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THE NUMBERS BEHIND MCS AND EHS

A HUMAN RIGHTS AND DISABILITY PERSPECTIVE

The numbers behind MCS and EHS: A human rights and disability perspective.

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ÍNDICE

ABBREVIATIONS

CCAA – Autonomous Communities

CDPD – United Nations Convention on the Rights of Persons with Disabilities

CEM – Electromagnetic Fields

COCEMFE – Spanish Confederation of People with Physical and Organic Disabilities

CDPD Committee – UN Committee on the Rights of Persons with Disabilities

CONFESQ – National Coalition of Entities for Fibromyalgia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Electromagnetic Hypersensitivity, and Multiple Chemical Sensitivity

DO – Organic Disability

UDHR – Universal Declaration of Human Rights

EHS – Electromagnetic Hypersensitivity

EMEA – European ME Alliance

ENFA – European Network of Fibromyalgia Associates

INSS – National Social Security Institute

WHO – World Health Organization

PAE – Pain Alliance Europe

PEC – Pain Mediterranean Coalition

ICESCR – International Covenant on Economic, Social and Cultural Rights

POP – Platform of Patient Organizations

SEFIFAC – Spanish Society of Fibromyalgia and Chronic Fatigue Syndrome

SFC/EM – Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

MCS – Multiple Chemical Sensitivity

1. INTRODUCTION

1.1 WHAT IS CONFESQ?

In 2004, the National Confederation for Fibromyalgia and Chronic Fatigue Syndrome was established. Fourteen years later, in 2018, it was officially registered as a coalition, expanding to include other conditions and becoming the National Coalition of Entities for Fibromyalgia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Electromagnetic Hypersensitivity, and Multiple Chemical Sensitivity (CONFESQ).

CONFESQ is a non-profit organization dedicated to defending the rights of individuals affected by these diseases, as well as their families, both nationally and internationally. The coalition works to secure appropriate solutions for the needs of affected individuals and their families, ensuring their full participation as citizens with equal rights in society.

To achieve this mission, CONFESQ's work focuses on four key areas: healthcare and social awareness, research promotion, political advocacy to improve the quality of life of affected individuals, and the defense of their rights.

CONFESQ comprises 65 associations and federations distributed across most of Spain's autonomous communities, representing over 11,000 individuals and their families. Approximately 80% of those affected are women.

Additionally, CONFESQ collaborates with like-minded associations that share its mission, vision, and values, including organizations advocating for the rights of individuals affected by chronic illnesses and physical and organic disabilities.

To carry out this collaborative work, CONFESQ is a member of international umbrella organizations such as, Pain Alliance Europe (PAE), European Network of Fibromyalgia Associates (ENFA), Pain Mediterranean Coalition (PEC), European ME Alliance (EMEA). At the national level, CONFESQ is affiliated with Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE), Platform of Patient Organizations (POP) and Spanish Society of Fibromyalgia and Chronic Fatigue Syndrome (SEFIFAC).

1.2 OBJECTIVES OF THE REPORT

Following the publication in 2023 of analytical reports on Multiple Chemical Sensitivity and Electromagnetic Hypersensitivity from a human rights and disability perspective, CONFESQ has decided to undertake a quantitative study of these issues. The objective is to understand and analyze, through concrete data, how these conditions affect individuals' daily lives and what barriers prevent them from fully exercising their rights.

This general purpose enables CONFESQ to consolidate its work from a human rights perspective, creating a quantitative basis that supports the claims of affected individuals and the entities

representing them. Understanding the magnitude of the problem is a fundamental step toward formulating public policies adapted to the realities of these conditions, and this commitment guides CONFESQ's work.

1.3 METHODOLOGY

To achieve the stated objective, a combined methodology incorporating both qualitative and quantitative techniques was implemented. The following analytical methods were utilized:

- **Documentary Analysis:** A bibliographic review of primary and secondary sources relevant to the subject matter, based on the latest published documents analyzing the state of the issue.
- **Qualitative Research:** For qualitative data collection, a focus group was organized with representatives from various patient associations affiliated with CONFESQ, covering both conditions. The participating associations included AFFARES Ibiza-Baleares, SFC-SQM Valencia, EQSDS, SFC-SQM Madrid, and SFC-SQM Castilla-La Mancha.

  The focus group was conducted online, lasting two hours. This approach allowed for the collection of valuable and high-quality information that complements and enriches the quantitative data gathered through corresponding methodologies.
- **Quantitative Research:** The data collection methodology was based on a structured questionnaire designed to systematically and quantitatively obtain information. This questionnaire contained questions addressing different dimensions of the study topic, ensuring the validity and reliability of responses.

  The questionnaire was distributed to CONFESQ-affiliated associations nationwide, which facilitated its implementation, as well as to other patient organizations and affected individuals. Data collection took place between August 27 and September 23, 2024, resulting in a total of 285 valid responses.

  From a statistical perspective, a stratified random sampling method was employed to select a representative sample of the target population, ensuring diversity of perspectives. The questionnaire was administered online to facilitate participation and maximize response rates. Subsequently, the data were analyzed using appropriate statistical techniques, enabling the identification of significant patterns and trends and providing a detailed insight into the national impact of Multiple Chemical Sensitivity (MCS) and Electromagnetic Hypersensitivity (EHS).

Despite its comprehensive approach, the analysis presents several important limitations:

- **Sample Size:** Although 285 valid responses were collected, they represent only a limited percentage of the 4,558 individuals affiliated with CONFESQ member entities. This raises concerns regarding the representativeness of the results and makes it difficult to claim statistical significance.

- **Questionnaire Length:** Given the health conditions of the respondents, the excessive length of the questionnaire led to fatigue, reducing the quality of responses in later sections and leaving some questions with insufficient information.
- **Lack of Official Data:** The absence of official statistics on the affected population complicates efforts to obtain a truly representative sample, constituting a structural obstacle. Previous reports have particularly highlighted this issue concerning women.

Despite these limitations, the study provides a relevant foundation for understanding the realities of individuals affected by MCS and EHS, serving as a starting point for future research and policy actions.

2. CHARACTERISTICS OF SURVEYED AFFECTED INDIVIDUALS

Of the total respondents, 92% are women, while 8% are men. This gender variable is complemented by an age analysis, as shown in **Figure 1**. The data reveal that most surveyed women fall within the 50 to 60-year-old age range, indicating a high prevalence in this demographic group. In contrast, men show higher representation in the 30 to 40-year-old age range.

This gender and age breakdown provides an initial perspective on the characteristics of individuals affected by these conditions, enabling the identification of relevant demographic trends for further analysis.

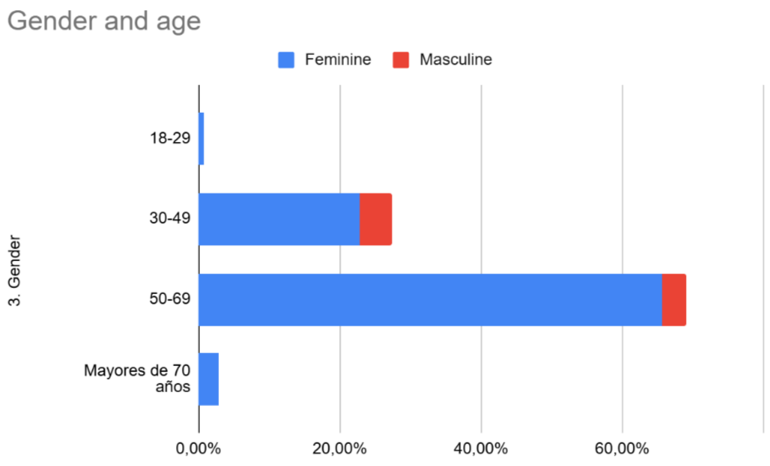

Figure 1. – Self-elaboration

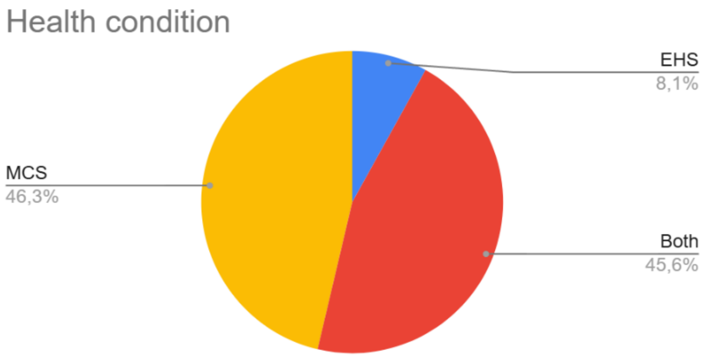

Figure 2 – Self-elaboration

Regarding the health condition of the surveyed individuals, the data indicate that 46% suffer exclusively from Multiple Chemical Sensitivity (MCS), 8% have only Electromagnetic Hypersensitivity (EHS), and 46% experience both conditions simultaneously.

With respect to association membership, 75.09% of respondents belong to an organisation integrated into CONFESQ, while 12.63% are members of other unregistered associations, and 12.28% are not affiliated with any organisation.

Regarding geographical distribution, most respondents reside in the autonomous communities of Madrid (15%), Valencia (14%), and the Balearic Islands (12%), highlighting a higher concentration of cases in these regions.

Lastly, a significant aspect of the analysis is that 38% of the surveyed individuals consider patient associations to be a key source of support in overcoming the barriers associated with their health condition. This finding underscores the crucial role of these associations in providing guidance and advocating for the rights of affected individuals, establishing them as an essential resource in their daily lives.

3. ORGANIC DISABILITY IN INDIVIDUALS WITH MCS AND/OR EHS

3.1 THE SOCIAL MODEL OF DISABILITY AND THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

As a starting point, it is important to highlight that this report is approached from a human rights perspective and, consequently, from the social model of disability. This model defines disability in relation to the social environment and its barriers, rather than as a strictly medical issue affecting the individual, which, under the medical model, is primarily focused on cure or treatment.

It is precisely the social model that has been adopted by the **United Nations Convention on the Rights of Persons with Disabilities** (hereinafter, 'CRPD').

In this regard, the **CRPD** states that *"persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others"* (Article 1, CRPD).

Consequently, disability is not inherent to the individual but rather arises from the interaction between an impairment or health condition and physical, social, or environmental barriers.

To eliminate these barriers and thereby ensure equality and non-discrimination for persons with disabilities, the Convention imposes an obligation on States to adopt a range of measures that facilitate the full enjoyment of all their rights. These measures focus on **accessibility** and **reasonable accommodations**.

- **Accessibility**

The CRPD enshrines accessibility as a fundamental prerequisite for persons with disabilities to live independently and fully participate in society on an equal basis with others[1].

In this regard, accessibility can be understood in a strict sense as equal access to environments, goods, products, and services. In a broader sense, it refers to equal access to the enjoyment of all human rights[2].

In any case, accessibility must be addressed in all its complexity, encompassing the physical environment, transport, information and communication, and services, regardless of whether they are publicly or privately owned, or whether they are in urban or rural areas. If these spaces, services,

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[1] Article 9 CDPD.

[2] COCEMFE (2023) Defence of the rights of persons with disabilities: A guide for action, p. 25.

and infrastructures are open to the public or intended for public use, they must be accessible to all individuals, regardless of the type of disability or impairment they may have[3].

This constitutes an ex-ante obligation for States, meaning that accessibility must be integrated into systems and processes proactively, regardless of the specific needs of an individual with a disability[4]. This obligation is realised through the identification and elimination of barriers that prevent access to objects, facilities, goods, and services[5], as well as through the implementation of what is known as universal design[6].

