

MIND THEIR HEALTH: INCLUSION AND HEALTH THROUGH FOOD

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Course Content Guide

Practical handbook of tips for good nutrition



MIND THEIR HEALTH



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Introduction

There are now many manuals on how to properly perform the tasks of the caregiver. The lack generally concerns practical methodologies and concrete advice that can be used with the person the caregiver is caring for.

Nevertheless, in case of difficulties or doubts, everything is left to the intuition of the caregiver himself, who builds his preparation on his experience.

For this reason, in this guide you will find a series of useful tips on the ordinary and extraordinary management of the disabled person.

Several topics will be discussed:

- Specific analysis of the needs of people with dystrophy or other neuromuscular diseases to improve their quality of life by providing clinical care, well-being and logistical assistance.
- Psychological analysis of people with disabilities and their families.
- Analysis of the generalisation of accessible tourism, and the exercise of the right to leisure time for people with disabilities through different lines of action: training and awareness, information and advice, prospecting and analysis and holiday programmes.

This guide is particularly dedicated to informal carers without any geographical or linguistic limitation.



Chapter 1

Definitions

In order to avoid misunderstandings, the following question must first be answered:

What is disability?

People with disabilities are those who have long-term physical, mental, intellectual or sensory impairments (resulting, for example, from a curable or incurable disease) that, when interacting with various barriers, can in the long run hinder their full and effective participation in society.

The following five groups of the population are especially at risk for the development of pathology and disability:

1. **Women** - in most cases they are at a disadvantage economically and culturally and socially. Also, in a family environment, they are more likely to take care of their disabled relative.
2. **Children** - congenital or early disability very often leads to isolation and limitation of their normal development.
3. **Elderly people** - about 65% of all disabled people.
4. People who are **victims of crime or violence**.
5. **Refugees** and **workers abroad** who are mostly **low-skilled workers**.

There are many types of disabilities, such as those that affect:

- Vision
- Movement



- Thinking processes
- Remembering (memory)
- Learning
- Communication
- Hearing
- Mental health
- Social relationships

According to WHO, disability has three dimensions:

- 1) Impairment in a person's body structure or function, or mental functioning; examples include loss of a limb, vision loss or memory loss.
- 2) Activity limitation, such as difficulty seeing, hearing, walking, or problem solving.
- 3) Participation restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

The WHO estimates that over one billion people, representing about **15%** of the world's population, have some form of disability and only 5% of these disabilities are congenital. According to the United Nations Development Program (UNDP), 80% of people with disabilities live in developing countries. The World Bank estimates that 20% of the world's poorest people have a disability.

People with disabilities are defined as the largest minority in the world, but unlike most minority groups, this one has an open membership: each of us can become a member at any time, whether due to an accident, illness or

old age. That is why disabilities are part of the human condition. In the vast majority of cases, disabilities are considered to be the result of socio-economic or political factors, accidents or armed conflict. At present, there may be more factors that contribute to the failure, including environmental pollution, HIV / AIDS and drug abuse. Disability is also a development problem, as it is two-way linked to poverty: disability can increase the risk of poverty, and poverty can increase the risk of disability.

According to the WHO, about 10% of children and young people on Earth, which makes up 200 million people, have **sensory, intellectual or mental disabilities**.

Groups from the community of people with disabilities may have a common socio-cultural history. Some groups have a common language, such as American English or sign language, or the Braille alphabet for the blind, or even some specific terms they use for disability or for themselves. They also often have common customs and traditions, such as celebrating the awareness and self-esteem of people with disabilities.

Disability culture can recognize and celebrate the lives of people with disabilities, thus demonstrating that this is not necessarily a tragic situation and should not be underestimated.

According to **Eurostat data** from 2017, **19%** of Bulgarians report the presence of health problems, which hinders their social activity, and every fifth Bulgarian over the age of 16 has a long-term physical disability. At the same time, statistics show that Bulgaria is among the top three countries with the lowest number of people with permanent disabilities of

working age.

Nearly 45% of Bulgarians over the age of 65 have **permanent disabilities**. Statistics over the age of 75 show that six out of ten people have similar problems.

There are still many barriers that prevent people with disabilities from fully exercising their fundamental rights, and these barriers limit their equal participation in society. Consistent and targeted policies, actions and measures are needed in this aspect. The full participation of people with disabilities in economic and social life is essential to succeed in achieving smart, sustainable and inclusive growth.

Who is the caregiver?

“Caregiver” is the person, usually a family member, who provides support and takes care of a sick and / or non-self-sufficient family member daily and free of charge.

They are called "informal caregivers", to distinguish them from "formal caregivers" (that are all personnel that is trained to provide health care).

The caregiver is important for two reasons:

1. The caregiver is essential in the journey of care, habilitation and rehabilitation of the sick family member.
2. Over time, the caregiver becomes the super specialist who deals with managing drugs, booking specialist visits, managing economic resources, dealing with transport, learning to manage motor, cognitive and psychological problems.

In the long run, the psychophysical balance of the caregiver is subjected to a load of suffering, discomfort, fatigue and stress that negatively affects not just their health but also their social and family life and they end up falling into a condition of almost total self-denial, as they consider their care responsibilities the priority.

In fact, according to statistics, care givers are forced to ask for part-time or smartworking in almost 10% of cases and to leave their jobs in 66% of cases.

Often there are also repercussions on their state of health: life expectancy is also reduced by 17 years compared to the normal population, as scientifically demonstrated by the studies of the Nobel Prize for Medicine 2009 Elizabeth Blackburn, due to the stress they are subjected to, considering also the lack of institutional support in Italy.

An important consideration has to be made regarding **caregiver burden**, which is the stress perceived by caregivers due to the home care situation.

Caregiver burden is defined as that emotional and / or physical exhaustion of the person who takes care of a patient.

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The burden includes multiple dimensions: physical, psychological, social and financial.

The main areas affected by caregiver burden are the psychological, emotional and physical spheres, the ability to adapt, satisfaction and the ability to provide assistance. The physical and emotional demands experienced by caregivers lead to significant energy exhaustion and modify their quality of life and social life.



The main symptoms of caregiver burden are the following:

- Motor symptoms of the sick family member
- Diagnosis and information
- Characteristics of the caregiver (pre-existing psychiatric symptoms, coping and coping skills, social support)
- Non-motor symptoms (depression, anxiety, apathy, cognitive disturbances, psychosis, impulse control disorder, sleep disturbances)

Usually the caregiver is faced with a series of psychotic phases:



This situation, in addition to amplifying the emotional exhaustion of the caregiver, clearly worsens the assistance to the sick family member.

Activities necessary to overcome the actualization of what has just been described are summarized in the following table:



INTERVENTION FOR THE PATIENT	INTERVENTION FOR THE CAREGIVER
INFORM	INFORM/INCLUDE
PYSCHOLOGICAL SUPPORT	PYSCHOLOGICAL SUPPORT
COGNITIVE / MOTOR REHABILITATION	-----
WELFARE SUPPORT	WELFARE SUPPORT

In practice, the caregiver can:

- ask for help
- get informed and be included
- maintain family and social relationships outside the context of "caregiving"
- legitimize these spaces

For a good quality of life, the well-being of the caregiver must go hand in hand with the well-being of the patient.

What is leisure?

The best possible interlocutor who can offer us a correct definition of this question is the WLO (World Leisure Organisation) which, in its 1993 Charter on Leisure Education, states the following words:

Leisure refers to a specific area of human experience with its own benefits including freedom of choice, creativity, satisfaction, enjoyment and increased pleasure and happiness. It is also a relevant resource for personal, social and economic development and is an important aspect of quality of life, promoting general good health and well-being. Finally, it is a basic human right and no one should be deprived of their right for reason of gender, age, health condition, handicap or economic status.



Therefore, as highlighted in the above quote, such leisure activities beyond receiving their **justification through a legal framework** are truly a vital part of both **people's development** as a free human experience *per se*, as **well as their health** by promoting the modern concept of "quality of life", thus maintaining a close connection with emotional well-being, the clear reflection of which is visible in the state of the psyche.

In fact, the WHO (World Health Organisation) itself establishes that one of the fundamental points for the care of our mental health is the enjoyment of a peaceful lifestyle. The time dedicated to leisure is an important tool to prevent, among other issues, pathologies such as anxiety and depression, illnesses which unfortunately have seen an increase of up to 25% in the world population since the start of the COVID-19 pandemic.



Other noteworthy aspects to highlight are the fact that these illnesses, as well as other types of stressors have the capacity to carry other negative effects that affect normal interpersonal, occupational or family functioning.

It is for this reason that the correct use of one's free time in those activities is a matter that surpasses banality due to the implications of the issues that we are pointing out. Therefore, despite the lack of awareness that we have as a society about these concerns, we need to internalise that these activities serve to achieve a healthy state of mind and thus fulfil the different needs that we have as human beings.

However, what kind of activities are we referring to exactly? The answer to this question is definitely complex and at the same time, paradoxically simple, because the list can be as varied as the individual differences as a result of the **heterogeneous human diversity** where aspects such as age, gender, family situation, health of the person, or even the level of studies

have an influence, the **socio-economic means** available to each person, or the **recreational offer of the context** in which one is located.

The existence of these variables and the very disparate nature of these leisure activities facilitate the multiplicity of ways in which they can be categorised depending on the criteria used by researchers to compose their analysis.

For these reasons, we will follow the definition of Culture offered by the Committee on Economic, Social and Cultural Rights (CESCR), which encompasses any activity in which the individual can express his humanity and the meaning he gives to his existence. Taking into account this definition, we propose the following categorisation according to three aspects:

- **Participation:** individual or collective
- **Nature:** formal (planned) or informal
- **Dimension:** Recreational, Creative, Environmental and Solidarity-based

Nevertheless, there is one type of activity that has in its genesis the power to encompass all of the above categories due to its multiple possible manifestations: **tourism**.

One of the main qualities of tourism is its heterogeneity both in its forms and in its purposes and possible benefits, with the distinctive exception that it requires travel (therefore an appropriate infrastructure) on the part of the consumer since it must be located outside the consumer's community or residence.

