be the best way to communicate to PwE that they would be in good hands if they join the company.

## Conclusion

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 cannot access higher education leading them to be under-skilled. Driving restrictions contribute to stigma, reduced quality of life and underemployment. Epilepsy also impairs social integration, social status and marital status. These factors, along 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, 2000; Keezer et al., 2016; Kerr, 2012).

The main issue that clearly emerged from our survey and collaborative lab is how to effectively handle seizures and foster an inclusive work environment. The emphasis on first aid instructions for seizures and the significance of professional training and inclusion programs reveal a keen awareness of the need for both immediate response strategies and long-term support mechanisms. Issues like seizure control, stress, and mental health also stand out, indicating a clear awareness of respondents of the multifaceted impact of epilepsy. While logistical aspects like medical appointments and shift work are deemed important, they are ranked lower, suggesting that the respondents prioritize immediate safety and inclusivity over these concerns. This feedback points towards a preference for a workplace that is not only prepared to respond to seizures but also actively supports the overall well-being and integration of individuals with epilepsy.

The outcomes reveal a collective recognition of the diverse challenges faced by people with epilepsy in the professional realm, qualifying a need for targeted interventions and policies that not only address the immediate medical management of epilepsy but also consider the broader social, legal, and psychological factors.

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