Failure to comply with this obligation should be considered an act of discrimination, except in cases where a justified reason applies[7]. Only when accessibility measures fail for a justified reason do reasonable adjustments come into play[8].

- **Reasonable accommodations**

Reasonable adjustments are defined as *"necessary and appropriate modifications and adaptations that do not impose a disproportionate or undue burden, when required in a particular case, to ensure that persons with disabilities can enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms"* (Article 2, CRPD).

These are, therefore, individual measures that must be implemented as soon as a person with a disability needs to access situations or environments that are not accessible or wishes to exercise their rights[9].

This is implemented through a series of actions, such as assessing the feasibility of the adjustment and determining whether it is appropriate and effective, evaluating the proportionality between the means employed and the enjoyment of the right being guaranteed, ensuring that costs do not fall upon the individual concerned, and, in cases where the adjustment is denied, ensuring that the refusal is objectively justified, among other measures[10].

Once again, failure to implement these measures must be considered an act of discrimination.

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[3] CRPD Committee, General Comment No. 2 (2014) Article 9: Accessibility, párr. 13.

[4] Ídem, párr. 25; CRPD Committee, General Comment No. 6 (2018) on equality and non-discrimination, párr. 24.

[5] CRPD Committee, General Comment No. 2 (2014) Article 9: Accessibility, párr. 14.

[6] Universal design is defined in **Article 2 of the CRPD** as *"the design of products, environments, programmes, and services that can be used by all people, to the greatest extent possible, without the need for adaptation or specialised design"*.

[7] Ídem, párr. 13.

[8] Ídem, párr. 19; CRPD Committee, General Comment No. 6 (2018) on equality and non-discrimination, párr. 24.

[9] Ídem, párr. 24.

[10] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

3.2 DISABILITY IN INDIVIDUALS WITH MCS AND/OR EHS

3.2.1 Definition of organic disability

Organic disability must be understood within the framework of the social model of disability and the CRPD. This perspective is clearly reflected in the White Paper on Organic Disability, published by COCEMFE in 2022[11], which defines it as follows:

> "Organic disability (OD) arises from the loss of functionality in one or more bodily systems, due to the development of chronic health conditions and the existence of social barriers that limit or prevent full social participation and the exercise of rights and freedoms on an equal basis with others"[12].

Unlike organic disability associated with other diseases, where the loss of functionality may preexist before encountering different barriers, in the case of individuals with MCS and/or EHS, symptoms manifest because of exposure to environmental barriers.

This implies that if these barriers were eliminated, symptoms would not manifest. However, since barrier-free environments do not exist, affected individuals continue to experience symptoms due to the chronic nature of their condition and the systemic impact it causes. As a result, they often require rehabilitative treatments and can only achieve improvement after a prolonged period without exposure[13].

Accessibility and Reasonable Adjustments in Organic Disability Resulting from MCS and/or EHS: Environmental Control

As previously explained, in the case of individuals affected by MCS and/or EHS, loss of functionality occurs upon exposure to environmental barriers. Consequently, the primary accessibility measures and reasonable adjustments focus on adapting environments, goods, products, and services used by affected individuals through what is known as environmental control, as this helps to prevent exposure to triggering factors.

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[11] COCEMFE (2022) White paper on organic disability: study on the situation of persons with organic disability.

[12] Ídem, p. 33

[13] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

3.2.2 The Lack of Diagnosis of MCS and/or EHS

At the international level, various organisations, such as the Parliamentary Assembly of the Council of Europe and the European Parliament, have expressed concern about the increasing prevalence of diseases linked to environmental factors, including MCS and EHS.

However, these conditions have not yet been recognised by the World Health Organization (WHO) in the International Classification of Diseases (ICD-11) with specific diagnostic codes.

- For MCS, it is currently only classified under the category of "Idiopathic Environmental Intolerance"[14]. As a result, in May–July 2023, a request was submitted to the WHO for its inclusion under the section "Allergic or Hypersensitivity Condition".
- For EHS, the WHO has included a section to document harm caused by exposure to radiofrequency radiation and other non-ionising radiation (Codes W90.0 and W90.8 in ICD-10, currently in force in Spain).

In Spain, the Ministry of Health published the "Consensus Document on Multiple Chemical Sensitivity"[15] in 2011, which was later updated in 2015 through the "Update on Scientific Evidence Regarding Multiple Chemical Sensitivity"[16]. These two documents serve as the primary foundation for the recognition of the disease in the country. Regarding EHS, it is only mentioned in the 2011 document, where it is classified as a condition associated with MCS, triggered by electromagnetic sources from modern technology devices.

In practice, this lack of official recognition directly impacts the diagnosis of the disease. This is reflected in survey data, where 22% of affected individuals reported that they had not yet received a formal diagnosis of their condition.

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[14] World Health Organization, International Classification of Diseases, 11th Revision (ICD-11).

[15] Ministry of Health, Social policy and Equality (2011) Consensus document on Multiple Chemical Sensitivity.

[16] Valderrama, M. (2015) Update on Scientific evidence regarding multiple chemical sensitivity (MCS), Ministry of Health, Social services and Equality.

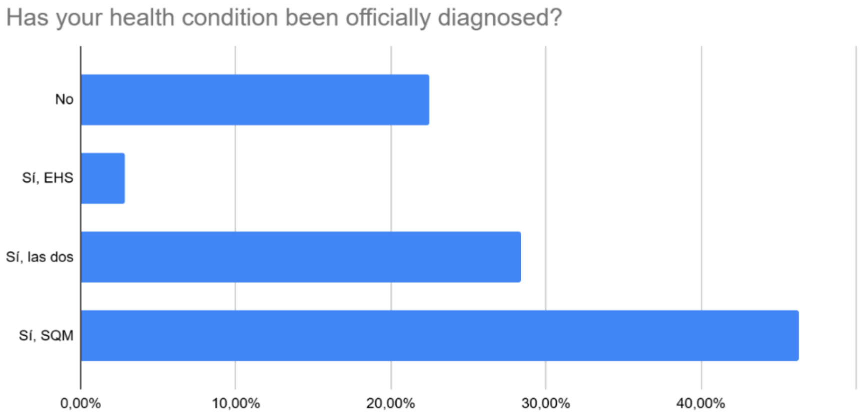

Figure 3 – Self-elaboration

It is important to highlight that the percentage of individuals diagnosed with MCS, whether exclusively (46%) or in combination with EHS (28%), is significantly higher than the percentage of those diagnosed solely with EHS (3%). This imbalance may be attributed to the fact that the survey was predominantly answered by individuals with MCS or both conditions, as detailed in Section 2 of the report.

However, these results also reveal a greater difficulty in diagnosing EHS. In some cases, individuals presenting both conditions have only been diagnosed with MCS, suggesting an underreporting of EHS cases. This highlights the urgent need for increased awareness and training in the clinical field to ensure the accurate identification of both conditions.

This lack of diagnosis not only affects the visibility of EHS but also hinders the development of adequate care strategies and support systems tailored to the needs of affected individuals.

3.2.3 The Lack of Recognition of Organic Disability Resulting from MCS and EHS

Difficulties in the recognition and diagnosis of health conditions such as Multiple Chemical Sensitivity (MCS) and Electromagnetic Hypersensitivity (EHS) have a direct and negative impact on the ability to obtain official disability recognition.

This, in turn, affects access to fundamental rights established within the framework of disability rights, including the right to demand accessibility measures and request reasonable adjustments[17].

In Spain, official recognition of disability requires an administrative declaration establishing a disability rating of 33% or higher[18]. This recognition is obtained through an administrative procedure, which, until April 2023, was predominantly based on a medical model of disability. This approach not only

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[17] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

[18] Article 4.2 of Royal Legislative Decree 1/2013, of 29 November, approving the Revised Text of the General Law on the Rights of Persons with Disabilities and Their Social Inclusion .

excluded the social and human rights model but also particularly marginalised individuals with organic disabilities, whose symptoms are often difficult to observe or quantify objectively.

In this context, the data reveal that 24% of surveyed individuals with MCS and/or EHS have not been officially recognised as having a disability, despite having initiated the corresponding process. This figure highlights the persistence of institutional barriers that hinder access to fundamental rights for these individuals, thereby perpetuating situations of exclusion and vulnerability.

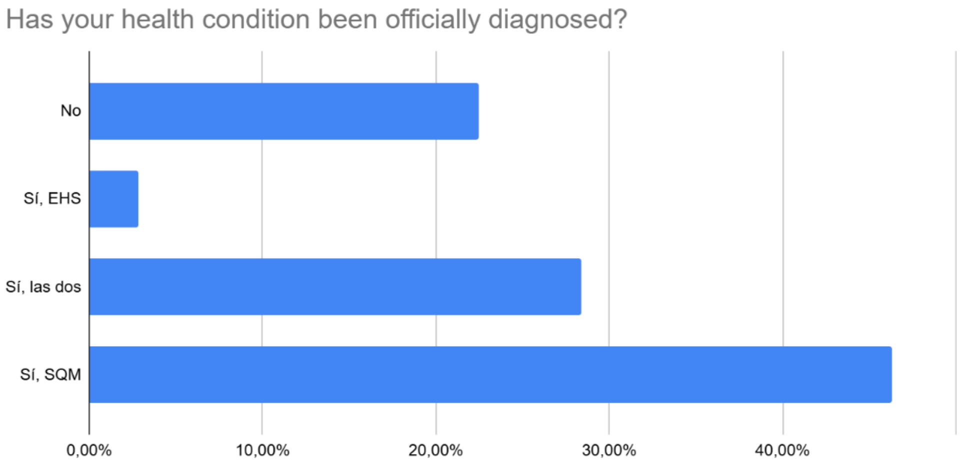


Figure 4 – Self-elaboration

Although 51% of surveyed individuals have been granted some degree of disability recognition, only 44% have obtained a degree of 33% or higher, which is necessary to access the rights and benefits associated with disability status in Spain.

This is a significant finding, as it reflects that in a considerable number of cases, the symptoms resulting from MCS and/or EHS—and in some instances, even the diagnosis itself—are not adequately considered during the evaluation process for disability recognition.

> *"Disability is a lottery. Some individuals have been granted a high degree of disability recognition, while others, who equally need it, have not been recognised at all. Depending on where you apply for the assessment and who conducts it, the rating varies."* – Focus group with key informants.

It is concerning that 25% of individuals affected by MCS and/or EHS have never applied for official disability recognition. This may be due to various factors, including lack of information, the perception that the process is too complex, or distrust in the system, fearing that their needs will not be recognised due to the invisibility of these conditions.

In April 2023, a new assessment framework was implemented for the recognition, declaration, and grading of disability, incorporating a broader evaluation of the contextual and environmental factors affecting individuals. This change represents a significant advancement towards a more comprehensive approach, better aligned with the social model of disability.

However, despite this regulatory progress, patient associations report that, in practice, no significant improvements have been observed in the recognition of disability associated with MCS and EHS. Affected individuals continue to face the invisibility of these conditions, as well as the lack of recognition of the disabilities that arise from them.

> *"Although [the new assessment framework] considers additional criteria, it is important to acknowledge that these conditions lack credibility and recognition. When disability is granted, it is often due to another condition the individual has, which is not related to MCS and/or EHS."* – Focus group with key informants.