This is where the international, national & regional legal frameworks come into play to cover the attention of this right, since its implementation requires economic means and a minimum infrastructure for tourism to exist. In other words, it is necessary to implement two concepts: **accessibility** and **inclusivity**.

In conclusion, throughout this section we will carry out an in-depth development of the characteristics of the so-called "inclusive tourism" in order to inform and raise awareness of the relevance that the implementation of this activity acquires due to its physical-emotional implications. We will also explain the legal framework that justifies its practice, given that leisure is an inalienable right that every human being possesses, discerning through the legislative work the keys that lead to the suppression of the different environmental and social barriers that we face as a society and that seriously limit tourism as a phenomenon. Finally, we will deal with the socio-economic and cultural benefits that this activity attracts, analysing some good examples of tourism entrepreneurship at an institutional level that will serve as reference models.

However, before embarking on such a path, it is essential that we re-emphasise the symbiotic relationship between leisure & health and economy in order to argue and understand, in a more holistic sense, the undoubted benefits that tourism can contribute to.



Chapter 2

Psychological analysis of people with disabilities

In general, people with disability report poorer mental health than people without disability. They also have higher rates of health risk factors and behaviours, such as poor diet and tobacco smoking, than people without disability. Overall, the likelihood of experiencing disability increases with age for both males and females. This means the longer people live, the more likely they are to experience some form of disability.

People with disabilities experience mental health issues almost 5 times more than people without disabilities. Although “people with disabilities” sometimes refers to a single population, this is a diverse group of people with a wide range of needs. Two people with the same type of disability can be affected in very different ways. Some disabilities may be hidden.

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Persons with disabilities report frequent distress and anxiety (33%). Self-reported psychological distress is an important indicator of the overall mental health of a population. Higher levels of distress indicate that a person may have, or is at risk of developing, mental health issues.

An estimated 36% of people with severe disability self-reported that they had mood (affective) disorders such as depression. This is associated with poor health behaviours, increased use of health services, chronic disease, and limitations in daily life. Especially during the pandemic, isolation, disrupted routines, and diminished health services have greatly impacted the mental well-being of people with disabilities.

Moreover, discrimination can take a significant toll on mental health. People with disabilities often continue to face discrimination and unequal access in employment, housing, medical care and other areas. In addition to this, many of them experience physical challenges including immobility or pain, and social challenges such as isolation or being excluded from social events and recreational activities.

Managing these types of obstacles can have a tremendous impact on a person's mental health. Having a disability, whether from a young age, or acquired later in life, is a risk factor for many mental health conditions (depression, anxiety). Moreover, loneliness, abuse from caregivers and low quality of life due to lack of access to proper care can increase the risk of mental illness.

Persons with disabilities also often face challenges when seeking out effective and accessible mental health care, whether it's live or online. Communication barriers make it difficult to interact with a mental health professional or the lack of reliable transportation for a person with a mobility-related disability.

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This is in addition to dehumanizing stigmas where people can be treated as “lesser” because of their disability. This is called **ableism**, which is characterized by the practices and attitudes in society that devalue and limit the potential of persons with disabilities. This may include practices and beliefs that assign inferior value to people who have developmental, emotional, physical or mental disabilities.

It is common for persons with disabilities to encounter mental health practitioners who share the belief that people with disabilities need to be

“fixed,” cannot function as full members of society or that having a disability is a “defect” rather than a difference. This stigma may result in being told that mental health symptoms are to be expected given the circumstances, and in some cases, being dismissed as unlikely to benefit from therapeutic interventions.

Stigma can also result in misperceptions that those with disabilities are not proactive about seeking care to make their conditions better. However,

considering the many barriers people with disabilities face, this perception fails to take into account the significant hurdles they must first overcome.

Despite all the diverse challenges described above, life with a disability does not have to mean a life of unhappiness, isolation or loneliness. Above all, persons with disabilities are increasingly thriving in the world, volunteering, engaging, and living full lives, even in the face of such structural and ideological barriers.

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Finding engagement and purpose are essential in overcoming isolation and combatting depression, no matter who you are, whether you have a disability or not. We all need to feel needed. And the best cure for loneliness is simply not to be alone—to get out even when you don't necessarily want to. Interacting with people and animals are perfect ways to get out of your head, and re-join the world.

All this is not to suggest, however, that it's always easy. Having to work so much harder than non-disabled persons to enjoy the same level of

opportunity and engagement is unfair. There's no getting around that. But

an even greater injustice would be for these inequities to deprive such persons of the life they want and deserve. To achieve it, though, they need specialized support. In addition to accessing community health and social support services, exploring alternative therapeutics to promote both physical and mental health is essential.

As conclusion, there is a significant connection between disability and mental health, but that connection is far more complex than it might at first seem. It's rarely about the illness or injury itself, but rather about the social and ideological barriers that make full engagement in our communities so difficult. It's about having to fight for opportunities that non-disabled persons may take for granted. But the result is a rich, full and joyous life alongside of the challenges.

Psychological analysis of families of people with disabilities

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Unfortunately, disability was associated with limitations and other negative concepts. The birth of a child with a disability has, throughout history, been considered to be a tragic, threatening and distressing event and a very painful occurrence for the parents. The majority of the scientific literature during the 40's and for almost two more decades about family and disability has been focused on describing the negative effects that the presence of a child with disability produced in the family dynamic, such as: **depression, anxiety, frustration, guilt, economic burden, isolation**, and others.

The event of having a child, in itself, is a process that requires an adaptation that begins from the moment that it is decided or desired to be a

mother/father, continuing through the pregnancy until the birth arrives,

when individual changes occur linked to the new functions as mothers/fathers, assumption of new roles, changes in habit, changes in the couple's relationship, etc. These changes are greater for parents that have a child with a disability, and other changes specific to this situation also take place. When, during the evolutionary development, various symptoms are shown that are atypical in normal development, emotions and feelings such as **loss, pain, doubt, threat, shock and helplessness** arise.

The stages through which a family passes in the process of accepting a child with a disability are known. In the first instance of shock or initial impact when receiving the diagnosis, there is a stage of reaction followed by another of adaptation and guidance. The course will depend on each family, the coping strategies, the members that form part of the family, the resources available of and the support received. Generally, the sense of loss or pain will progress and will be resolved without the need for any specific support.

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The parents will progressively manage to adapt to the new situation and recreate their life project, and the pain will reduce until disappearing. Furthermore, there is a stage of removal from the news or diagnosis that is experienced with unreality and various negative affective-emotional states such as shame, humiliation, rejection, denial, helplessness, guilt and resent and even social withdrawal and isolation.

Faced with the situation of children with certain functional limitations, or situations of high dependency, family stress is produced as apart for the doubt surrounding the diagnosis, there are changes in the family organisations and routines and even changes on an employment level. This

stage is characterised by the demonstration of anxious symptoms: irritability, confusion, fear in relation to the doubt, emotional instability, reactions of avoidance and fleeing. The quality of life factors where the families show greatest dissatisfaction, are the support of the person with a disability, support from the governments and support from local entities. Due to the risk of these negative effects appearing, there should be consideration of an intervention with the family.

At present, psychological models focus on the **strengths and support** in order to encourage greater autonomy of the person and higher quality of life for that person **and their family**. The paradigm about disability and family evolves from a psychotherapeutical model (since the 50s), through a parent education model (the 70s), to a quality of life and empowerment model (from the 80s). This new period is characterised by a basic idea: the families are capable of handling the disability when provided with the necessary **support**, i.e., they are resilient families.

With the psychotherapeutical model, people with disabilities were secluded in hospitals, schools or psychiatric homes. The experts assumed control and issued opinions about the reactions, educational style and opinions of the parents. They considered the parents to be the origin of the children's limitations, obstacles for their development and irrelevant for the intervention process. The mothers and fathers were considered to be vulnerable patients in a situation of **mourning**, requiring a treatment complementary to that received by their children and considered, in general, less competent and objective than the professionals.

In contrast to the previous approach, contemporary models defend the rights of the people with disability, deinstitutionalisation, normalisation,

empowerment. It highlights the role of parents in the improvement of their children's quality of life, which has been described by many as an act of courage. The mothers and fathers of people with disabilities have been and continue to be founders and members of organisations, promoters of services, teachers and therapists for their children and responsible for making decisions about the intervention. In this new stage, the families moved from being guilty of the disability to being **collaborators** with the professionals and recipients of specific services.

What does collaboration between families and professionals mean? A collaborative relationship is understood to be "interaction of mutual support, which focuses on satisfying the needs of the person with a disability and their family, and is characterised by a sense of competence, commitment, equality, communication and trust" (Summers et al., 2005). A second question would be, are the parents satisfied with the collaboration of the professionals? According to studies such as that by Bailey et al. (2012), the response is positive, and this is also obtained from other studies, with 68% of parents having a good or very good general experience (Arellano & Peralta, 2015).

Currently, the model addressed by the efforts for change in the work with the families is the "family-focused" model, for quality of life and empowerment, which means providing the family with various tools in order to cope with the disability. To be a mother/father involves assuming a new role or various functions marked by responsibilities and obligations towards a third person, in aspects such as: food, safety and hygiene, health, personal dedication that changes depending on the evolutionary moment of the child. This is a changing process which requires adaptation to the

specific needs of the development.

Various studies have highlighted that early intervention, directed towards the parents, is a decisive factor in the modification of behaviour that adapt to the needs of the child. The education of mothers/fathers aims to promote the development of parenting skills in order to educate their child. One of the most complete definitions with regards to education for parents states: "it is a set of voluntary learning activities by the parents with the objective of providing adequate models for educational practice in the family context and/or modifying and improving existing practices with the objective of promoting behaviour with the children that is positively judged and eradicating that which is negative".

In conclusion, the presence of a child with a disability alters the quality of family life, as it requires greater adaptation to the needs of all of the members. Said needs, marked by the illness and an atypical development, have a more exclusive character for these families as they are based on a lack of knowledge that must be resolved. They must seek information about each of the differential characteristics of their child and the risks involved. This "extra" and "unknown" work generates a weariness that may alter the quality of family life, as it requires greater dedication of time to the child with problems, and may lead to lack of care for other members. This logical consequence can be remedied if support and education is offered to these families.



