



# POLICY RECOMMENDATIONS AND GOOD PRACTICES FOR THE CAREGIVING OF BRAIN INJURED PATIENTS



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## 1

#### **Current state of Adquired Brain Injury**

#### **España**

In Spain there are **420,000 people with Acquired Brain Injury (ABI)**, according to the report made by FEDACE with the collaboration of the Royal Patronage on Disability during 2015. ABI occurs suddenly and unexpectedly and entails a series of physical, cognitive and behavioral consequences that will limit the functionality and independence of the person, assuming an abrupt change in their vital project. However, we must not forget that the impact can be as devastating for the affected person as for the family, on which care and attention of the dependent person usually falls. Nobody is prepared for it: neither the people who suffer it nor their relatives and close friends.

With the brain injury, a **long recovery process** begins that usually begins with the reception of the affected person in the emergency services. Once the clinical stability is achieved, and after a period of variable admission, the patient is referred to the home. Unfortunately, on many occasions, the return home is not optimally addressed by health and social services due to the shortage of temporary, economic and social resources. At that time the responsibility for the management of a clinically stable patient but with complex sequelae is transferred to the family. Family members approach the care of patients with ABI without having specific knowledge and training, without adapting the environment or the necessary support products for their management and without the relevant social and health support.

At present there is a great imbalance between the areas of **health and social care**; the perception of support and coverage decreases as time goes by. The technical, medical and pharmacological advances that are used during the acute phase have improved dramatically during these last years and have been generalized to all citizens. In fact, treatments today save many more lives. However, this homogeneity in the quality of care is diluted when progressing to the subacute or rehabilitation phase and becomes anecdotal when social media coverage is analyzed. The implementation in 2007 of the *law on personal autonomy and attention to dependency situations* has partially solved this overload, but there is still a long way to go.

The **impact of ABI** in the family environment is usually associated with its severity, but it differs from one family to another depending on variables such as previous family structure and cohesion, communication style, coping strategies and available resources. An especially important variable is the type of relationship that links the person with ABI and the main caregiver. In any case, it implies a reorganization of personal resources and family roles, the need to articulate supports that were not previously necessary and a rethinking of the vital project. Family members should be responsible for the care, attention and financial support immersed in a process of emotional adaptation in which mixed feelings emerge. They go through different emotional stages that ideally culminate with a personal and family readjustment that allows an optimal adaptation to the dependency situation. The uncertainty and anguish of the initial phases gives way to hope and euphoria based on the survival of our family member, something that few days before seemed impossible. The complexity and length of

the rehabilitation process, the scarcity of social and health resources and addressing the care of a family member who "is no longer the one who was not or behaves as such" usually generate a feeling of emotional and physical overload known as *Caregiver Syndrome*.

The aim of the **programs of attention to family and / or formal and informal caregivers** is to contribute to the development of coping strategies that facilitate the construction of new balances in which happiness, hope and personal growth are possible. To this end, three large groups of needs have been recognized, that of giving information, training of new skills and facilitating psychological adaptation. In 2007, FEDACE worked with the IMSERSO and various professionals in the field of neurorehabilitation in order to develop a model of attention to brain damage in which the needs of people with ABI and their families were analyzed and basic principles that should guide its approach from the socio-health field.

#### **Portugal**

In Portugal, as in any other country, suffering a traumatic brain injury (TBI) causes damage to oneself, to all family members, friends and surroundings. "Novamente" is the only association in the country dedicated to support families and victims of severe TBI. The association "Novamente", in the last 10 years, has done studies, in partnership with other hospitals and universities, like "POAT 2014", has cooperated with all hospitals that have neurotrauma and trauma emergencies, with all rehabilitation centres.

Novamente has evaluated the morbidity data and annual meetings at the caulouste Gulbenkian foundation with the main stakeholders. Considering a stakeholder all professionals, entities that act in one or more ways in the total path from the day of the accident of the person until their return or desire to return to active life.

#### Incidence, morbidity and causes:

According to a survey carried out by the association "again" in partnership with DGS (General Directorate of Health), it is estimated that **in Portugal there are more than 220,000 people** living with the consequences of having suffered a severe brain trauma.

Until 1992, the number of new trauma cases increased to a record number of 15 cases per day. Portugal was, until that date, the country in western Europe with the highest number of road accidents (per capita) which generated and justified this high number of traumas. The country's entry into the European community forced strict road rules for the country, especially with regard to the blood alcohol limit with which it is allowed to drive, the mandatory seat belt on all passengers, special rules on public transport or service, mandatory helmet use, among others.