> *"Professionals are still not well trained in using the new assessment framework. Affected individuals often rely on what has worked in other cases to accumulate conditions in order to apply for disability recognition, even if those conditions are not the most relevant to them—for example, loss of vision or hearing."* – Focus group with key informants.

3.2.4 Consequences on the Lives of Affected Individuals: Invisibility and Lack of Understanding

The lack of sufficient diagnosis for MCS and EHS, combined with the failure to recognise organic disability, pushes affected individuals to the margins of society, further deepening their invisibility.

> "On countless occasions, people have not addressed me directly but have instead spoken to my companion to explain things about me. They make you invisible and exclude you from the conversation."

This reality is closely linked to the lack of training and awareness regarding these conditions, leading to a lack of understanding both within an individual's immediate environment and in key areas essential for personal and social development.

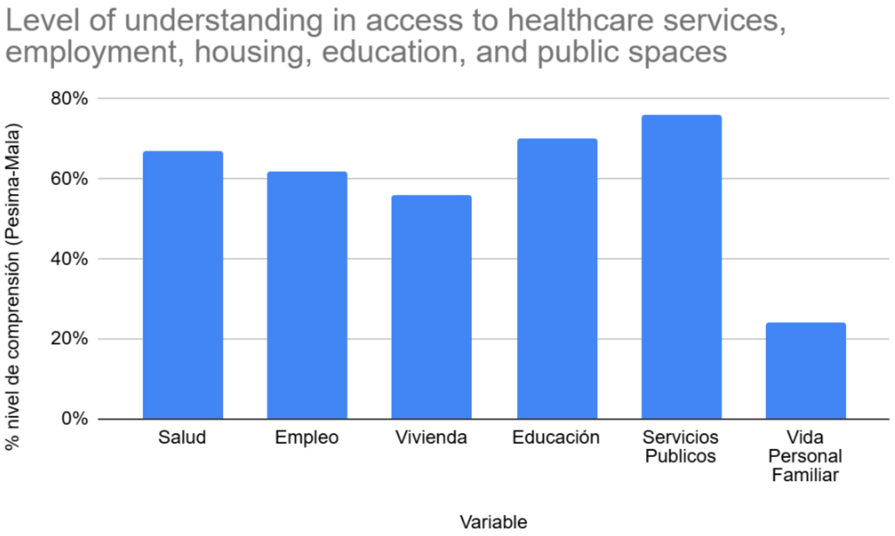


Figure 5 – Self-elaboration

According to the data, surveyed individuals feel particularly misunderstood in the following settings:

- Public spaces: 76% of respondents encounter barriers to both access and understanding in these environments.
- Educational institutions: 70% report difficulties in these settings, which are essential for learning and development.
- Healthcare facilities: 67% feel that their condition is neither understood nor adequately addressed within the healthcare system.

In contrast, affected individuals find greater understanding within their immediate social circles, such as family, friends, and acquaintances. This underscores the critical role of close social support in contrast to the lack of inclusion in other settings.

This situation highlights the urgent need to raise awareness and train professionals across various sectors, as well as to promote public policies that ensure fair, inclusive, and respectful treatment for individuals with MCS and EHS in all areas of society.

4. BARRIERS ACROSS DIFFERENT ASPECTS OF LIFE

4.1 CHAPTER I: HEALTHCARE

4.1.1 The right to health

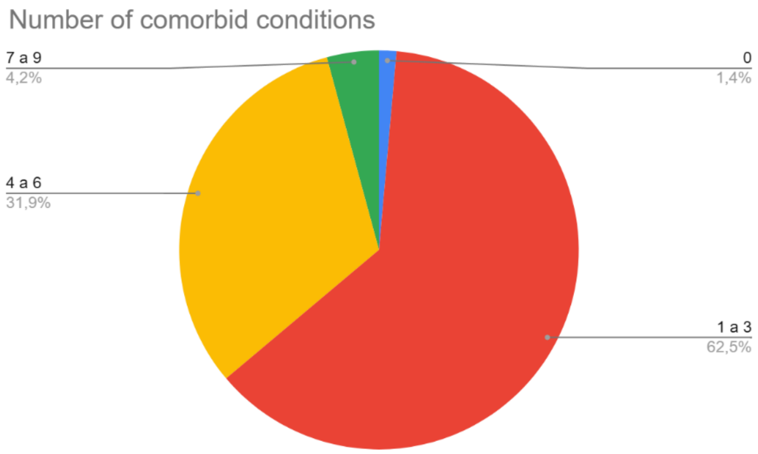
Article 9.1(a) of the CRPD obliges States to identify and eliminate barriers that hinder access to medical facilities, adopting accessibility measures, including universal design, to ensure equal conditions for all individuals.

Article 25 reinforces this principle, stating that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination. It further mandates that States must provide accessible, free, or affordable healthcare services and programmes, tailored to their needs and as close as possible to their communities. Additionally, healthcare professionals are required to offer care of the same quality as for others, prohibiting any form of discrimination in service provision.

The CESCR Committee, in alignment with Article 12 of the ICESCR, emphasises that the right to physical and mental health can only be fully realised if persons with disabilities have access to medical and rehabilitation services that enable them to achieve and maintain an optimal level of autonomy. These obligations apply to both public healthcare systems and private healthcare providers, which must also ensure equal access and quality of services, as established in the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.

4.1.2 The particular importance of access to healthcare services for individuals with MCS and/or EHS

Individuals with MCS and/or EHS, as they experience organic disability resulting from a chronic health condition, have a critical need for adequate access to healthcare services. This necessity is further amplified by the frequent coexistence of these conditions with other comorbid disorders, such as fibromyalgia, gastrointestinal disorders, food intolerances, and musculoskeletal impairments.



The majority of individuals affected by MCS and/or EHS experience between one and three comorbid conditions (62%), while 32% live with between four and six additional health conditions (figure 6). These comorbidities most commonly include fibromyalgia, gastrointestinal disorders, and food intolerances (figure 7).

Figure 6 – Self-elaboration

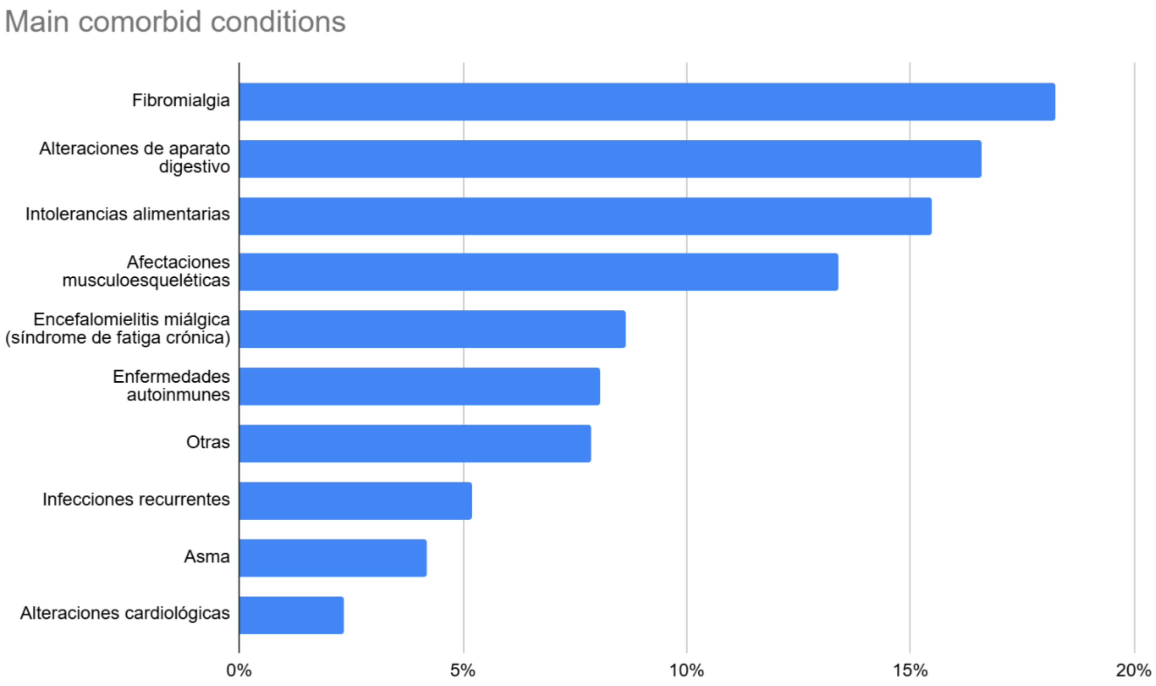


Figure 7 – Self-elaboration

This reality implies a high frequency of hospital and healthcare visits, highlighting the importance of ensuring adequate and continuous access to medical services to address the multiple health needs of individuals with MCS and/or EHS.

In addition to the specific healthcare needs related to MCS and EHS, affected individuals may also encounter other health conditions unrelated to these disorders, such as illnesses or accidents requiring urgent medical care.

Furthermore, affected individuals may need to accompany family members or loved ones to hospitals or healthcare centres, either by choice or necessity. In such cases, they often face even greater neglect, being overlooked and sidelined in the medical process. This leads to associative discrimination, where their rights and needs are disregarded simply because they are supporting another person in a healthcare setting.

What is associative discrimination?

Associative discrimination is a form of discrimination directed against third parties due to their association with a person with a disability. For example, when individuals with MCS and/or EHS are unable to accompany their relatives to medical appointments or hospitalisations, this prevents those family members from exercising their right to healthcare on an equal basis with others..

> "I had to accompany my father during the final stage of his life in the hospital. I requested at reception that the staff entering the room refrain from using perfumes, but they told me there was no protocol for companions. I explained my diagnosis to the staff, and while some were understanding, others told me that it was impossible. In the end, I endured as much as I could because it was my father, and I chose not to leave him. I ended up in a very bad condition."
>
> "I had to take my daughter to the emergency room, but I was not allowed to be with her during the consultation."