Focus: Neurodegenerative diseases as disability

Neurodegenerative diseases include a range of conditions that mainly damage **neurons in the human brain**. Neurons are the building blocks of the nervous system, which includes the brain and spinal cord. Neurons usually do not reproduce or self-replace, so when they are damaged or die, they cannot be replaced by the body itself. Examples of neurodegenerative diseases are Parkinson's, Alzheimer's and Huntington's.

Neurodegenerative diseases are incurable and disabling conditions caused by progressive degeneration and / or death of nerve cells. This leads to problems with movement (for example, "ataxia") or mental functioning ("dementia"). Neurodegenerative diseases are one of the most common and important causes of disability, as progressive neurodegeneration will eventually lead to limited function and a progressive inability to cope with the demands of the environment, requiring external support and varying degrees of assistance.

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Dementia is the biggest problem in neurodegenerative diseases, given that **Alzheimer's disease** affects about 60-70% of cases.

Some neurodegenerative diseases and their characteristics are:

- Alzheimer's disease (AD) and other dementias- AD is a form of dementia in which mental functioning, particularly memory, is impaired.
- Parkinson's disease and related disorders - a condition resulting from the degeneration of certain neurons, leading to impaired control of body movements.
- Prion diseases - a disease of structurally abnormal proteins.



- Motor neurone disease – a group of diseases in which the neurons that control the muscles degenerate and die, leading to loss of muscle control and eventually paralysis.
- Huntington's disease - an inherited neurodegenerative disorder that causes problems with both movement and mental functioning.
- Spinocerebellar ataxia (SCA) - a progressive neurodegenerative inherited heterogeneous disease that mainly affects the cerebellum.
- Spinal muscular atrophy (SMA) – a genetic (inherited) neuromuscular disease that causes muscles to become weak and waste away.
- Multiple sclerosis (MS) - a condition that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance.

What are the causes?

Neurodegenerative diseases affect many of your body's activities, such as balance, movement, talking, breathing, and heart function. Many of these diseases are genetic. Sometimes the cause is a medical condition such as alcoholism, a tumour, or a stroke. Other causes may include toxins, chemicals, and viruses. Sometimes the cause is unknown.

Treatment of neurodegenerative diseases

There are currently no drugs to prevent or cure neurodegenerative disorders. Medications to control symptoms can be very effective. Other approaches to manage symptoms and maintain daily activities include physiotherapy, speech pathology, occupational therapy and psychiatry. A multidisciplinary approach is typically applied to improve the quality of life for people with neurodegenerative disorders.

Dementia

There are nearly 10 million new cases of people with dementia each year. Dementia can be the result of a variety of diseases and injuries that affect mainly or secondarily the brain, such as Alzheimer's disease or stroke. Alzheimer's disease is still the most common type of senile dementia, but elderly men are also at risk for vascular dementia. In this case, the problems are related to the damage to the blood vessels in the brain.

It develops when narrowed blood vessels cannot deliver enough oxygen to the brain. This in turn leads to a series of microstrokes that kill brain cells and causes confusion and speech and memory problems in adults. About 15-20% of cases of senile dementia are cases of vascular dementia.

It has been observed that up to 10 years before the diagnosis of dementia, cognitive impairment is likely to appear in individuals and it declines sharply in the final stage of 3 years. Individuals with deficits in vitamin B12, folate, and thyroid-stimulating hormones (TSH) are found to involve with poorer cognitive performances. Deficiency of vitamin B, C, and E are also associated with AD development.

Prevention of dementia and AD

The strongest risk factors of dementia and AD is age and lifetime cumulative multiple risk factors like genetic susceptibility, environmental exposure, and biological factors etc. As such, they need to be considered for identification of preventive measures.

Dietary components are found to be effective in the prevention of neurodegenerative diseases in general. Enriched diet with fish, shellfish, and algae plays a relevant role in the preservation of the neuronal tissue and

helps in memory and learning maintenance.

Evidence suggests that sufficient intake of vitamin E, omega-3 fatty acid and omega-6 fatty acid, vitamins A, C, and whole grains increase neuronal activation and has a significant positive effect on neuronal health.



Chapter 3

Mealtime

Mealtime is a very delicate moment. A meal is a pleasant break in the day, an opportunity to socialize and also to relax.

For many patients, difficulties during this time - such as difficulty swallowing - tend to have the opposite effect: meals become boring, embarrassing, tiring, unpleasant and sometimes scary.

Taking the example of the difficulty in swallowing, there will be a greater risk of malnutrition, i.e. a strong impact on the nutritional content of foods with a reduction in the content of vitamins and fibers, nutrients and energy, as well as:

- decreased appetite
- fear of eating
- inability to eat independently
- overestimated consideration of "inaccessible" dishes

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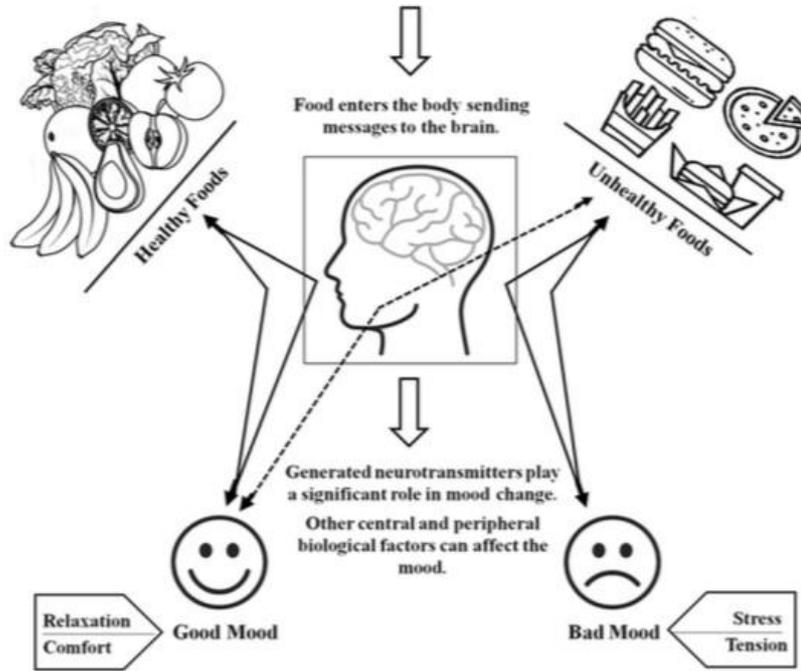
It is not just a moment of supplying the energy and nutrients necessary for survival, it is also an emotional and relational moment.

It is advised to keep other aspects in mind as well, such as:

- Emotional → don't sit at the table angry
- Relational → eat together with the patient
- Visual → presentation is important!

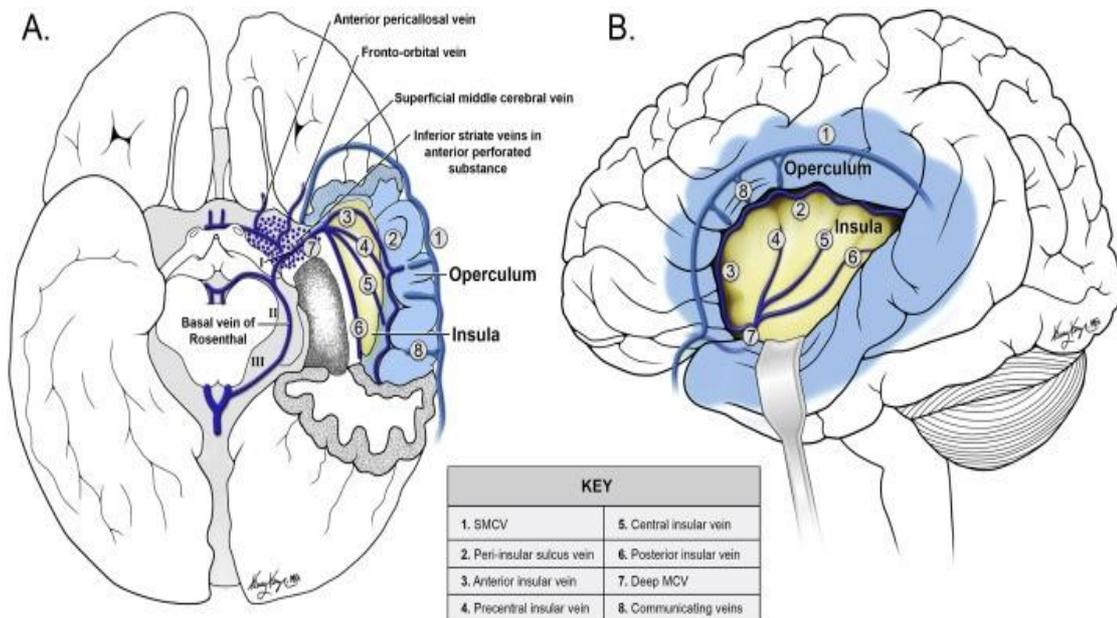
The above is motivated by the fact that it has been scientifically proven that our brain can influence food choices.





In fact, the perception of taste is the representation at the brain level of the activity about to take place, namely that of eating.

Inside the brain is the insula, a cerebral region located in the depth of the Sylvian fissure between the temporal lobe and their frontal, considered a cerebral correlation of taste perception.



Some argue that the nucleus of our "consciousness" is located here. The insula is actually the source of the impulses of sensations and emotions sent by our brain.

Thanks to the insula, we push ourselves to understand the behavior of others and respond emotionally to music and also to the presentation of dishes. The color and position of the food allows us to acquire qualitative information.

However, despite a food's excellent flavor, the eyes also play their part and if a dish is not appealing to the eye, it seems that something is missing.

Another non-negligible element is the sense of smell. This also affects the taste. For example, a common cold does not allow us to properly take in the aromas.

Texture is also important in determining the final flavor: when dishes are reduced to the same consistency, taste alone is not enough to provide the brain with the information necessary to distinguish foods despite flavors.