In the years that followed 2016, the number of incidents decreased to 6,000 new cases of severe stroke per year, 10% with death in a hospital environment. The main cause of TBI, until 2016, was the road accidents (more frequent in people of active age with a higher incidence in males), the second biggest cause was falls (main cause in older people, especially those who live alone).

The most recent data on the Portuguese population show a negative balance in population growth in the last 10 years. There are few births (first due to the serious financial crisis and then due to the youth employment crisis) and an increase in the age of death of older people, justify the TBI numbers that Portugal has in the last knowing data. 4,000 in the year of 2018 severe cases of TBI with a special incidence in people over 65. Despite these new cases each year, we have to reinforce the existence of the numbers of TBI that existed in young people until 10 years ago, people who live today isolated, without solution and without understanding their sequences.

#### Turquía

**Traumatic brain injury (TBI)** is the most common form of brain injury. In cases such as less anoxia than brain damage, some types of stroke, infections and brain tumors, TBI can also occur. Rehabilitation is required for the vast majority of people with traumatic brain injury. Basic skills, such as lost walking or speaking, may need to be re-learned.

The purpose of this **rehabilitation process** is to provide the necessary skills for patients to perform their vital functions at home and in the community. Traumatic brain injury is a condition that anyone can encounter, anytime, anywhere. It is especially common in young people between the ages of 15-25. It is more common in motorcycle and / or bicycle accidents. Using a helmet or a protective cap significantly reduces the occurrence of traumatic brain injury.

People who have TBI need **primarily medical attention**. Providing oxygen support to the brain and the rest of the body, ensuring adequate blood flow and controlling blood pressure is a priority. Imaging techniques such as x-ray, tomography and MR are very important in determining the diagnosis and treatment of the patient with TBI. After viewing and diagnosing the damage, necessary medical and surgical interventions are performed.

In later periods, individual therapy programs are organized that are suitable for the patient. These programs can be physiotherapy, occupational therapy, language and speech therapy, psychological and social solidarity.

The main purpose of **rehabilitation** in the period after leaving the hospital is to maintain the life of the person as independently as possible. In the acute period of traumatic brain injury, vital problems are at the forefront. However, this situation should not neglect what should be done in order to prevent future complications. With the disappearance of edema in the brain tissue in the post-acute period, the medical condition stabilizes and recovery in the brain tissue continues. In the later chronic period, recovery may occur in the central nervous system.

Research has shown that most neurological improvement is greatest in the first 6 months. Those who have traumatic brain injury but are well rehabilitated and have no problem with their cognitive functions such as learning and remembering can become independent. However, those with severe traumatic brain injury can remain addicted for life. The families of patients who fall into this category need support. Home care services should be provided. In addition, follow-up by appropriate rehabilitation centers, re-hospitalization and lifelong

support programs can be implemented if necessary. The rights of the disabled people in our country are secured by the Prime Ministry Circular No. 2002/58. Arrangements for individuals with TBI are also covered in this circular.



### 2 Policy recommendations

#### **Spain**

The recommendations that are detailed below are based on the incidence and prevalence of brain damage in Spain, the extraordinary severity of its effects in all areas (motor, cognitive, behavioral, emotional) and importance, in terms of efficacy and efficiency, of a rehabilitation intervention as early and planned as possible and in the notorious lack of health and social resources in our country, aimed at the comprehensive and intensive rehabilitation of people with brain damage.

- **1.** Adopt the relevant initiatives for the preparation of an **epidemiological study** on the incidence and prevalence of brain damage in Spain be assessed, in order to plan for resources, design and development of the necessary actions in matters of prevention, prevention and social integration.
- 2. Study the necessary measures to **improve the health care** provided by the National Health System to patients affected by brain damage through:
  - a) the possible adoption of agreements in coordination with the competent administrations in the field of social services, to respond to the needs of the segment of the population that suffers from brain damage that has occurred and that requires the integral provision of health and social measures.
  - b) elaboration of a **consensus document**, about the clinical criteria and guidelines that should preside over the specialized, integral, intensive and multidisciplinary treatment required by people with supervening brain damage.
  - c) assess the feasibility of **creating specific and national reference units** for people with moderate-severe involvement, when the clinical criteria so advise and their care in the family home is not possible.
  - **d)** promote the knowledge-based quality through **research and other academic activities** aimed at training and information of professionals of the National Health System related to the care of brain damage and to patients and family members.
- **3.** The **information given to caregivers** in relation to existing aid should be increased to facilitate their work.
- **4.** It would be necessary to have a socio-sanitary coordination that provides the users and their families of specialized resources for **continuity of care**. It should be included rehabilitation after the acute phase, once life has been saved and there is medical stability, within social services, without forgetting coordination with health. It is a more sustainable model and whose evidence of effectiveness can be verified in CEADAC (Centro de Referencia Estatal de Atención al Daño

Cerebral): 18 years in operation and more than 5,500users who have received programs to promote personal autonomy, managing to improve their situations of dependency.