4.1.3 Barriers to Accessing Healthcare Services for Individuals with MCS and/or EHS

Individuals affected by MCS and/or EHS tend to avoid hospitals and healthcare centres always or frequently **(49%), and when they do attend, their health worsens in 46% of cases**. This is because most healthcare facilities have not implemented specific accessibility measures for these conditions, making them unsafe environments for those affected

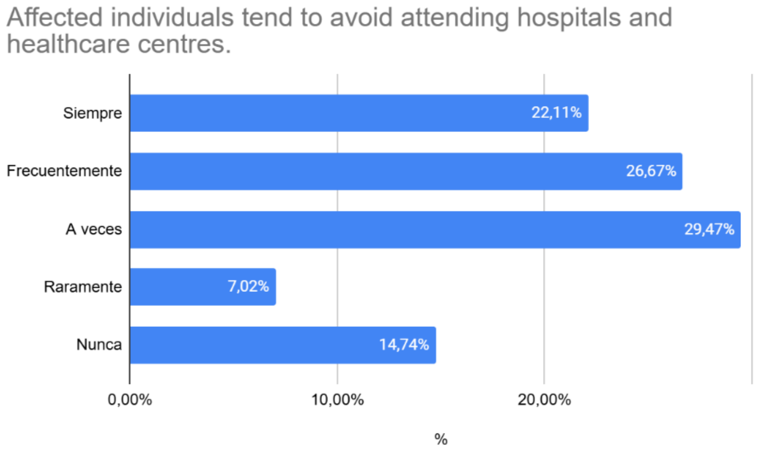


Figure 8 – Self-elaboration

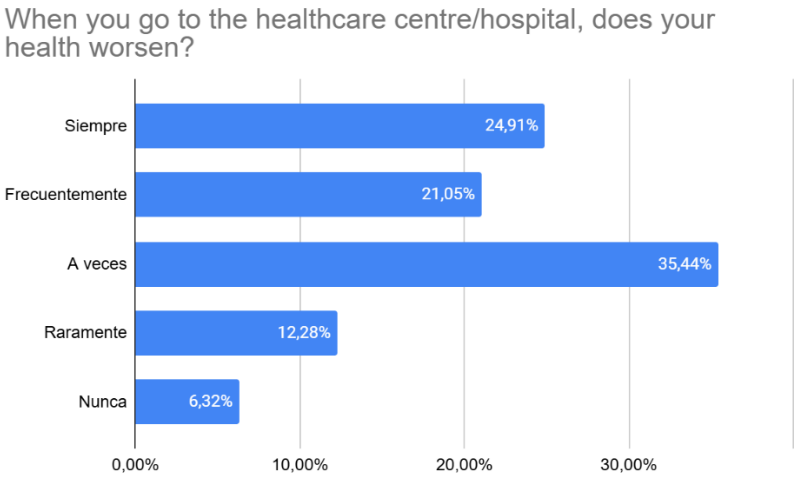


Figure 9 – Self-elaboration

The lack of specific protocols is one of the main barriers. According to the data, 72% of healthcare centres and 61% of hospitals do not have guidelines related to MCS and/or EHS. This means that, for example, environmental control measures are not implemented in medical facilities when treating affected individuals. However, in cases where protocols do exist and are correctly applied, the experience of affected individuals improves significantly:

> "Most scheduled consultations where there is time to implement the protocol usually go well.
>
> "In a surgical procedure I underwent, the SQM and EHS Protocol was taken into account, both in the operating room and on waking up. The healthcare and non-healthcare staff were very responsive, and they expedited the discharge so that I didn't have to stay in hospital to avoid exposure as much as posible".

What Are the Main Environmental Barriers in Healthcare Facilities?[19]	
Individuals with MCS	**Individuals with EHS**
● Use of detergents, fabric softeners, and disinfectants with high chemical toxicity for cleaning healthcare facilities, as well as for bed linens and hospital clothing. ● Disinfection of surgical instruments and other medical equipment using highly toxic chemical products.	● Electromagnetic fields (EMFs) emitted by personal wireless devices used by hospital staff and patients (e.g., mobile phones, smartwatches, and tablets). ● EMFs from the hospital's own wireless transmission systems, including Wi-Fi, Bluetooth, workstations, pico-antennas, and

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[19] For further information, refer to: Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective and Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective.

● Presence of air fresheners in restrooms and other hospital areas. ● Medical equipment containing toxic chemical components, such as IV lines and oxygen masks. ● Medications that contain allergens or substances causing intolerances. ● Personal care products and perfumes worn by healthcare staff, other patients, and visitors.	repeaters, as well as other sources of EMF emissions such as lighting systems and medical equipment. ● EMFs from external sources impacting the healthcare facility, such as mobile phone towers, electrical substations, and high-voltage power lines.

67%[20] of affected individuals report that healthcare personnel lack knowledge about MCS and EHS, which leads to questioning their symptoms, denying them care, or even failing to apply established protocols.

> "In the allergy department, they told me that my diagnosis does not exist. They also refused to read the reports I brought, which supported it."
>
> "Some doctors have told me that my condition was an exaggeration or that I might be making it up."
>
> "I requested the application of the protocol, but since they did not want to implement it, they referred me to telephone consultations. Even so, I still had to go in person (without the protocol being applied) to collect sick leave forms and process specialist referrals."
>
> "This year, I needed surgery, and when I asked them to follow the protocols, they refused. They postponed the surgery the day before and told me they would not follow any protocol. They laughed at me and spoke to me as if I were making things up."
>
> "A doctor told me that I had bought the reports and that what I really wanted was sick leave to avoid working—that everything was a lie. She even cancelled the sick leave granted by other doctors."

This lack of knowledge is closely linked to the stigmatisation faced by individuals with MCS and/or EHS. However, there are also positive experiences when healthcare personnel have received training or demonstrate empathy.

> "Once, I was treated by a doctor who was familiar with the condition, so she attended to me without delays and in isolation."

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[20] Level of understanding in healthcare centres/Hospitals: excellent, 1%; Good, 7%; fair, 25%; poor, 30%; and very poor, 36%.

> "My doctor is quite understanding because he took a course on MCS."

However, lack of knowledge and lack of empathy among healthcare personnel are not mutually exclusive, as there are cases where affected individuals, despite being treated by professionals unfamiliar with their condition, still received dignified care.

> "On one occasion, a substitute doctor added my latest MCS report to my medical history, even though he was unfamiliar with the condition. He also listed it as the primary diagnosis so that any doctor treating me would see it first."
>
> "Although the health centre does not acknowledge MCS/EHS protocols, a midwife did everything she could to perform my cervical screening. It finally took place after a year, not under optimal conditions, but she did everything possible to help."
>
> "I used to have the support of my primary care doctor, who would facilitate my referrals to different specialists and help me prepare medical documentation for disability pension hearings. She never made excuses or caused any issues."

The lack of protocols, knowledge, and empathy in healthcare services not only affects the health of people with MCS and/or EHS but also perpetuates the exclusion and invisibility of these conditions. Despite some positive experiences, it is fundamental to implement structural measures that include training for personnel, the creation of specific protocols, and the adoption of accessibility measures that allow for dignified and adapted care for these needs.

4.1.4 How to Improve This Situation: Reasonable Adjustments

Faced with the environmental barriers that make it difficult or prevent people with MCS and/or EHS from accessing healthcare centres, they can request **reasonable adjustments**[21]. These requests are usually focused on measures related to the space, the personnel (healthcare, cleaning, or security staff), and the materials used for cleaning or medical care, among other aspects.

Despite the importance of these adaptations, most affected people (64%) have never requested reasonable adjustments in healthcare services. When they are requested, 62% of the requests are neither accepted nor implemented, and only occasionally are alternatives proposed. This reflects a clear lack of accessibility and understanding in the healthcare system.

Some of the adaptations mentioned by the surveyed individuals include:

- Priority care and specific appointment times:

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[21] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

"My family doctor usually gives me the first appointment in the morning, so I don’t have to spend too much time in the waiting room."

"My doctor sees me on Sundays or public holidays in a non-busy, isolated, and ventilated area."
"They arranged for me to undergo a test before any other patient entered so that the space wouldn’t be contaminated."

- Appointments outside the healthcare centre or via telephone

"My primary care doctor, since they cannot see me inside the healthcare centre, consults with me over the phone, and if they need to explain something or perform a blood test, they do it in my vehicle in the emergency parking area of the healthcare centre."

- Isolated, ventilated rooms free from electromagnetic contamination

"I was assigned a private room after giving birth."

"A nurse was understanding and found me a more isolated room to administer my treatment."

"They placed me in a room that was further away from the Wi-Fi router."

"I was allowed to set up an anti-radiation canopy in the room."

- Expedited discharge to reduce time spent in the healthcare facility

"After a surgical procedure, the medical and non-medical staff were very receptive and expedited my discharge to prevent me from having to stay in the hospital, minimising exposure as much as possible."

- Preparation of operating rooms, medical equipment, and staff for surgical procedures.
- Turning off mobile phones when attending to the affected person.
- Granting of a special care and accompaniment card (AA)[22].

Example of a Positive Experience from a Person with EHS

"At the General Hospital of the province, whenever I have requested it, I have been given priority care and placed in rooms that are not regularly used. The doctors have also called me in advance to explain the procedure in detail and check if I had any issues with the methods they were going to use. In my usual hospital, where no protocol is applied, the reception staff took the thermal paper with the visit code on their own initiative when they

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[22] This is a special healthcare resource aimed at improving accessibility and assistance for persons with disabilities in healthcare services. It is available only in certain Autonomous Communities, with specific characteristics in each region.

> saw me wearing gloves. They also provided me with paper and a pen that had not been contaminated by contact so I could write down the sequence of my appointment code."

Although there are positive experiences, the survey data reveal significant difficulties in the implementation of adaptations for individuals with MCS and/or EHS. These difficulties include significant delays in the application of adjustments, limited effectiveness of many adopted measures, and, in numerous cases, affected individuals are forced to cover the full or partial costs of these adaptations[23].

These barriers highlight the urgent need to establish more effective protocols, ensure their timely implementation and guarantee that adaptations are accessible without placing additional financial burdens on those who need them.

Overall, affected individuals rate the quality of adaptations in the healthcare sector as "average" (59%).

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[23] Difficulties in the implementation of adaptations: no issues, 28%; delayed process, 23%; ineffective, 13%; cost bone by the individual, 10%; and other issues, 26%.

4.2 CHAPTER II: Employment

4.2.1 The right to work

The CRPD Committee recognises the right to work as fundamental for the realisation of other human rights, inherent to human dignity, and essential for the survival of persons with disabilities and their families. Within this framework, Article 27 of the CRPD obliges States to guarantee this right through effective measures that eliminate employment barriers and promote equality in both the public and private sectors. These obligations are linked to the principles of accessibility and non-discrimination and require addressing matters such as indirect and intersectional discrimination, identifying and eliminating obstacles in the workplace, and facilitating the provision of reasonable adjustments. Employers, in turn, must establish clear and accessible procedures for the implementation of these measures, in cooperation with the affected workers, if they do not impose a disproportionate or undue burden.

Likewise, the right to a safe and healthy working environment requires coherent national policies that consider the needs of workers with disabilities, preventing harm related to their professional activity. Failure to comply with these obligations not only violates the right to non-discrimination but also infringes the rights to work and to just and equitable working conditions, as enshrined in Articles 6 and 7 of the ICESCR. Ensuring these rights necessitates a joint effort to eliminate barriers, implement accessible solutions, and promote the labour inclusion of persons with disabilities on an equal basis with others[24].

In the case of persons with MCS and/or EHS, only 27% are currently employed, while 73% are not working. Within this 73%, 33% have been recognised as having permanent incapacity, 13% are in a situation of temporary incapacity, and 27% are unemployed. Lastly, 2% have never been employed.

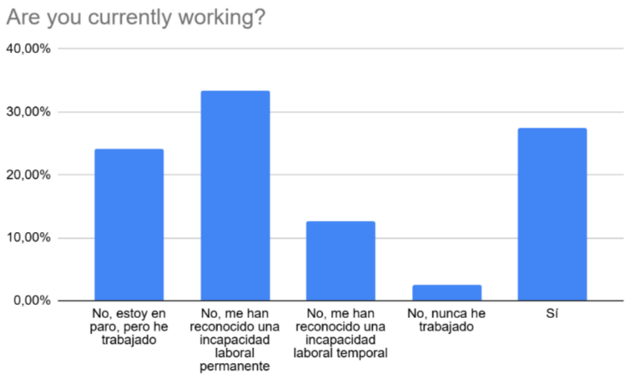

Figure 9 – Self-elaboration

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[24] CRPD Committee, General Comment No. 8 (2022) on the Right of Persons with Disabilities to Work and Employment, para. 2.