An experiment showed that by having people taste mashed foods: 80% distinguish apples from fish, 50% identify the flavor of lemon and carrots and only 20% distinguish rice and potatoes, but only 4 % distinguishes lamb from cabbage!

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Another important aspect is the environment where the meal takes place:

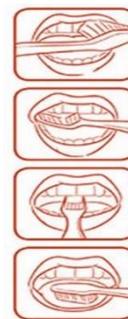
- It plays an important role in making a person feel relaxed, which can affect how much and how they will eat.
- It must be attractive and welcoming to stimulate the senses.
- The room should be well lit. The use of contrasting colors defines the table, dish and food well.
- The environment where you eat must be calm and relaxing, as a noisy environment can be distracting.

Eating Safely

1. **Level of consciousness.** No one should be given food or drink if unconscious or semi-conscious. In this case, alternative nutrition and hydration options should be discussed with the responsible physician.
2. **Distractions.** Reduce distractions during meals to facilitate concentration and awareness.
3. **Time.** Allow yourself adequate time to eat and drink properly. Consider using thermal containers / food warmers to keep foods at the right temperature if you plan on prolonged meals.



4. **Position.** Sit with your back straight during meals, snacks, or when drinking. Remain seated with your backs straight for at least 30 minutes after a meal to avoid reflux.
5. **Oral Hygiene.** Poor oral hygiene can lead to an increased likelihood of infection, including of the lungs. Make sure your mouth is clean and free of residue at the end of the meal. Remove residue from the mouth with a sip of water or even with saliva. It is good practice to clean your teeth and mouth at intervals throughout the day.



6. **Position of the assistant.** The assistant should position themselves at eye level in order to detect any signs of difficulty and immediately provide suggestions and encouragement.

Sitting sideways forces the patient to turn their head, which can make swallowing more difficult.

7. **Aids.** Swallowing requires multi-sensory stimulation.

So it is important that if we need glasses or hearing aids we also wear them when we eat: this facilitates swallowing because it improves sensory awareness.

Food should be visually appealing in its presentation and also have a pleasant smell to stimulate appetite (and salivary flow).



8. **Prosthetics.** Prostheses, if worn, should fit well. Some people prefer to eat without their prosthesis, in this case it is important to use foods that do not require chewing.

9. **Diet modification.** Changing food's consistency is a common practice—adding extra sauces, gravies or custard makes chewing and swallowing easier as well as making the dish tastier and more energy-giving.

Practical directions for preparing meals

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Often patients need a different texture than the original one.

Changing the consistency of dishes does not mean eating less nutritious, less appetizing or less "attractive" food!

Changing the texture of foods can affect their taste:

- Foods can become bland and lose the intensity of sweet or sour flavors.

- It is important to taste the food once it has been changed to ensure the right seasoning.

- It is preferable to keep foods separate, not only for their appearance, but if the foods are mixed together, their taste profile is also confused and may be less



palatable, making them more difficult to digest.

- By separating the components on a plate, each bite is tasted more adequately and it is easier for larger quantities to be consumed.

In this regard, there are several cooking methods to create meals with modified consistency.

The methods change according to the ingredients and the consistency we want to obtain:

- boiling, steaming or braising foods will keep them soft and suitable for making purees
- grilling, baking, or roasting foods can increase the flavor, but the crust or skin needs to be removed before serving
- whole foods, which requires more time to prepare and includes a certain amount of waste
- the foods then need to be blended, softened or thickened to get the right consistency

Steaming

When steaming, boiling and braising foods, the following is recommended:

- adding moisture during cooking keeps ingredients soft and makes it easier to change the texture.
- Suitable methods from level 3 to level 6.
- for level 5 and level 6, food must first be cut into small pieces, cooked and served with a thick sauce.
- For level 3 and level 4, the ingredients must be cooked in the same way then completely mashed to obtain the right consistency.
- Level 3 and Level 4 foods are totally "smooth", so it is better to sift the foods.



Grilling, baking or roasting

For grilling, cooking, roasting and frying:

- These are great methods for adding flavor... but they are more challenging to get the desired consistency
- A crust can form in the cooking process and the ingredients become harder
- These cooking methods provide direct heat which can dry / dry up the food. However, we can find some strategies to still make them usable: for roasts choose a fatter cut, like a shoulder, and roast it slowly - this will keep the meat moist during cooking, or you can add a sauce or gravy at the end to soften and still achieve a change in consistency.



Thickening and diluting dishes

Thickening:

- Thickening powders take time to thicken because they need to hydrate first, so we must add small amounts at a time and wait. Always check the consistency according to what is indicated by the speech therapist.
- Thickeners require a prescription and must be treated as medications: they should be stored appropriately and used for the person named on the prescription.

Diluting:

- The dilution of a pureed food also "dilutes" the flavor and nutritional value of the dish.
- To enhance the flavor, you can use broth or a sauce or some ingredients that also provide nutrients and energy such as plain milk, vegetable milk, plain or vegetable cream, yogurt.
- Investing in a good quality food processor can help you prepare purees of the right consistency and save time in the kitchen.
- Allows you to create excellent creams even with "fibrous" foods and with various types of meat.
- If you use a food processor, consider preparing larger quantities which can then be stored (correctly) for later use, which is yet another time saver.



Other Practical Advice

When creating dishes suitable for those who have problems at mealtimes, it is recommended that the individual components of the dish be modified separately.

This will ensure a better presentation and a taste that is as close to the original as possible.

In any case, never forget that presentation is important...we also eat with our eyes!

Choose common recipes that can be easily adapted for a variety of texture levels. This saves time in the kitchen and allows everyone to enjoy the same menu choice.

Think about the cooking method: How can you achieve the absolute best flavor and what is the best method to change the texture effectively? Cooking the dish at a lower temperature for a longer period of time makes the dish softer and easier to blend.

Seasoning food during the cooking process helps to improve the flavor profile of different foods. It is more difficult to obtain good seasoning after cooking (although the nutritionist generally recommends “cooking without fat” etc.), especially if the food has been diluted with liquids.

Always check the requirements regarding consistency of foods that depend on the specific pathology. Check at the moment of serving because foods can change consistency when we heated or left standing in a pot.

This is especially important in hospitals or residences where food is prepared and stored in hot carts for varying periods of time.

It is also important to remember that when it comes to food, we often forget that it is a fundamental component, especially in recent years, where the economy has created the “new poor.”

This is why this aspect of malnutrition assumes greater importance: "A poor person's cooking that can be served on a king's table" and each of us is a KING, who can make use of the means that the institutions and associations make available, especially for those who — in addition to not being able to access shopping due to lack of economic possibilities—also

have particular illnesses or disabilities.

There is another aspect that especially those who live with dysphagia and other neurodegenerative and neuromuscular diseases must take on, which is cooking.

As we know, muscles throughout our body lose their strength with advancing age, due to trauma or a pathology.

It is therefore necessary to start thinking about developing a home delivery service for meals and to apply a dual method of collaboration, where a volunteer with specific culinary skills is able to handle healthy and safe meals for people with disadvantages and can support the person and / or his caregiver in preparing meals.

Together, respecting their own culinary traditions, they will have to identify the right ingredients and achieve the necessary consistency.

Furthermore, a balanced diet requires the consideration of various factors: type of food, proportionate quantities, methods and times of preparation.

Being able to prepare a tasty and nutritionally balanced dish can only help maintain a proper diet, and over time, create a culture and an awareness of inclusion and collaboration, which foresees the risk of malnutrition and related pathologies.

This last aspect is of fundamental importance to make our daily meals one of the best moment of our day because food is about creating, following rules, collaborating, and learning about the recipes of others.

It is possible to feed oneself, while at the same time enjoying the flavors of each season with its scents and colors. The same goes with a well-served dish. Even the vision of food produces activity at the brain level that acquires qualitative information and includes infinite aspects that involve both the caregiver and the person cared for, thereby improving interpersonal relationships and the quality of one's daily life.

Chapter 4

Throughout the previous pages we have begun to appreciate the absolute importance of being able to enjoy activities that fall into the category of leisure or recreation for the physical and mental health of all people. This is because they fulfil psychological functions that go beyond the purely physiological primary needs of individuals.

Leisure and Health

As mentioned in the introductory section, we have illustrated the positive connection between leisure-recreational activities and the mental and physical health of individuals throughout this guide.

This relationship could be seen especially in chapter “Mealtime”, where the processes involved in the act of eating were described, thus starting a necessary awareness of the challenges that people with neurodegenerative disabilities have to face every time they are confronted with such a daily issue.

However, it is precisely here where the inclusion of leisure as an activity is self-justified, since we have to understand that, depending on the contextual conditions in which an action such as feeding oneself is located, it manages to reach and acquire another register of meanings and values.

Thus, within a social context, the aforementioned **emotional value** would be obtained as a result of the interactions between the participating individuals, with two interrelated forms occurring that have a notable influence on the physical-psychological well-being of the subject; Firstly, there would be the already described perceptive alterations in the brain whose effects, as we know, are manifested from the moment of making decisions about our culinary preferences to the actual appreciation of the flavour tasted, with absolute independence of the correct functioning of the sensory organs



responsible for collecting the information that is subsequently processed in the brain within the insula.

Secondly, we must talk about the effects generated at the **motivational** level in the individual, since the consumption of food in social contexts would be inserted within the so-called secondary human needs, which are all those that exceed the homeostatic functions.

Examples include the search for **security** (physical, occupational and resource security), **affiliation** (socialising with other individuals as a reflection of human gregarious behaviour, and building & maintaining sentimental interpersonal relationships) and **recognition** (seeking the approval of others as a manifestation of self-respect and self-realised success).

Therefore, **the satisfaction of these needs also becomes a very important reason for the mental and therefore physical health of all individuals**, and can bring benefits or harm depending on whether what is desired is obtained or even on the degree of satisfaction achieved.

BASIC HUMAN NEEDS



Leisure and the Economy

The **economic value** of recreational activities is also one of the truly essential aspects for society as a whole and for people on a purely individual level.