#### **Portugal**

Over the 10 years of existence and the result of the spirit of cooperation and interconnection between entities in the health public and private departments, government, social, employment, civil society, other NGOs and other entities in the TBI area in other countries, who, on the initiative of Novamente, meet once a year to discuss the state of the nation's TBI in Portugal, it was concluded that there are enormous needs and the possibility of reducing the impact that severe traumatic brain injury causes to the person and family.

The design of a solution is centred on two points:

- **1. Update of the norma** (law/procediments) that defines the guidelines on how to treat and rehabilitate the TBI area of Health. Novamente has asked the formal government to revise it and the secretariat of state has accepted the challenge but has not done it. Novamente is negotiating with this government the revising of this guidelines.
- 2. The main solution is the existence of a **national strategy for brain damage**. A strategy that defines the steps that any professional in any area will have to take into account whenever dealing with a traumatized person or family member, a strategy that indicates a single interlocutor to continue with the family and the traumatized person throughout the recovery process for life, starting from the day of the accident until forever, ensuring that the traumatized person is never left without solutions, ensuring that the specialists in each area give personified and appropriate treatment to that case and work in communicating with other specialists, using a network system and that the rehabilitation and recovery objectives for each person's life is designed and implemented by and with the TCE victim himself, with the support of his family and reviewed whenever necessary.

The strategy is already discussed in general, with Novamente' intervention and round tables creation, but will have to be draw in agreement with different ministries, like the health department, the ministry of health, the social security ministry, the area of employment, and some others.

In addition, an Holistic approach should be mandatory since the acute phase and psychological care should be included for families from the initial moment and for the patient once the coma has been overcomed.

#### **Turquía**

The most important issues that patients with TBI need is the lack of detailed information about the condition of their disease and what their reports cover. Although it is beneficial to **open new rehabilitation centres for individuals with TBI**, the number of centres that will fully meet the needs has not been reached to the sufficient level yet. In addition, the number of

experts and specialized professionals should be increased.

Rehabilitation centres that have been opened in recent years serve with new technological methods, but they are insufficient in total number which may make possible to reach all TBI patients. It is a general expectation that the number of well-equipped and quality places such as the Veterans Physical Therapy Centre, which we have heard frequently in recent years. Veterans FTR provides a world-class service today and is among the leading organizations in the world ranking with its service.

It will be useful to **share the content on current issues** for individuals with TBI which is created in Europe in more detail. In this sense, the TOOLS4BRAIN project was useful.

As the Ministry of Family and Social Policies, more active policies should be implemented in our country regarding the rehabilitation and treatment of TBI individuals. It would be beneficial to **evaluate regulations for individuals with TBI separate** from regulations for individuals with disabilities. These individuals should be included in working life with the help of experts. Social awareness programs should be developed to prevent the increased incidence of ABI patients.

Training needs of the employees in the field of TBI should be supported with formal and informal training contents in services carried out under the coordination of the Ministry of Health.



## 3 Good practices

#### **Spain**

#### Good practice 1: IMSERSO (Institute of Elderly and Social Services)

The care for family members and caregivers of patients with ABI should be organized and structured around three main concepts: information, training and support.

- 1. Information about the pathology, its consequences and how to handle them. It can be offered through physical media (guides, books, mobile applications ...) or in person through meetings with family members or informative talks. Additionally, it is important that the professionals involved in the therapeutic process advise on aspects related to the support resources for the family (home care service, financial aid, search for caregivers ...); the adaptation of the environment and acquisition of support products, and labor and legal aspects (processing of the degree of disability, the Law on Dependency, labor and legal disabilities, etc.).
- **2. Training:** includes training in specific skills and abilities of the care of the patient with ABI that will facilitate their daily management. The training must be carried out individually and adapt to the needs that both the patient and their families have in each of the phases of the process. Some topics to be addressed are transfers and mobilizations, hygiene and food, management of behavioral disorders, guidelines for addressing communication problems, etc.
- **3. Family support:** interventions focused on the emotional support of family members/ caregivers through the recovery process. It is essential to start from empathic listening: our clinical experience should allow us to listen, understand and help family members/ caregivers to prioritize needs, develop appropriate coping strategies, adjust expectations and implement relevant changes and modifications to achieve adequate adaptation to the situation. Individualized sessions, family therapy and support groups can be included in the interventions developed.