What Are the Main Environmental Barriers in the Workplace?[25]	
For persons with MCS	**For persons with EHS**
● Cleaning products that emit high levels of Volatile Organic Compounds (VOCs). ● VOCs emitted by office equipment, such as printers, photocopiers, and fax machines. ● Personal hygiene and cosmetic products used by colleagues. ● Air fresheners in shared spaces. ● Poor ventilation in office buildings. ● Frequent entry and exit of clients, students, or administrative staff wearing cosmetic or fragranced products. ● Retail environments, such as dry cleaners, cosmetic stores, and hair salons, where highly chemical-intensive products are used. ● Toxic gases produced in industrial sector jobs. ● Synthetic fertilisers and pesticides used in agricultural or forestry work.	● Electromagnetic fields (EMFs) from telecommunications and wireless devices in the workplace. ● Higher-than-usual EMF levels in certain job sectors. ● Exposure to EMFs not only in the workplace itself but also during commuting, where public and private transport often involves intense wireless connectivity.

Considering the data and the employment barriers faced by individuals with MCS and/or EHS, it is essential to analyse their job-seeking process. In general, these individuals encounter significant difficulties due to their health condition, with 61% reporting problems always or frequently during this stage. This is because both job searching and selection processes are often not accessible, and the range of available job opportunities is severely restricted.

> "When you ask about the protocol in an interview, they simply never call you back".

On the other hand, the stigma associated with these health conditions further worsens the situation. Many affected individuals choose not to disclose their condition during the selection process, fearing discrimination and being excluded as candidates due to their health status. This reflects not only an accessibility issue but also the need to promote prejudice-free and more inclusive work environments.

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[25] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

4.2.2 Barriers to Accessing an Accessible Workplace for Individuals with MCS and/or EHS

According to the data, 81% of surveyed individuals report a deterioration in their health when attending their workplace. This decline may be one of the main reasons why many affected individuals are unable to remain in the workforce, underscoring the urgent need to adapt workspaces and working conditions to protect their health.

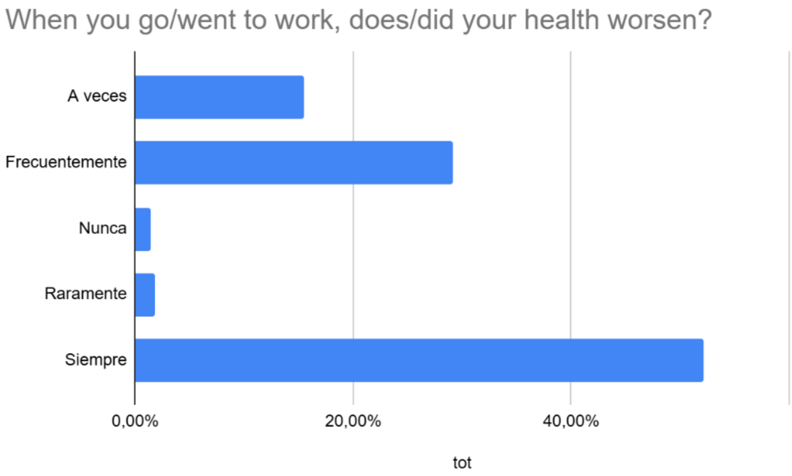

Figure 10 – Self-elaboration

This occurs because most workplaces have not implemented accessibility measures for individuals with MCS and/or EHS, making them unsafe and exclusionary environments for those affected.

The accessibility of a job for an individual with MCS and/or EHS depends largely on the nature of the role and the tasks involved. Certain work environments tend to be particularly problematic, including:

- Offices or workplaces where chemical cleaning products are used or where wireless systems are in operation.
- Retail spaces or establishments open to the public, including educational institutions and public sector offices, where exposure to perfumes, cosmetics, or cleaning products is common. These workplaces also frequently rely on wireless systems such as Wi-Fi, mobile phones, or other smart devices as part of their operations.
- Industrial sectors with high levels of toxic agents or strong electromagnetic fields (EMFs) from both low and high-frequency sources.
- The telecommunications sector, which inherently involves constant exposure to electromagnetic radiation.
- Conventional agricultural or forestry sectors that use pesticides or chemical fertilisers.

In some cases, certain jobs may be entirely incompatible with these conditions, as exposure to triggering agents is unavoidable. Additionally, there are situations where individuals develop these conditions directly due to their workplace environment, further emphasising the need for preventive policies and specific workplace adaptations.

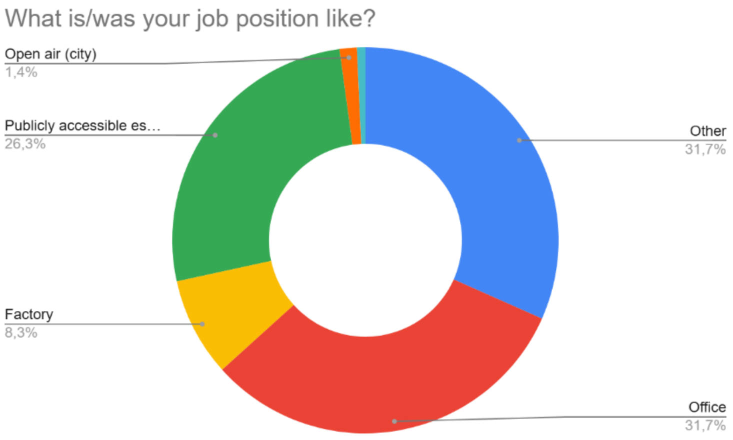

Figure 11 – Self-elaboration

Among the surveyed individuals who have been employed at some point, the main types of jobs are concentrated in offices or administrative workplaces (32%), public-facing establishments (26%), and other categories (32%). However, the lack of workplace adaptations remains a significant barrier, as only 20% of workplaces have implemented protocols related to MCS and/or EHS, according to the collected data.

This situation is further exacerbated by a lack of understanding in the workplace, reported by 61% of surveyed individuals, both from employers and colleagues. This leads to stigmatising and discriminatory attitudes, which not only hinder the professional inclusion of affected individuals but also have a negative impact on their health and well-being in the workplace.

> “The company director called me lazy and overly sensitive. She said that what was happening to me was just an excuse not to work."
>
> "My colleagues would throw substances at me that harmed me to ‘prove’ that my illness was fake. I ended up in the emergency room and was on sick leave for 16 months."
>
> "All those times the company told me they were trying to contact me and couldn’t because my phone was always on airplane mode. They said that wasn’t acceptable, that the company was investing heavily in tracking technology to know where we workers were and what we had done so far, and that I had to turn my phone on and keep it always connected, despite my illness”.

Finally, individuals with MCS and/or EHS also face significant difficulties in commuting to their workplace. The journey often involves exposure to triggering agents, such as chemical products, pollution, or electromagnetic fields, which are virtually impossible to control from the workplace itself.

In this context, remote work (teleworking) emerges as a viable and necessary solution, particularly in cases where EHS is not highly severe. It allows affected individuals to perform their job responsibilities without being exposed to factors that could worsen their health condition.

> “The commute to the office was a problem. I was unable to drive (I didn’t want to be a danger to others), and public transport reeks of perfume. It was very difficult to explain to my bosses all the things I could no longer do and to admit that I couldn’t continue like that. Work was my priority. It was humiliating for me, and I needed psychotherapy to accept that I could no longer work. I felt like I was useless”.

4.2.2. How to improve this situation: reasonable adjustments.

Pursuant to the right to reasonable adjustments for persons with disabilities resulting from these conditions, affected individuals may request workplace adaptations.

It is important to highlight the Occupational Risk Prevention Act[26], which aims to protect workers' health by requiring companies to design and implement occupational risk prevention plans, as well as health monitoring plans, assess risks and update them regularly, plan preventive action measures, and provide worker training, among other obligations.

Under this law, however, the employer is only required to adapt the workplace if the affected individual has been recognised as a "particularly sensitive worker”.

What is meant by «particularly sensitive worker»?

A "particularly sensitive worker" is defined as a person who, due to their own personal characteristics or known biological condition, including those recognised as having a physical, psychological, or sensory disability, is particularly sensitive to work-related risks[27].

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[26] Law 31/1995, of 8 November, on Occupational Risk Prevention.

[27] Article 25 of Law 31/1995, of 8 November, on Occupational Risk Prevention.

In this regard, the Practical Encyclopaedia of Occupational Medicine states that workers affected by MCS should be considered particularly sensitive workers under the Occupational Risk Prevention Act (LPRL) and even suggests specific adaptation measures for such cases.

However, individuals with MCS, and especially those with EHS, face significant difficulties in being recognised as particularly sensitive workers, mainly due to a lack of understanding and insufficient training among relevant professionals[28].

In practice, 52% of individuals affected by MCS and/or EHS have requested adaptations in their workplace. However, 70% of those who submitted requests report that they were either denied or, if approved, not implemented. Additionally, when adaptations are carried out, affected individuals report significant difficulties, including delayed implementation, ineffective measures, or the requirement to cover the costs partially or entirely.

Despite these obstacles, many individuals rate the quality of the adaptations as "good" (51%), although this varies depending on the type of employment.

In cases where workplace adaptation is impossible, alternative solutions are considered, such as remote work (teleworking), which, for some individuals, proves to be an effective solution. Working from home allows them to control their environment and minimise exposure to triggering agents, as reflected in several testimonials.

> “I worked from home teaching English and was able to control my environment. Some students were kind and would come without wearing any fragrances».
> «I work alone at home, which is an advantage”.

4.2.3. When this is not enough: the right to social protection.

When it is not possible to adapt the workplace or implement alternative solutions such as teleworking, affected individuals resort to sick leave or apply for temporary or permanent disability benefits. However, these processes are often lengthy and complex, largely due to the lack of official recognition of the disease or disability[29]. Even employers frequently question the legitimacy of such requests.

> “They tell me that I want sick leave just because I don’t want to work”.

Difficulties also arise in how these illnesses are classified within the benefits system. For example, some cases are classified as common illnesses rather than occupational diseases, which prevents individuals from accessing the appropriate benefits.

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[28] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

[29] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

> "I worked as an administrative assistant in a centre where rubber materials were handled. Despite my bosses supporting me, the INSS classified my condition as a common illness because my illness was not officially recognised for my job category".

Nevertheless, some individuals do manage to obtain disability benefits after long processes.

> "When I became so ill that I could no longer go to work and requested sick leave, they prepared a report listing all the wireless devices I was exposed to at work, and that report helped me obtain full disability".

When neither sick leave nor disability benefits are granted, 43% of affected individuals end up leaving their jobs, often without access to any benefits, and 14% of surveyed individuals report having been dismissed due to their health condition.

> "I had to leave my job because of my illness, without any income because the INSS did not recognise it".

These experiences illustrate why 67% of affected individuals live in fear of losing their job, underscoring the urgent need to ensure workplace inclusion and access to appropriate social protection measures for those facing these conditions.

4.3 CHAPTER III: HOUSING

4.3.1 The right to housing

The right to accessible housing is based not only on the principles of accessibility, equality, and non-discrimination, but is also intrinsically linked to the right to an adequate standard of living (Article 28 of the CRPD and Article 11 of the ICESCR) and the right to live independently and be included in the community (Article 19 of the CRPD). To ensure these rights, it is essential to have a sufficient number of accessible homes in all areas, allowing individuals to freely choose their place of residence. Moreover, these homes must be affordable to guarantee universal access[30].

4.3.2 Barriers to accessing accessible and dignified housing for individuals with MCS and/or EHS

In practice, individuals with MCS and/or EHS face significant limitations in securing adequate housing. According to the data, 38% of surveyed individuals have been forced to relocate, while 31% wish to move, highlighting the lack of housing options that meet the necessary accessibility and affordability conditions for these individuals.