First of all, we can underline that "leisure is also a cultural industry that creates jobs, goods and services", said by the 1993 Charter on Leisure Education. Thus, this industry offers a wide range of opportunities for people to access the labour market thanks to its diversified and versatile catalogue of employability niches, which is directly linked to the increased possibilities of inclusion to which a person with a disability can aspire.

Consequently, increasing the labour supply is a crucial issue for the **sustainability** and **viability** of many of the public social policies and all those projects planned or underway, since access to a job for this vulnerable group is an essential requirement for the achievement of the objectives proposed by The European Union. These objectives are included in the document "Strategy for the Rights of Persons with Disabilities 2021-2030" and we can say that it also follows the main lines of action drawn up by the UN in terms of recognition and support for persons with disabilities.

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The objectives of this strategy include the resulting:

- Full enjoyment of human rights without limitations
- Equal opportunities and access to participation in society and the economy
- Respect the autonomy of decision of this group to choose where, how and with whom they want to live.
- Move freely in Europe regardless of their care needs.
- Eradicating the experience of discrimination

Analysing these objectives, we can find a guiding principle that would be uniting them all; we are talking about the **emancipation of people with disabilities**. Until relatively recently, this group was the passive object of a series of social policies that followed a welfare and charitable model.

Fortunately, the perspective has changed thanks to a paradigm shift in mentality that was undoubtedly necessary and in which respect for the dignity and freedom of every human being, regardless of their condition, emerge as inalienable rights.

This is the reason why **the empowerment of this group is a priority that matters** because if they manage to be provided with a series of tools, they will be able to exercise fully as individuals and therefore, in a collateral way, the fulfilment of the principles of **autonomy** and **social inclusion** will be achieved.

Once both principles are covered, equality in human rights is one step closer to being realised. Precisely, some indicators of success in achieving this goal are **access to employment** or **involvement in cultural activities**, one because it gives the person economic independence as well as helping personal growth and protecting mental health by preventing ostracism, and the other because it enables the person to participate in a fulfilled existence according to modern standards of quality of life.

Finally, within this section we should also talk about another type of wealth that is obtained thanks to leisure and that by its essence is not exclusively aligned to the materiality of the mundane world, even though it also emerges as a reason for being or fostering business entrepreneurship; we are talking about **knowledge**. This wealth is exponentially diffused and self-refined through the flow of ideas that involve contact between human beings, helping in the process to the aforementioned personal growth from multiple intellectual perspectives, but we are especially interested in those related to social values as it is presented as a set of undeniable tools to unite increasingly intercultural spaces as a result of globalisation.

In conclusion, leisure or recreational activities are, as we can see, extremely relevant due to the social, cultural and economic implications they have. It is for this reason that, within this logic and in keeping with the purposes we seek through the creation of this guide based on the promotion of values that support inclusivity, human development and other aspects that have an impact on the physical and mental health of people with disabilities, we are going to start on a journey of discovery of the multiple benefits that tourism, as a heterogeneous form of leisure, can offer us from a humanistic and economic point of view.



Inclusive Tourism

Exploring the many riches that our planet has to offer beyond the limits of one's usual place of residence is no longer seen as a purely socio-economic status symbol but has become an essential commodity due to the considerable increase in the quality of life of the population, at least in the developed countries.

This is why these societies are increasingly demanding active participation in cultural leisure activities, whatever their variants.



We have already indicated above the benefits of leisure's participation, so we will not refer to them again beyond pointing

out, because of their inexorable relevance, their importance in linking with concepts such as respect for **human dignity** or **full development** and **personal growth**, concepts that are ratified by a whole body of law that we will also discuss below.

However, even though this need is manifested in the desire of millions of people who practice this social phenomenon known as tourism (which has seen a boom in the number of people interested for decades), there are countless barriers that seriously limit its practice, especially for the most vulnerable groups such as people with disabilities for economic reasons or due to a lack of the necessary infrastructures.



This is largely due to the limitations that the design of public and private spaces has represented for them, given that historically they were conceived without taking into account the requirements that these groups demanded. Thus, although the tourist offer has been expanding exponentially over time, it has not always been accompanied by the public or private will for it to be enjoyed by and for everyone.

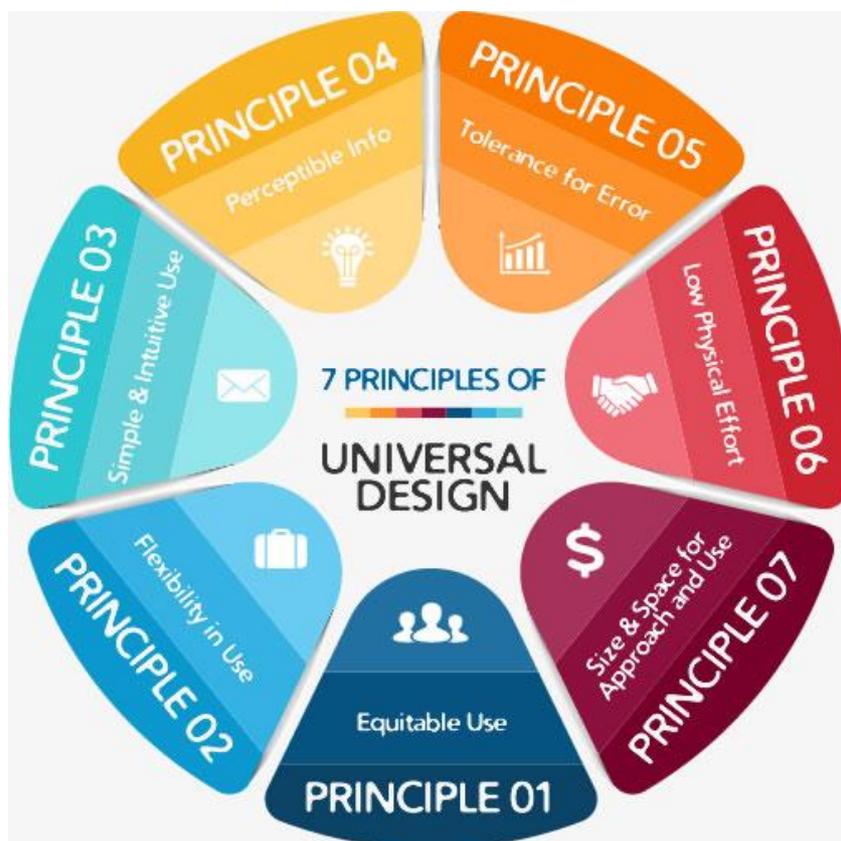
Faced with such a panorama and thanks to the awareness of the last



decades, the elaboration of a regulation that seeks to avoid such deprivations was initiated, giving way to the so-called **"accessible tourism"** whose guiding principle is the elimination of all types of barriers (environmental or social) in order to facilitate the full exercise of the rights of people with disabilities as human beings on equal terms.

Today, we are at the dawn of what is presented as a decisive qualitative leap by incorporating, within tourism, a new concept; the so-called **"inclusive tourism"**. This, unlike its predecessor, does not justify itself on the basis of the elimination of the aforementioned barriers as a pretext for facilitating the achievement of its human rights objectives, but rather it is these rights that constitute the unavoidable normative source of compliance by all social agents, whether public or private, also broadening the perspective of who benefits from the implementation of what is called **"universal design"**.

Universal design advocates for making goods, environments and services easier for all people to use. In order to achieve all of that, the experiences and advice of these people are first taken into account before the formulation is carried out and their advice is also sought in order to evaluate the final product, which must successfully comply with the seven principles that function as fundamental pillars, see the following image:



The essence of this concept lies in the unstoppable factor of the **natural ageing of the population** (especially in the countries that make up the so-called 1st world), which is the result of improvements in health and economic conditions in their countries of origin and which has led to a substantial increase in life expectancy. This variable, together with the fall in birth rates, means that every year the total percentage of the population over 65 years of age increases, which is why attention to the multiple needs of this sector is an issue to be taken into account, both from a fully socio-political and humanistic point of view and because of the window of economic possibilities that this undoubtedly generates.

In order to put this data in a visual form, let's look at an image captured from a *Eurostat* report that not only shows the current figures, but also creates a short-term projection for the following decades. The link to the report can be found at the bottom of this page:



Thus, we can clearly see that the forecast growth of the over-65 population is going to be unstoppable in the coming decades, which is why it makes more sense (from any of the variables presented) to implement this new more inclusive and socially responsible vision that is encompassed under the so-called universal design of both the goods and services offered to citizens, and from which inclusive tourism can be a great beneficiary as an incentive for economic and cultural attraction. We will now deal with the legal bases that support this type of tourism and its users.

Legal framework

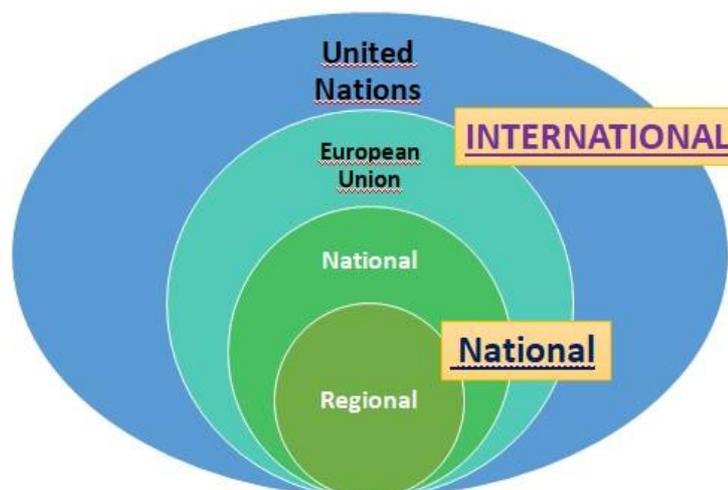
In order to talk about the legislative framework, we must first of all point out to the reader the enormous complexity that its synthesis entails for several reasons, and that is that the laws that have constructed the rights of persons with disabilities, as well as those related to leisure and in particular to tourism, have been shaped over time and not necessarily in a linear fashion.

This is why sometimes the legislation emanating from different international organisations such as the **UN** or the **EU** (as well as

institutions dependent on one of the above, such as the **UNWTO**), have been able to go ahead (or behind) the corresponding national laws of the different countries that are associated with the above within their diplomatic commitments. In any case, it has been **a process in which reciprocity and interaction have been key to the success of the enshrinement of these rights.**

However, we must add a further level of concreteness in order to be able to complete this scheme satisfactorily, since we must also take into account the fact that in some States there are different degrees of political-legislative decentralisation that give rise to autonomous-regional legislation to be considered, although for reasons of space we will not go into detail here.

In summary, this whole structure would be built as shown below:



In the following, we will set out this complex system with its main legislative works, dividing them according to their **origin** (UN, EU and others) and their **jurisprudential framework**.

A) rights in the united nations

1. Universal Declaration of Human Rights, UN (1948):

This is the first major piece of historical legislation on human rights, which includes, among others:

- **Art. 1:** "All human beings are born free and equal in dignity and rights".
- **Art. 2:** "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
- **Art. 3:** "Everyone has the right to life, liberty and security of person".

2. UN Convention on the Rights of Persons with Disabilities (2006) (hereinafter CRPD):

It is an international treaty guaranteeing the rights and freedoms of persons with disabilities.

- **Art. 1:** "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

"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".

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B) rights in the european union

1. European Convention for the Protection of Human Rights and Fundamental Freedoms (1953).

It is expressly inspired by the 1948 UN Universal Declaration of Human Rights, and ratifies and disseminates its principles.

United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities. A/RES/48/96.

From this important catalogue of standards, we are going to highlight 4 principles as they are totally related to the rights of people with disabilities and the tourism sector:

- Standard 1 → Awareness-raising
- Standard 5 → Accessibility

➤ Rule 10 → Culture

➤ Rule 11 → Sports & entertainment

3. European Charter of Fundamental Rights (2010)

Implementing the CRPD resolutions ratified by the EU in 2010, it recognises the right to an independent way of life, employment, security and access to the benefits and opportunities derived from leisure and tourism on an equal footing with other citizens.

4. Other EU policy initiatives:

- **Directive 2000/78/EC** establishing a general framework for equal treatment in employment and occupation
- **European Parking Card (2008)**
- **Directive (EU) 2016/2102** on the accessibility of public sector bodies' websites and mobile applications for mobile devices
- **European Disability Card (2016)**
- **European Pillar of Social Rights (2017)**
- **European Accessibility Act 2019/882** on accessibility requirements for products and services

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5. Equality Union: Strategy for the Rights of Persons with Disabilities 2021-2030.

It continues the strategy already initiated in the previous decade, the results of which have been very successful. It aims to "improve the lives of people with disabilities for the next decade, in Europe and beyond".

C) tourism and leisure rights

1. Leisure Charter, OMO (1970):

We have already referred to the World Leisure Organisation and its important role in achieving respect and promotion for this type of activity. To be highlighted:

- ✓ **Art. 1:** "Leisure is a basic human right. It is therefore understood that governments have the obligation to recognise and protect this right and citizens have the obligation to respect the right of others.

Therefore, this right may not be denied to anyone on the basis of any ground, creed, race, sex, religion, physical disability or economic condition".

2. The Declaration on World Tourism, UNWTO (1980):

The World Tourism Organisation pointed out that "the right to tourism, which must be conceived in harmony with the priorities, institutions and traditions of each country, implies a duty for society to create for all citizens the best practical conditions for effective and non-discriminatory access to this type of activity".

- ✓ **Annex to General Assembly resolution A/RES/284(IX) adopted at the 9th session entitled "Towards handicapped accessible tourism in the 1990s", UNWTO (1991):** Agrees on the basic criteria for action by the tourism sector in terms of information, training of tourism personnel, and general and specific requirements to be met by tourism facilities in order to be considered accessible to persons with reduced mobility.
- ✓ **Global Code of Ethics for Tourism, UNWTO (1999):** This is a decalogue addressed to governments, the tourism sector and tourists, although it is not legally binding. However, it was the first document to justify tourism through law and cultural integration and diversity.
- ✓ **Resolution A/RES/492 (XVI)/10 "Towards Accessible Tourism for All", UNWTO (2005):** agrees on the requirements that the tourism sector should adopt to enable equal opportunities for persons with disabilities.

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3. Convention on the Rights of Persons with Disabilities, UN (2006):

- ✓ **Art. 24:** "Everyone has the right to rest and leisure, to reasonable limitation of working hours and to periodic holidays with pay.
- ✓ **Art. 27.1:** "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits".
- ✓ **Art. 30.1 (Participation in cultural life, recreation, leisure and sport):** "States Parties recognize the right of persons with disabilities

to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities have access to cultural materials in accessible formats, activities and access to places where cultural performances or services are offered, such as monuments and sites of national cultural significance.

Thus, after this brief overview of the main legislative lines of emphasis and in view of all the applicable regulations, the tourism sector has only two possible responses to these changes:

1. Proactive approach: Public administration and the private sector are leading the change because ...

- a. They are sensitised to the values of human rights for society as a whole.
- b. They understand the application of universal design as a factor of quality and added value to the tourist service that also ensures the durability and profitability of its use.
- c. They understand the benefits that an investment such as the implementation of universal design can bring to boost such a lucrative market as tourism, under the prism of inclusivity.

2. Reactive approach: Employers and public administrations are obliged, after the implementation of regulations, to carry out a series of modifications or even the elimination of some of the...

- a. Products
- b. Facilities
- c. Service

Although most of the time the changes brought about by the latter type of policies, the reality is that we can only maintain long-term viability and sustainability if we internalise the need to transform our environment not through imposition, but through self-fulfilment.

This is why **awareness-raising** is an indispensable prerequisite that has to permeate society in order to eradicate the barriers that stand between individuals and their environment.

Accessibility Barriers

As previously established, accessibility is a *sine qua non* requirement for the practice of tourism, but it is also a social right to be provided by States for each of their citizens.

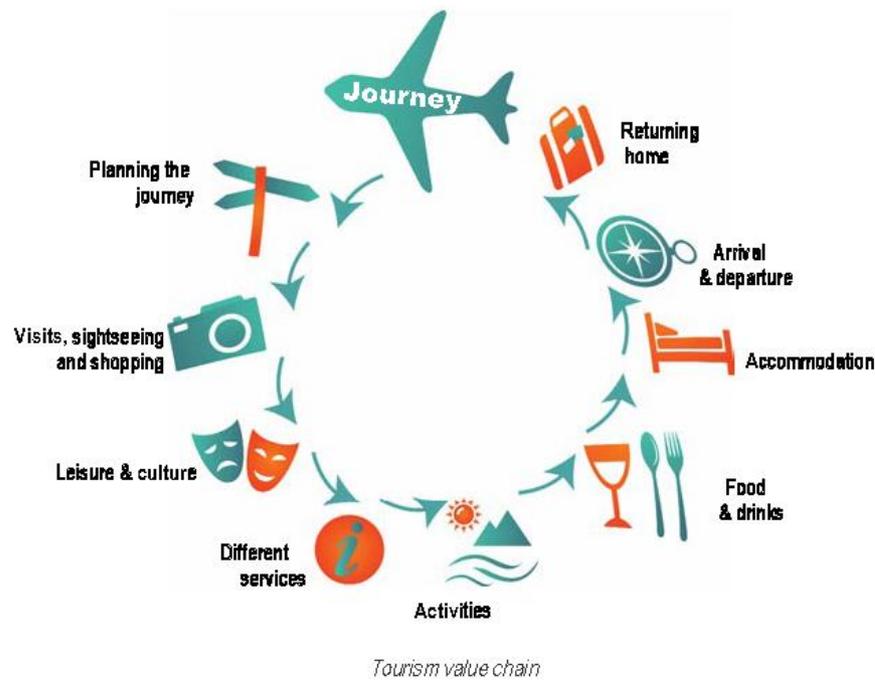
Addressing this right requires a series of changes in order to eradicate what are called "**accessibility barriers**", barriers that are not always physical and therefore pose a real challenge to society as a whole.

The following table is therefore intended to explain in a very visual way the different types of existing barriers, where they are located, their effects and give some examples. However, first of all, we would like to point out that in the table shown a last category has not been included for reasons of simplification, which would have to do with the so-called **primary** or **secondary levels** of barriers:

- **Primary:** Those limitations or barriers that prevent access to the use and enjoyment of a good or service.
- **Secondary:** All restrictions that a user may encounter once he/she is located within a facility or environment.

Types of Barriers					
Environmental		Social			
Language	Architectural	Training	Attitudinal		
Effects	It can be easily visible through communication, which is seriously compromised. This influences both upstream when planning, booking and downstream in the normal development of the tourist activity.	It affects the infrastructure of the surrounding environment in general, as well as transport, so the main effect is on mobility, which is reduced or made impossible.	It is perceived in the incorrect treatment of people dedicated to the tourist service towards PWD, which is the most prominent social barrier within tourism.	There are two variants; the first is a lack of awareness of the problems and needs of PWD, while the second is linked to social exclusion on grounds of discrimination.	
	<ul style="list-style-type: none"> - Limitation or impossibility of access to information. - Digital accessibility not in line with needs. - Buildings without appropriate signage. - Ordering and planning an activity is severely hampered. 	<ul style="list-style-type: none"> - Getting around by public or private vehicles is sometimes impossible due to lack of means. - Pedestrian accessibility is compromised. - There are restrictions on access to certain areas. 	<ul style="list-style-type: none"> - Not knowing the basic needs of the people they have to care for. - Not having adequate resources to facilitate the normal development of the tourist's holiday activity. 	<ul style="list-style-type: none"> - Not being involved in the care that is due to this population group. - Develop discriminatory attitudes due to a lack of empathy or ignorance. 	
Examples					

Although there is still a long way to go as it is a gradual process that has only started less than a century ago, we can boast in general of great and remarkable changes that have made the development of "accessible tourism" possible in certain geographical areas. This is because tourism itself is an interconnected chain of goods and services that affect and influence each other as can be seen in the following picture:



Within this whole process and to conclude this section, we will focus on the importance of a factor that is becoming decisive for the modern information society; the **use of ICT** (Information and Communication Technologies).