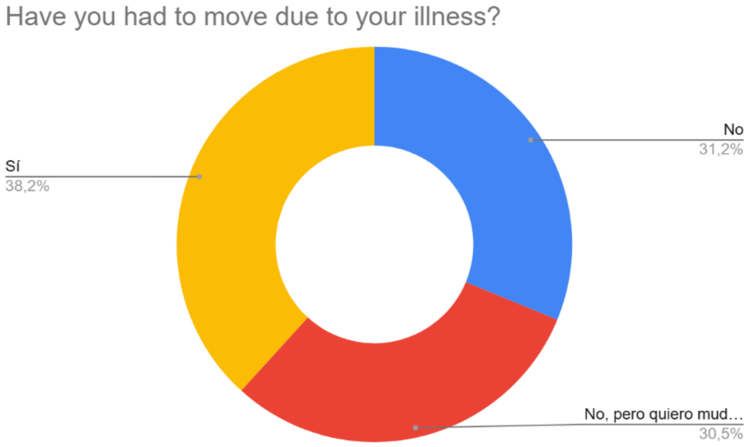

Figure 12 – Self-elaboration

A major challenge for individuals with MCS and/or EHS who wish to move—but have not been able to do so or have only considered it—is their financial situation. As previously mentioned, most affected individuals are unemployed, and many do not receive unemployment benefits or any other form of financial assistance. This lack of income severely limits their ability to afford a housing relocation, as well as the necessary adaptations to ensure a safe and accessible living environment for their health.

> "Access to housing is impossible without financial resources, as I am unable to work".

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[30] CRPD Committee, General Comment No. 5 (2017) on the Right to Live Independently and Be Included in the Community, para. 34; CRPD Committee, General Comment No. 6 (2018) on Equality and Non-Discrimination, para. 57.

> "We recently moved and were fortunate that the seller also had MCS and EHS. The search was not too long. The main obstacles we have encountered before were the difficulty of finding a rural area suitable for MCS and EHS in the Autonomous Community (Basque Country), as there is heavy industry, pollution (including electromagnetic), everywhere. House prices are €300,000 or more, and my husband cannot leave his job (our only source of income), so we cannot look for housing too far from his workplace".

Among surveyed individuals with MCS and/or EHS, there is a slightly higher concentration in suburban areas (38%). However, the differences are not significant compared to those living in rural areas (32%) or urban centres (31%). This reflects a relatively even distribution across these environments, although each presents specific challenges in terms of accessibility and necessary adaptations for affected individuals.

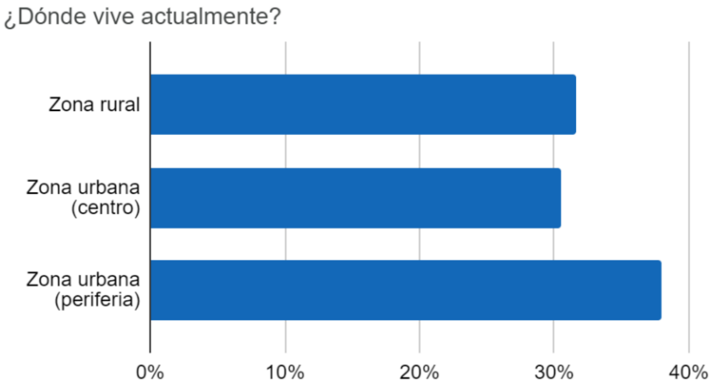

Figure 13 – Self-elaboration

The place of residence has a direct impact on the health of individuals with MCS and/or EHS, as the characteristics of the area can either increase or reduce exposure to triggering factors—many of which are beyond their control. In urban areas, factors such as pollution, noise, proximity to establishments like hair salons or perfume shops, and exposure to EMFs from public Wi-Fi networks, smart meters, or mobile phone base stations can worsen symptoms. In contrast, rural or suburban areas tend to have lower exposure levels.

Additionally, the experiences of surveyed individuals vary significantly depending on their type of housing. Detached houses or homes without close neighbours tend to provide a safer environment, whereas living in shared buildings, particularly in city centres, can make it much more difficult to manage their health. Some testimonies illustrate these differences:

> "When I'm in the countryside, I have a home with no neighbours, so I don't have any problems".

> "We found a house in the outskirts before I got sick; there's plenty of nature for walks, and it's far from hair salons, perfume shops, and bars...".

> "I own a house near a rural area. Living in a community building or in the city is impossible for me".

"At home or in a caravan with land, without close neighbours, I can live practically a normal life, without thinking about my illness—except for occasional situations".

"I live on the second floor of a flat in the city centre, and there are always lots of people, lots of noise, and heavy traffic".

What are the main enviromental barriers to accessing housing?[31]	
For persons with MCS	**For persons with EHS**
● Toxic emissions from construction materials used in buildings, renovations, or minor works carried out in shared spaces or by neighbours. ● Cleaning products and air fresheners used in communal areas, corridors, and lifts. ● Pesticides and insecticides applied in building maintenance or outdoor communal areas. ● Disinfection and pest control treatments in garages, basements, and public spaces. ● Swimming pools treated with chlorine or other strong disinfectants. ● Septic tanks or industrial waste facilities near the residence. ● Businesses located in ground-floor premises of residential buildings, such as dry cleaners, hair salons, or perfume shops, which use chemical-based products. ● Street fumigation and pest control in parks and gardens near the residence. ● Asphalt fumes from road resurfacing. ● Residential areas near motorways, industrial zones, or agricultural areas where chemical products are used.	● External factors: Any infrastructure or device generating electric, magnetic, or electromagnetic field emissions that has not been properly manufactured or installed with adequate shielding, affecting the residence. ● Internal factors: Any installation generating high levels of magnetic, electric, and/or electromagnetic fields. In buildings, these factors are present in common areas and adjacent homes; in semi-detached houses, they come from neighbouring properties.

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[31] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

The need to relocate[32], as reported by many individuals affected by MCS and/or EHS, is primarily due to the lack of accessibility measures both within homes and their surrounding environments. This deficiency turns these spaces into hostile environments for their health and well-being.

A key factor is the lack of action by local authorities. According to the survey, 78% of affected individuals state that their municipal councils have not implemented any measures related to MCS and/or EHS, while 56% feel misunderstood not only by these institutions but also by their neighbours and landlords, where applicable.

> “Regarding 5G, I asked the council if they would apply a moratorium as they did in Durango, explaining my situation and submitting all the necessary documents. They did nothing. They said that if a request were submitted, the entire town would have to vote on it, but until then, nothing would be done”.
>
> “The council has refused to notify me when there are roadworks (asphalting, fumigation nearby, etc.)”.
>
> “The council has changed the positioning of the streetlights. They now shine directly into my bedroom window, affecting my health. However, the council refuses to remove or reposition them”.
>
> “They were going to install a mobile phone antenna at a clinic located 150 metres from my home (which is a detached house). I wrote a letter to all my neighbours suggesting we coordinate to oppose its installation. No one responded”.

Furthermore, housing adaptations are hindered by the lack of knowledge among technicians and professionals responsible for carrying them out. Some testimonials highlight dismissive attitudes and a lack of training.

> “When ordering modifications for adaptation, professionals made inappropriate comments, laughing at the shielded cables or saying they were useless”.
> “Complete lack of knowledge from technicians regarding the materials they use or could use”.

Despite these barriers, positive experiences have also been reported, thanks to the empathy and understanding of some neighbours. These individual actions demonstrate that, with awareness and education, it is possible to create more inclusive environments.

> “The community president wrote a statement to raise awareness about MCS”.
>
> “I live in a small housing estate. My neighbour installed an antenna for her business data transmission. I explained my condition and asked if she could place it further away from my terrace. She called a technician to solve it, but they couldn’t get a good connection elsewhere, so she decided to remove the antenna”.

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[32] Persons affected who have been forced to move: «yes» 38%, «no, but I want to move/I have considered it» 31% and «no» 31%.

> "There was a proposal to install solar panels, and the neighbours agreed to adopt the necessary measures to prevent them from affecting me".
> "The painters hired to varnish the wooden balconies and the façade of the building, on their own initiative and without an increase in budget, used a special odour-free, water-based, eco-friendly varnish to accommodate my condition".

> "A young couple of neighbours showed concern about not harming me when washing clothes by hand and in the washing machine. I provided them with suitable, fragrance-free detergent and fabric softener. They even bought the same product themselves, despite me offering to pay for it".

These cases show that, although there are major structural and attitudinal barriers, community-level understanding and support can make a significant difference in the quality of life of affected individuals. This underscores the importance of greater awareness and training at all levels to address the accessibility needs of people with MCS and/or EHS.

4.3.3. How to improve this situation: reasonable adjustments

Although affected individuals have the right to request reasonable adjustments in their homes, in practice, only 23% of respondents have formally requested adaptation measures. In most cases (58%), individuals themselves undertake the necessary modifications, particularly when they have not officially requested adjustments.

However, certain situations remain beyond their control, such as the cleaning of communal areas, construction work in the building or on the street, or access to their homes by third parties for maintenance work. These circumstances make adaptation measures essential to enable affected individuals to live in their homes without health deterioration. Despite this, when adaptations are requested, 61% of the time they are not implemented.

The survey highlights examples of measures taken by community associations or individual neighbours, demonstrating how specific actions can significantly improve accessibility:

- Cleaning communal areas with appropriate products and at specific times

  > "The concierge waits for me to leave before cleaning".

  > "The property manager facilitated an arrangement with the cleaning company to use non-toxic, fragrance-free cleaning products".

  > "The stairwell cleaning company cooperated from the outset and used suitable products without perfumes, such as alcohol and vinegar...".

- Modifications to the building's lift

  > "The community proposed installing a fan/extractor in the lift to help remove perfume and odours more quickly. Otherwise, it was almost impossible for me to use the lift, and we live on the 6th floor".

- Turning off electronic devices

> "My neighbours turn off their mobile phones so that I can sleep. One of them even wired their home to eliminate Wi-Fi so that it wouldn't affect me".

- Providing advance notice of construction work in neighbouring properties

> "My neighbours always inform me in advance when they plan to carry out any kind of construction work in their apartments. They even let me know when a neighbouring building's terrace was being painted so I could keep my windows closed".

Additionally, some landlords have allowed modifications, such as the use of shielding paint in homes.

Overall, affected individuals rate the quality of these adaptations as "good" (46%) or "average" (42%), although they report problems such as delays or limitations in the scope of the measures. Además, algunos arrendadores han permitido realizar modificaciones como el uso de pintura apantallante en las viviendas.

> "Although it took a long time, it had to be brought before the residents' association because the cleaning company refused to change their products voluntarily. Eventually, they switched to non-toxic cleaning products, but only for my entrance, meaning I cannot access other entrances or areas of the building".

4.4 CHAPTER IV: EDUCATION

4.4.1 Right to education

Article 9.1(a) of the CRPD obliges States to eliminate barriers that hinder access to schools, promoting accessibility through universal design and reasonable adjustments. Article 24 reinforces this right by establishing inclusive education at all levels, covering infrastructure, support systems, and teacher training. The CRPD and CESCR Committees emphasise the importance of accessible transport, suitable buildings, and educational support to ensure equal opportunities in education.

States must ensure that inclusive education is available, accessible, acceptable, and adaptable. This requires safe infrastructure, adjustments without additional costs, and services designed to meet the needs of persons with disabilities. Furthermore, educational institutions must be flexible, allowing students to attend schools within their communities. This approach necessitates cultural and institutional changes to guarantee an inclusive and effective education system.