New technologies have burst into our lives, bringing with them a socio-economic and cultural revolution that influences the way we communicate and relate to our environment, making it possible for traditional barriers to be blurred with the inclusion of new tools. These, in many cases, are specifically designed to meet the needs of PWD, thus facilitating accessibility to environments in an instantaneous, versatile and economical way.

This multi-purpose value of ICT has convinced the EU to fully commit to these new tools by adopting, among other measures, the so-called "**Web Accessibility Action Plan**" in 2021.

Therefore, **the training of citizens in Digital Competence in order to disseminate the implementation of the use of ICT in a globalised way** is one of the requirements on which the representatives of public and private authorities must focus a great deal of their attention, as their empowerment opens up a whole market of possibilities that help to boost any activity, be it economic or cultural in nature.



However, a lack of ICT literacy brings with it another type of barrier known as the "**digital divide**" that has a huge impact on equal opportunities as well as social inclusion, and the effects on physical and mental health can be truly damaging.

Socio-economic and Cultural Benefits

The current number of people with disabilities in the world is over 1 billion according to data collected in 2021 (15% of the global population), reaching 138 million people in Europe (30.8%). These high figures are mostly due to the aforementioned population ageing, which explains why EU countries are among the 30 most ageing countries in the world.

Therefore, the practice of **inclusive tourism is a business opportunity as it is a growing market**, as stated in several reports, including the European Commission's 2015 report on the rights of tourists with disabilities in the EU. It points out that some 96 million PWDs (70% of the total) could be potential customers because they are the ones who are physically and economically able to travel.



In addition, attracting this type of tourist has two economic advantages:

- ✓ **Multi-customer:** As they are people with needs, they are often accompanied by family, friends, or personal assistants, making them a type of tourist that promotes even more economic activity.
- ✓ **Non-seasonality:** This type of user is characterised by being, in the majority of cases, free of work burdens and therefore with a large amount of free time, although they do not always have many financial resources. However, precisely because of the aforementioned factors, they can be a group that covers the periods of less tourist activity or low seasons.

On the other hand, recent research with PWD has yielded very interesting data that help us to continue promoting our line of argument regarding the importance of leisure at different levels, whether for its impact on physical and psychological health, on the promotion of culture, or on the economic benefits it brings with it. This data would reflect the relevance that this group gives to the practice of leisure because of the social benefits such as their **integration into the community** or others that have to do with their **physical-cognitive well-being**.

It also shows that they **have the same interests and expectations as the rest of society in terms of leisure, but they are deprived of its use because they face greater difficulties**, including barriers that make universal accessibility impossible. Hence, 2 out of 3 respondents expressed that they would like to engage in other types of recreational activities than those they usually engage in, especially sport, holidays and travel.

Therefore, translating these desires into percentage numbers, we have that 59% wished to undertake some cultural activity, followed closely by sports and leisure activities (55.8%), which means that tourism and the client who consumes this type of leisure **is a decisive agent for sustaining and disseminating culture**, with the lack of accessibility being its main constrictor.

Chapter 5

Best Practice

In these chapter you will find same Best practices from the association partners (set of guidelines, ethics, or ideas that represent the most efficient or prudent course of action in a given certain situation).

Best practices in Bulgaria - Association of Young Psychologists in Bulgaria (AYPB)

The Association of Young Psychologists in Bulgaria (AYPB) is a nongovernmental, non-profit professional organization representing psychology students and young psychologists in Bulgaria. Over 300 young psychologists, students, PhD students and young specialists from throughout the country are members of the Association. The Association is represented in any major university in Bulgaria teaching Psychology.

The main goals of the AYPB are:

1. Advocate the professional interests of psychologists and psychology students in the country, provide support to their education and professional realization.
2. Take care of psychology students in the various universities in the country by means of providing information, cooperation with their qualification for projects of a wide spectrum of foundations and institutions, foster their professional qualification, integration and interaction with other student communities.

3. Improve the quality of training in psychology in Bulgarian universities.
4. Encourage and optimize the communication and interaction of young psychologists on a national and international scale.
5. Interact and partner with organizations of psychologists from Europe and the rest of the world.

AYPB is a member of EFPSA (European Federation of Psychology Students' Associations).

First European Fair of social enterprises and cooperatives of people with disabilities

Type of practice: Development of social entrepreneurship, exchange of experience, increasing the employment opportunities of people with disabilities.

The first European fair is a follower of the nine National Exhibitions held so far and initiated by the non-governmental organizations of which they are members. The Fair was implemented in connection with the implementation of the objectives of the Strategy "Europe 2020".

The overall goal is through participation in an international forum to promote the active public position of members of specialized enterprises and cooperatives of people with disabilities, their achievements in employment, in the process of integration into social and public life.

In the long run, the goal is to overcome the low awareness of the public about the opportunities of people with disabilities. The European Fair is a message that cooperatives, social and specialized enterprises for people with disabilities must be actively supported by implementing special programs to support this type of activity.

Art therapy center - Theatrical youth formation "Who am I?"

Type of practice: Vocational rehabilitation and integration of young people with disabilities.

Main objectives:

The main idea for the establishment of the Art Therapy Center is to provide disadvantaged youth with access to vocational rehabilitation, non-formal education, development of talents and meaningful leisure time.

Other goals:

- supporting the integration of disadvantaged young people in civil society by encouraging their initiative;
- creating equal access for young people with special needs to various forms of development of their talents - social work, special protection and development of their skills in culture and the arts;
- providing an opportunity to acquire new knowledge and skills, with a view to removing them from the marginal group and encouraging the desire of people with disabilities to lead normal life;
- building positive public attitudes towards the desire and ability of young people with disabilities to experiment.

Calendar for persons with Down Syndrome

Organization: Association of parents of children with Down syndrome

Description: In 2015, for the second year, the parents of children with Down syndrome organized the preparation and production of a special calendar in which children with Down syndrome are shown together with prominent personalities - singers and actors. The calendar presents children with Down syndrome as happy, completely normal children who are liked and participate in a joint project with prominent personalities, well known to the general public.

The campaign shows that children with disabilities can be happy by emphasizing the human rather than the different - the syndrome.

Origin: Bulgarian practice

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Achieved results and impact:

- Persons with Down syndrome were acquainted with prominent public figures, singers and actors. As leaders of public opinion, they are motivated to recognize persons with disabilities as full citizens.
- The calendar is professionally designed and enjoys interest from a wide range of individuals and organizations. Because of the good aesthetic quality it reaches a lot people who can learn more about children with Down syndrome and the fact that they too can be happy like all other children. The happiness of children with Down syndrome makes happy the parents and adults around them.

Good Practices in Spain - Confederation of People with Physical and Organic Disabilities (COCEMFE)

The Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE) was founded in 1980 with the mission of coordinating the efforts of different entities in the search to guarantee and extend the rights of people with disabilities, specifically those affected by a physical or organic disability. In its more than 40 years of history, the milestones achieved towards the inclusion, autonomy and improvement of the quality of life of this group have been very numerous, and this is largely due to the institutional strength it has acquired over time, a strength that today gives voice to and represents more than 2.5 million people with physical and organic disabilities through its 92 territorial organisations and more than 1600 affiliated associations.

As this section focuses on the benefits of inclusive tourism, we are going to dedicate the following lines to talk about the important work that an entity such as ours represents for its achievement. Thus, COCEMFE has as a priority among its fields of action the promotion of inclusive tourism and the exercise of the right to leisure of people with disabilities through different lines of action. These include the promotion of accessibility throughout the tourism chain, training and awareness-raising in this area, and carrying out research and analysis of destinations, hotel establishments, services and tourism resources. It also offers a holiday programme for people with disabilities and their companions.

Within the confederation, but at a provincial organisational level, we, the authors of this section (COCEMFE Seville) are working on the same strategies and services to facilitate the social inclusion of people with physical and organic disabilities and to promote the active participation of the associations that make up the confederation in our geographical area

located in the south of the country.

That is why our federation is actively involved in the structures of social participation where both public and private organisations meet to deal with issues related to the full inclusion of people with disabilities in society.

An example of this is the annual organisation of the "accessibility roundtables", which are working areas in which representatives of different

entities, institutions, administrations, organisations and professionals related to universal accessibility participate in order to exchange experiences, good practices and information, propose solutions and present to the participating administrations and institutions their concerns, demands and proposals on accessibility in Seville and its province. The focus of these roundtables is always on accessibility to tourism goods and services in Seville and its province.

COCEMFE Sevilla also collaborates by offering advice on accessibility to many tourist companies in Seville and its province, such as GA Andalucía (Guiding Architects Andalusia), an expert team of local architects who organise routes around Andalusia dedicated to architecture, urban planning and landscaping. This association is committed to the creation of inclusive routes throughout the historical heritage of Seville and Andalusia, thereby encouraging inclusive tourism.

Precisely with regard to inclusive tourism, the federation favours alliances and agreements that promote, inform and improve services to achieve the objectives and requirements for this type of tourism. For example, it leads accessibility groups at national level or participates in CERMI (Spanish Committee of Representatives of People with Disabilities) where it works for the promotion of universal accessibility.

Along these lines, the entity actively participates in working groups at national level under the theme "tourism for all", where special consideration has been given to include people with severe disabilities. Therefore, facilitating the accessibility of these people to popular cultural events in which they were never able to participate is one of the internal objectives we work on. An example of this was the celebration of the activity "1st Camino de la diversidad" where we undertook a very important work of organisation, recruitment of volunteers for personal assistance and elimination of architectural barriers during a particularly famous pilgrimage to the south of Spain "La Romería del Rocío". This important event was held over 3 days in April 2022 and involved 80 people with disabilities in wheelchairs, including 40 people with severe disabilities.

This is why it **is vital for an organisation such as ours to act as a link between potential users and the specialised goods and services they**

require, ensuring that the needs of these people, particularly those who are severely affected, are met.