4.4.2. Barriers to accessing inclusive education for individuals with MCS and/or EHS

Although 85% of surveyed individuals developed their condition after completing their studies, it is important to remember that the right to education includes lifelong learning[33]. This means that affected individuals not only may wish to continue their education but also have the right to do so.

According to the survey data, 33% of affected individuals always or frequently avoid attending educational institutions, suggesting that this is not a universal trend. However, 54% report a significant deterioration in their health when attending, highlighting the urgent need to ensure more accessible and safer educational environments for these individuals.

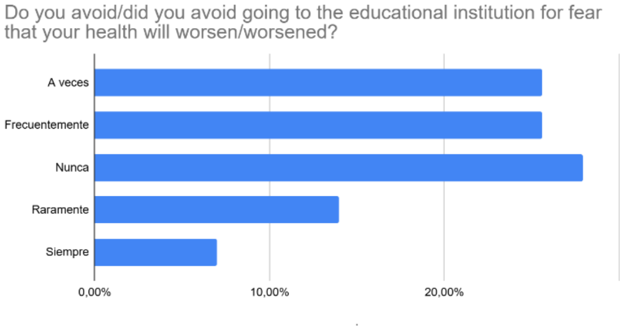

Figure 14 – Self-elaboration

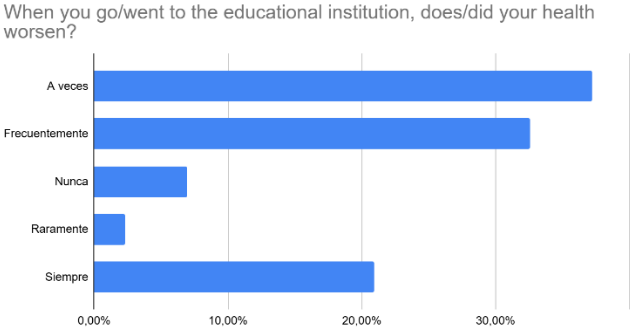

Figure 15 – Self-elaboration

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[33] General Comment No. 4 (2016) on the Right to Inclusive Education.

It is important to highlight that, although some affected individuals had not yet received a diagnosis of MCS and/or EHS, they were already experiencing symptoms that worsened when attending educational environments[34].

> "At university, they had no accommodations, but at that time, I didn't have my current diagnosis—only severe asthma, which was easier for people to understand than MCS/EHS".
>
> "No había sido diagnosticada aún de SQM. Siempre me ha gustado estudiar y sin embargo me ha costado la vida hacer el máster: nieblas mentales, no entendía lo que leía, no era capaz de encontrar las palabras o dudaba del significado de estas. Era muy frustrante".

What are the main environmental barriers to accessing education?[35]	
For persons with MCS:	**For persons with EHS:**
● Cleaning products with fragrances and high toxicity levels, as well as air fresheners. ● Personal care products and perfumes used by teachers and/or classmates. ● Poor air quality due to inadequate ventilation systems. ● Rodent control treatments and other fumigations with biocides inside buildings. ● Minor construction or renovation works inside or outside the school building. ● Fumigation of playgrounds and gardens. ● Asphalting works in schoolyards.	● EMFs from personal wireless devices used by teachers and classmates. ● EMFs from the school's own wireless transmission systems, including Wi-Fi, Bluetooth, workstations, pico-antennas, and repeaters, as well as other EMF sources such as lighting systems and electronic equipment. ● EMFs from external sources that impact the school environment

Why does this happen? The lack of accessibility measures in educational institutions for individuals with MCS and/or EHS makes these environments unsuitable for their needs. At the time when many of the surveyed individuals were studying, their institutions did not have policies addressing these conditions, which exacerbated their difficulties. Testimonies illustrate how factors such as cleaning products, inadequate temperatures, and intense lighting worsened symptoms:

> "The smell of cleaning products in the bathrooms, the cold in the classrooms, and the bright lighting. I felt extremely fatigued and unwell from sitting for so long».
> «When the classroom had been used in the previous session, no care was taken regarding the products that had been used".

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[34] Information obtained from the open-ended survey questions.

[35] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

Additionally, the experiences of affected individuals were largely influenced by the attitudes of teachers and classmates[36]. According to the survey, 70% of respondents felt misunderstood by them. Some testimonies highlight these challenges:

> "Two years ago, I enrolled in the Official School of Languages (EOI), and the teacher wore a strong perfume. I told her about my condition, but she refused to help, so I couldn't attend any more classes and ended up dropping out".
>
> "Most of my classmates didn't want to do group work with me because I didn't have WhatsApp".
>
> "I had a terrible experience with an instructor in a workshop at my local council. I had no choice but to tell him about my illness because he was using hairspray, bleach, etc., inside the classroom. I informed him that, for health reasons, the council did not allow the use of toxic products in the workshop, and that the course materials specifically stated that such products should be used outside the classroom to avoid toxic effects. From that moment on, he started discriminating against me. He ridiculed me in front of the other students. It got to the point where he called me a fraud. I had to report him in the course evaluation and change my schedule and instructor".
>
> "A teacher interpreted my absences as a lack of interest and penalised my grade by making me take resit exams. This lowered my average score for university admission".
>
> "As a student at the Official School of Languages (EOI), they told me not to attend classes and only to come for exams. When I went to take exams, they didn't turn off the Wi-Fi or mobile phones in the classroom, despite having wired internet throughout the building".
>
> "I had to enrol my child, who has EHS, in a private school without Wi-Fi because all public schools have it, and the Department of Education did not provide a solution. They also refused to grant home tutoring, as we live in a remote area due to our health condition".

Lastly, surveyed individuals also highlighted significant difficulties in commuting to educational institutions. These additional barriers further complicate their access to education.

4.4.3. How to improve this situation: reasonable adjustments.

Since few individuals developed their condition before or during their studies, and even fewer requested adaptations, this section focuses on the main measures implemented in educational institutions, based on open-ended survey responses:

For MCS:

- Online class access.
- Private tutoring at home with protocol application.
- Adaptations made by teachers and classmates.
- Classroom change or adaptation when modifying conditions is not possible.

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[36] Information extracted from the focus group discussions.

- Opening windows to improve ventilation.

For EHS:

- Separate room and extra time for final exams.
- Retention of grades in resit exams, treating them as first attempts if attendance was prevented due to health reasons.
- Wiring the student's classroom to eliminate Wi-Fi during lessons, as well as disabling Wi-Fi in common areas.
- Encouraging teachers and students to turn off mobile phones during lessons.
- Providing home tutoring if the severity of EHS prevents school attendance.

Surveyed individuals provided testimonies reflecting the importance of these measures:

> "My tutors provide online tutorials». «My teachers have informed me when I was unable to attend classes".
>
> "When I attended English classes, I requested a change of classroom because it had just been painted, and they moved the entire class to another floor".
>
> "Once, my tutor attended to me in a room on the lower floor of the school, in a well-ventilated room. She also wasn't wearing any fragrances".
> "They let me sit by the window when I felt dizzy".

Although isolated, these adaptations demonstrate the positive impact of accessibility measures on the educational experience of affected individuals.

4.4.4 Case of children of affected individuals

The survey identifies two main situations affecting the children of individuals with MCS and/or EHS. Firstly, parents with these conditions often cannot attend school activities, such as meetings, tutoring sessions, or events, nor can they pick up their children, as their health is affected by exposure to triggering agents in these environments. This limitation impacts both daily family life and the active participation of parents in their children's education and school activities.

En el caso de los hijos e hijas de personas afectadas por SQM y/o EHS, la encuesta identifica dos situaciones principales. Por un lado, los padres y madres con estas condiciones a menudo no pueden acudir al colegio para participar en actividades como reuniones, tutorías o festivales, ni siquiera recoger a sus hijos, ya que su salud se ve afectada por la exposición a agentes desencadenantes en estos entornos. Esta limitación afecta tanto a la vida cotidiana de las familias como a la participación activa de los progenitores en la educación y actividades escolares de sus hijos.

> "It is impossible for me to attend Christmas performances or similar events, in-person parent meetings, pick up or drop off my children at school, or take them to their friends' birthday parties...".

> "When my son was in primary school, I wore a mask—this was 12 years ago—and his teacher belittled me and called me crazy. The teacher and headmistress told me that if I was sick, I should stay home, as my mask scared other parents, and they didn't like seeing me there".

In this context, children whose parents have MCS and/or EHS experience associative discrimination. The limitations their parents face in participating in school activities or picking them up negatively impact their educational experience. This prevents them from accessing education on equal terms with their peers, restricting their integration and full participation in the school environment.

Secondly, there are cases where the health of parents with MCS and/or EHS deteriorates when receiving their children after school, as the children have been exposed to triggering agents at school.

> "When the school was undergoing construction, my children would come home carrying chemical residues on their clothes, causing me diarrhoea, constant nausea, vomiting, and headaches...".

This highlights how the lack of control over chemical agents in school environments not only affects students but also their families, significantly impacting their quality of life.

4.5 CHAPTER V: PUBLIC SPACES

4.5.1 The right to access public or publicly accessible spaces

Access to public spaces is linked to several fundamental rights: the right to human dignity and personal development (Article 1 of the UDHR), the right to freedom of movement and choice of residence (Article 12 of the ICCPR), the right to an adequate standard of living (Article 11 of the ICESCR), and the right to live independently and be included in the community (Article 19 of the CRPD) [37].

According to the CRPD Committee, independent living requires access to transport, public roads, cultural and religious activities, among others[38], while inclusion in the community implies full participation in cultural, recreational, and sporting activities, in accordance with Article 30 of the CRPD.

Therefore, for the purposes of this report, access to public spaces includes transport, public roads, healthcare and educational institutions, sports facilities, leisure or recreational venues, and those where cultural life takes place[39]. It also includes supermarkets and banking institutions, as they are essential for the development of an autonomous life.

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[37] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

[38] General Comment No. 5 (2017) on the Right to Live Independently and Be Included in the Community. Para. 16.

[39] For further information, refer to: *Multiple Chemical Sensitivity and organic disability: Analysis from a human rights perspective* and *Electromagnetic hypersensitivity and organic disability: analysis from a human rights perspective*.

4.5.2 Barriers to accessing public or publicly accessible spaces for individuals with MCS and/or EHS

In practice, many individuals with MCS and/or EHS avoid leaving their homes due to the risk of their health deteriorating, reporting this happens always or frequently (51%). Even when they do go out, 46% state that they end up feeling unwell.

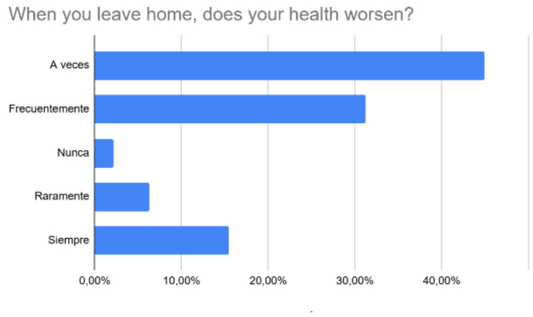

Figure 16 – self-elaboration

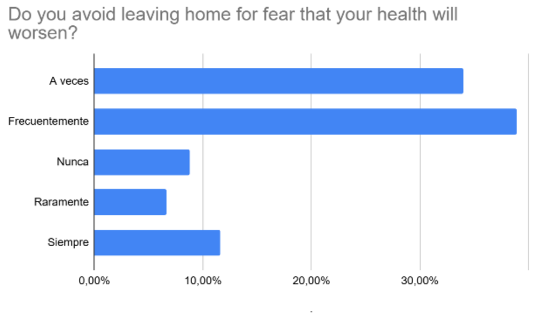

Figure 17 – self- elaboration

This fear limits their access to essential spaces such as public transport, sports centres, and cultural venues, which they tend to avoid more frequently. Some testimonies reflect this situation:

> "Since my diagnosis, I have not used these spaces except for the supermarket, where I go at midday when there are fewer people".
>
> "I usually avoid places where there are a lot of people. If I need to buy something, I do it when there are hardly any people, and only if the store has not been perfumed. Otherwise, I do not enter".
>
> "I absolutely avoid public spaces. If I go to the supermarket or walk in public, it is because I have no choice".

This occurs because, in most cases, public spaces have not implemented accessibility measures for individuals with MCS and/or EHS, making them inaccessible environments. On the one hand, this situation is due to the lack of specific policies by local councils, a deficiency reported by 67% of surveyed individuals.

However, some spaces have implemented accessible measures for other conditions, which could also benefit individuals with MCS and/or EHS. For example, it was mentioned that Carrefour has introduced low-light emission hours for individuals with autism, a measure that could also be useful for people affected by these conditions.

On the other hand, 76% of surveyed individuals report feeling misunderstood by people or authorities responsible for these spaces. Testimonies reflect these experiences:

> "When I have gone somewhere wearing shielding clothing (such as a hat), people stare at me strangely".
>
> "I enrolled in a course run by the local council and paid for the full year. After the first class, I realised there was excessive radiation, but they did not refund my money, despite me providing my medical diagnoses. I understand, but it was not a positive experience".

These situations highlight the urgent need for institutional and social actions that not only implement specific measures for individuals with MCS and/or EHS but also promote greater understanding and empathy toward their needs.

4.5.3 How to improve this situation: reasonable adjustments

Although affected individuals have the right to request reasonable adjustments, only 23% of surveyed individuals have ever done so. Moreover, in 86% of cases, these requests were not accepted or implemented. An example of this rejection is reflected in a testimony:

> "I requested an adaptation at the bank, and they told me that if I was feeling that unwell, I should just not go and delegate the task to someone else".

However, the survey also includes testimonies of positive experiences that demonstrate the impact that appropriate adaptations can have:

> "In small shops, they bring the items outside and charge me at the door so I don't have to go inside".
>
> "A supermarket employee offered to go to the cleaning products aisle to get vinegar for me".
>
> "I have been able to attend dance classes because the venue is cleaned with suitable products, and there are no perfumes or fragranced products used by other students. I even had the option of a private instructor".
>
> "During a flight, they allowed me to board after all passengers had turned off their mobile phones. They also switched off the Wi-Fi during the journe".

Although these positive experiences are isolated, they highlight the importance of reasonable adjustments and how they can significantly improve the quality of life and social inclusion of individuals with MCS and/or EHS.

5. HOW THESE BARRIERS IMPACT THE LIVES OF AFFECTED INDIVIDUALS?

The barriers described in this report have a profound impact on the lives of individuals with MCS and/or EHS, leading 72% of surveyed individuals to feel excluded from society always or frequently. This exclusion is particularly evident in areas such as employment (40%) and access to public spaces (39%), followed by healthcare services (34%) and educational institutions (33%).

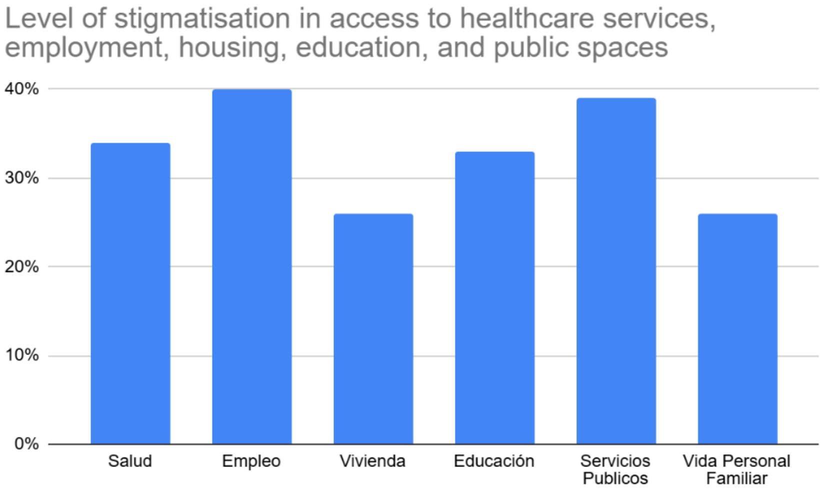

Figure 18 – Self-elaboration

This situation not only limits their participation in society but also severely affects their mental health. According to the data, 21% of respondents state that their mental health always worsens, while 33% indicate that it frequently deteriorates. Only 7% report that their mental health is never affected, highlighting the urgent need for measures to reduce stigma and address the barriers these individuals face.

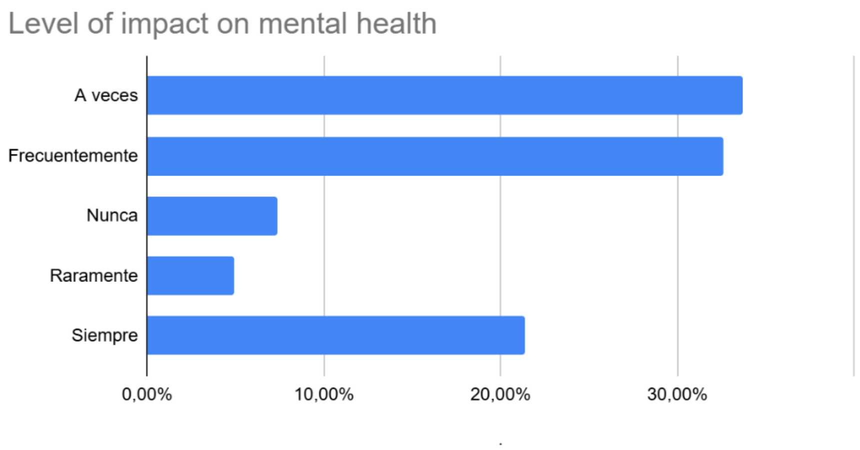

Figure 19 – Self-elaboration

6. CONCLUSIONS

Individuals affected by MCS and/or EHS face multiple barriers that create organic disability, limiting their access to fundamental rights and their full participation in society. These barriers, caused by exposure to trigger agents such as chemical products or electromagnetic fields, impact essential aspects of their lives, including health, employment, education, housing, and leisure. This set of obstacles not only worsens their social exclusion but also reflects a systematic violation of human rights and an underdeveloped social disability model in Spain.

Barriers and their impact on the daily lives of individuals with MCS and/or EHS

Exposure to environmental and attitudinal barriers turns everyday spaces into hostile environments, limiting mobility and access to essential services. Affected individuals tend to avoid leaving their homes for fear of their health deteriorating, as they frequently become ill when exposed to these environments. These limitations are particularly severe in public spaces, where the lack of specific measures and environmental control reinforces their exclusion.

Inaccessibility is also present in healthcare, education, and employment settings, where no effective accessibility measures have been implemented. The accumulation of these barriers has a significant impact on their quality of life, forcing many affected individuals to forfeit basic rights and opportunities for inclusion.

Invisibility as the main barrier

Invisibility is one of the greatest challenges faced by individuals with MCS and/or EHS. In the healthcare sector, the lack of awareness about these conditions, combined with difficulties in obtaining a diagnosis, leads to stigma and misinformation. This results not only in delayed or incorrect diagnoses but also in limited access to appropriate treatments and support measures.

This invisibility also affects the official recognition of disability, which is a crucial requirement for accessing rights and benefits. Additionally, women, who represent most affected individuals, face increased exclusion due to gender stereotypes that minimise their symptoms, often attributing them to psychological or emotional issues. This situation contributes to social isolation and severely impacts the mental health of affected individuals, who experience constant emotional distress due to barriers and lack of understanding.

Restricted access to fundamental rights

The barriers described severely limit the ability of individuals with MCS and/or EHS to access fundamental rights.

Health: Access to healthcare services is one of the greatest challenges for individuals with MCS and/or EHS. The lack of environmental control in hospitals and healthcare centres turns these spaces into hostile environments, due to the use of toxic chemical products, the presence of electromagnetic fields, and the lack of understanding from healthcare personnel. This results in difficulties in obtaining proper diagnoses and treatments, while their symptoms are often minimised or ignored, leading to neglect and exclusion that affect both their physical and emotional well-being.

Education: Those who wish to continue their education face significant barriers, such as the absence of reasonable adjustments and the lack of awareness among teachers and classmates. These barriers include difficulties in accessing environmentally controlled spaces or remote learning options, forcing some individuals to abandon their studies. Additionally, the lack of understanding from educators further reinforces their exclusion, as their special needs are often misinterpreted as a lack of commitment.

Employment: The workplace presents serious challenges due to the absence of adaptation measures. Work environments generally lack environmental control, which worsens symptoms for affected individuals. Moreover, the stigma associated with these conditions limits their job opportunities, leading to discrimination that affects their financial independence and contributes to their social exclusion.

Social Protection: The lack of official recognition of organic disability associated with MCS and EHS makes it difficult to access social protection systems and financial assistance, particularly for those who are unable to work and rely on these benefits. Bureaucratic obstacles and institutional ignorance further complicate access to an adequate standard of living.

Housing: Urban inaccessibility forces many individuals to relocate to rural or suburban areas, seeking housing where they can minimise exposure to triggering agents. While necessary, this solution often results in social isolation, loss of support networks, and increased financial difficulties. Even in these environments, housing adaptation remains challenging due to high costs and the lack of understanding from landlords and technicians.

Participation in social and cultural life: Limited access to public spaces, such as cultural, sports, or recreational centres, restricts the integration of affected individuals into community and leisure

activities. The lack of adaptations, combined with the fear of worsening their health, significantly reduces their participation in social and cultural life, further reinforcing their isolation.

Lack of reasonable adjustments

Although affected individuals have the right to request reasonable adjustments, their implementation is extremely limited. Many adaptation requests are not accepted or carried out, and in numerous cases, affected individuals must cover the costs themselves, further increasing their economic vulnerability. This lack of accessibility reflects the absence of clear procedures for evaluating and guaranteeing these adjustments, which worsens exclusion and restricts the full exercise of their rights.

Urgent need for structural accessibility measures

The accumulation of barriers demands urgent action from public administrations and society. It is essential to:

- Implement accessibility policies that consider the specific needs of individuals with MCS and EHS, including environmental control measures.
- Establish clear procedures for the evaluation and adoption of reasonable adjustments in both public and private settings.
- Raise awareness and provide training for key stakeholders, particularly in the healthcare, education, and employment sectors.
- Promote research and data collection to develop public policies tailored to the needs of this population.

Individuals with MCS and/or EHS face systematic exclusion, which violates their fundamental rights. The lack of accessibility measures, combined with social and institutional invisibility, leads to an accumulation of barriers that deeply affects their quality of life. It is urgent to adopt structural measures to eliminate these barriers, foster empathy, and ensure equal access to goods, services, and rights, moving toward a more inclusive and equitable society.

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