Otherwise, the aforementioned "tourism value chain" would not be initiated in the first place, since barriers would be put up in the planning of the trip itself, and neither would the tourist or beneficiary of these services achieve a feeling of security that we, from COCEMFE Seville, want to provide as part of our purpose to spread the right to an autonomous and full life for all people.

To conclude, we would like to add that due to the continuous effort of years of work and the people involved, our actions have resulted into a remarkable agent of social transformation. These actions have gradually permeated society as a whole and with it the necessary awareness of the state of inequality and the support that this group requires.

For all these reasons, we can proudly say that in addition to providing services adapted to the demands of our users, we provide a service to the whole community based on the example and sacrifice that our struggle exemplifies, and that day by day, is transforming the reality of the socio-cultural context towards an inclusive future.

Good Practices in Inclusive Tourism

We will now present three initiatives related to tourism practice and its dissemination to serve as reference models. The first of the examples comes from the international European sphere, while the next two are national examples from Spain and France respectively.

a) European Capital of Smart Tourism:

This initiative was launched in 2019 by the European Commission, and has quickly achieved a high degree of popularity as a pioneering measure for the promotion of tourism and socio-economic modernisation. The objectives include:

- To improve the tourism offer of European countries and, collaterally, to promote economic growth and employment.

- Disseminating local culture as a sign of identity
- To increase the attractiveness of cities that hold the title of "Smart tourism", serving as models of good practice for other municipalities.
- To generate a pan-European feeling among the citizens of the participating countries based on mutual respect and cultural interest.
- Promoting partnerships and cooperation between cities and European institutions.

Any European city can participate in the project, starting a competition against the other registered cities in 4 individual categories: **sustainability, accessibility, digitalisation and cultural heritage & creativity**. In each of these categories, one city is awarded as the winner for the degree of commitment and realisation achieved.

Likewise, the two cities that obtain the most points in the final sum total are declared the winners of the competition, acquiring various prizes, including advice from experts in communication and tourism to promote their city as a destination, a promotional video and a sculpture, etc.

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In short, this initiative rewards and recognises the most outstanding achievements of European cities in these areas and serves as an incentive for others to continue on the path of necessary transformation.

(b) Hérault-tourism:

It is a tourism development agency in the Department of L'Herault, France, which carries out coordination, dissemination and training tasks for the various tourist offices and tourism companies in the region in question. The objectives include:

- Design action plans to promote tourism in the region in coalition with the public authorities and private agents in the area.
- Promote access to leisure for all users through projects that facilitate accessibility thanks to the eradication of existing barriers, using technology as a great ally.

- Educate tourism professionals and the general public about disability-related needs, raising awareness in the process.

This agency has been the promoter of some measures that have certainly been very popular, such as the **creation of a mobile application** ("Hérault Mobility") that informs users with physical or visual disabilities about the existence and location of adapted routes. This application also has the function of indicating the degree and type of accessibility of the environment, thus making it easier for authorities to identify where they should focus their efforts to implement accessibility improvements.

Another measure we can highlight is to encourage and reward those who carry out the relevant transformations by awarding them a **quality control seal**.

With this initiative, the values related to an inclusive tourism concerned with the wellbeing of its users are expanded, serving as a call for attraction for the tourism sector as well as for entrepreneurs.

Good Practices in Italy – La Forza di Nemo sezione UILDM Montecatini Terme

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Founded in August 1961 by Federico Milcovich, UILDM – the Italian Union Fight Muscular Dystrophy - is the national association of reference for people with dystrophies and other neuromuscular diseases.

Its aims of the national association are:

- FAVOUR the social inclusion of people with disabilities;
- PROMOTE scientific research and health information on progressive muscular dystrophies and other neuromuscular pathologies.

The Association 'La Forza di Nemo' is the Montecatini Terme section for Pistoia and its province.

The main objectives of "La Forza di Nemo" is to encourage the social inclusion of people with disabilities and promote scientific research and

health information on progressive muscular dystrophy and other diseases neuromuscular/ neurodegenerative diseases.

In particular, the aim of “La Forza di Nemo” is to break down barriers, promote a culture of diversity, from an inclusive perspective, grasp diversity in diversity and recognise the specificity of the situation of women with disabilities.

Mind Their Health – Inclusion and health through food

The objectives that 'Mind their health' wants to achieve are three:

1. Raise and implement public awareness public awareness of people with neurodegenerative diseases.

This project is designed to support, encourage and socially include these individuals, reducing the distance between their reality and the one we are used to.

The expected results are increased awareness of the topic of neurodegenerative diseases.

2. Support and encourage the social inclusion of people with neurodegenerative social inclusion of people with neurodegenerative diseases.

Inclusion and appreciation of diversity has always been a cornerstone of European community values.

The creation of the “practical handbook of tips for good nutrition” will make it possible to strengthen social ties between people with neurodegenerative diseases and civil society at mealtimes.

Since mealtimes represent a major obstacle in the daily lives of people suffering from these pathologies, the creation of a practical handbook with advice on how to prepare meals, containing recipes suitable for such pathologies, is one of the best means of achieving the objective of social inclusion and valorisation of differences in the educational, training, youth and sports spheres.

The expected results are linked to the number of interactions and downloads of the “practical handbook of tips for proper nutrition”.

3. Train the staff of partner organisations by developing specialised knowledge and soft skills in the field of neurodegenerative diseases.

The course will train 24 staff members of the partner associations in the development of competences in the field of special nutrition for people suffering from neurodegenerative diseases.

Six staffs will be trained for each partner association, with the exception of CrowdAid, which will deal exclusively with the technical and multimedia part. Staff training is the main priority of this project, as well as being one of the priorities of this European programme.

This objective will make it possible to develop the staff's skills and improve their knowledge of nutrition for patients suffering from these diseases. In addition to the specialised training, it is planned to share the experiences of individual carers.

This activity will increase the soft skills of the associations' staff. The expected results are No. 24 staff trained; No. 1 course programme realised; No. 1 e-learning module realised.

Conclusions

About 15% of the world's population, have some form of disability.

There are still many barriers that prevent people with disabilities from fully exercising their fundamental rights, and these barriers limit their equal participation in society.

The presence of a disability in a family can be a cause of emotional distress and the development of mental health conditions such as depression and anxiety. Consistent and targeted policies, actions and measures are needed in this aspect.

The full participation of people with disabilities in economic and social life is essential to succeed in achieving smart, sustainable and inclusive growth.

Active participation in leisure activities is an issue that has to be understood as part of the whole range of human needs and therefore requires our attention, otherwise its absence can have harmful effects on the mental health of individuals and thus, always in a collateral way, on their physical health.

Moreover, the health benefits of leisure are incalculable, as it is the gateway to fundamental aspects such as social inclusion or personal development, which, as we have seen, are two points that are quite relevant to the achievement of secondary motivations such as the need to feel part of the community in which one lives or the need for self-realisation.

Leisure therefore acquires a value of unquestionable excellence within the complex world of disability as it naturally becomes a requirement for the successful achievement of personal self-realisation, since recreational activities, especially tourism, are the most reliable example of the achievement of concepts such as full autonomy or emancipation in people with disabilities.

The fact that tourism is the pinnacle of these concepts, especially that which advocates inclusivity, is due to the very nature of tourism, since it requires the mobility of the user in order to take part in any

type of cultural activity, which in itself represents a challenge both for the person with a disability and for the society that welcomes him or her into its midst. This is why we can call it inclusive.

This challenge is constituted by overcoming what are known as barriers to accessibility, which can be found both in the environment and in society itself.

The former can be solved through investment in infrastructure to improve and expand services, for example by implementing the concept of universal design, which does not seek to eliminate accessibility barriers in infrastructure and communication only for people with disabilities, but has a holistic sense of being, taking into consideration the needs of all people in order to facilitate their access to goods and services, and is also justified by the projection of the demographic evolution of our societies.

As for the latter, they are rather more complex to solve because they are not strictly material as they have to do with the perception and attitude of individuals and societies towards disability. The way to work towards the elimination of this barrier is through training and information, as they involve awareness-raising and assimilation of concepts such as inclusiveness.

However, tourism, among its polysemic values, has precisely this power of social awareness as it is a natural mechanism for the flow of ideas. This is why tourism activity also brings benefits to societies that work to promote this economic sector, benefits that translate into greater employability and economic stability, but also into dissemination and sustainability for culture.

Thus, inclusive tourism is undoubtedly a great commitment to the future because of all these social, economic and cultural benefits. Its positive effects can be felt and shared by society as a whole from the present onwards, and is therefore a driving force for change and social transformation.

Last but not least, is necessary to consider the treatment of the topic of food and cooking.

It is really important talking about food, especially in recent years where the economy has created the ‘new poor’.

The centrality of catering and cooking in the pursuit of meeting nutritional goals in the social, health and family fields that establishes that the pleasure of food, the gratification of taste, the aroma, the chromatic connotation, the recognizability of the dishes, and food memory are in effect of great importance.

In the health, social health and family sectors, feeding oneself should not be perceived only as a physiological necessity but as a moment of pleasure, affection, communion and as the fundamental elements of the person's well-being.

The comparison between the various figures involved can represent a starting point for reflection on the objectives, problems and solutions that all those who work in this sector have in common with different and specific responsibilities.

For this it is necessary that the patients themselves, caregivers, family members, cooks, nutritionists, dieticians, speech therapists, geriatricians, nurses and all social and health professionals work in constant dialogue, united in the common goal of offering guests, especially the most fragile ones, the best solutions from the point of view of safety, nutritional intake and pleasure.

Together in accordance with individual culinary traditions, we had to identify the right ingredients and the consistencies that are needed. A balanced diet requires consideration of various factors: type of food, proportionate quantities, methods and times of preparation.

Being able to prepare a tasty, nutritionally balanced dish can only help maintain a proper diet over time.

In the future, we hope that this kind of approach (a mix of cultural but also operational and practical nature) help patients suffering a temporary condition to overcome it and for those who suffer from it permanently to face it in the best way - thus creating a culture and an

awareness of inclusion that predicts the risk of malnutrition and related diseases.

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