#### Impact:

- Family care should be approached from a holistic and interdisciplinary perspective. Professionals from different clinical, health and social specialties should address the needs of patients with ABI and their families from their scope of action.
- The family care program must cover the entire recovery process and must be structured based on three basic pillars: information, training and emotional support.
- For its implementation, there must be specialized professionals in the field who also show an empathetic attitude and active listening to facilitate the adaptation of the contents and strategies used to the specific needs of each case.

- It must be dynamic and flexible. It requires a continuous adaptation of the information, training and support provided to the needs of the affected person and their families in the different phases of the recovery process.
- Family care must be personalized and individualized. Beyond the needs of the affected we
  must consider the situation and family dynamics, their coping skills and strategies and the
  social environment. All of this must be re-evaluated at different times in the process to adapt
  the procedures put into operation.
- The training program is aimed at family members and caregivers who do not have technical knowledge a priori. It is essential to regulate the medical and technical terminology used during communication with family members to ensure the understanding of the message.

#### Good practice 2: Defensor del Pueblo

The **report made by the Defensor del Pueblo** analyses the situation of the ABI in Spain. it analyses the socio-sanitary assistance received by those affected in both acute and subacute and chronic phases.

The universal coverage of the public health system, with regard to hospitals and primary care, places people with brain damage and their families before the moment of better and greater attention, despite the differences between different centres, territories, with their achievements and needs to be resolved.

After ABI, the shock of the whole family environment presides over the first moments, when the close one is torn between life and death. The scope of clinical stability and the search for information among physicians are then the family's top priorities. The biggest problems perceived by families regarding the acute phase are in the disinformation and, above all, in the disengagement of the health system at the time of hospital discharge, which gives the family a patient with serious sequelae and needs care Extremely complex (health care, rehabilitation, psychological support, social assistance, legal guidance ...), with hardly any preparation or additional support.

Once the vital risk is over, the patient will **go from the ICU to the hospital ward** where he will remain a variable period of time until his medical discharge. However, the effectiveness to achieve higher survival and stabilization rates does not necessarily imply adequate attention to brain injuries in the hospital. The most experienced approaches in the treatment of brain injury indicate the need to implement a comprehensive rehabilitation approach from the acute phase.

To achieve improved results in the functionality of the affected person, this rehabilitation requires **specific attention and care** adapted to each patient in each of the phases from early stimulation, physiotherapy, occupational therapy, neuropsychology ... to social work.

Unfortunately, there is **heterogeneity between hospitals** in terms of protocols for attention to

brain injury. The critical expression regarding hospital rehabilitation by associations and family members refers to the punctual nature of it - only a few minutes when it takes place - and in addition to the lack of adaptation to the complexity of the sequelae of those affected, especially when they present behavioral problems misunderstood by physiotherapy teams (before which they are ruled out) and neglect of speech and cognitive problems.

The heterogeneity of guidelines in early and basic rehabilitative care is also projected in **informative actions**, beyond medical aspects, especially as regards the role played by social work departments. There is, in general, an informative inadequacy, in the context of family shock. The improvement actions should include information adaptation programs. The information must include medical aspects related to the diagnosis, prognosis and care of the patient as well as information of a welfare and social nature.

We must consider the **contextual dimensions of this communicative intervention**: the extreme commotion that the family is going through, the imminence of hospital discharge, which usually involves the transfer to the environment of a clinically stabilized patient but with severe sequelae and the absence of accessible resources for rehabilitation and social integration

Only **specialized rehabilitation services** carry out medium-term work with families that can prepare them to address the new situation, through a process of gradual elaboration in which the search for alternatives in different areas: from understanding cognitive and behavioral changes, home adaptation, social services in the environment. In the absence of this attention to emotions as part of the process and context, family trauma is multiplied with greater stress, feeling of helplessness, the family to whom it is assigned, often without other support and as "cured" or "chronic", without that another social or social health network maintain continuity in support in the face of such serious consequences.

#### Good practice 3: Estrategia para la atención al DCA en la Com. Valenciana

In order to establish the coverage policies, it is proposed to comply with the following general principles of assistance:

- a) **Equity:** the attention to the group of patients with ABI should reach in the same way and with the same level of opportunities to those who meet the criteria and requirements indicated in the document, making them candidates to receive such assistance. This opportunity should not be mediated by other variables such as age, sex, place of residence, etc ...
- b) **Sustainability:** care for patients with ABI should provide value to people and society in general that justifies its costs.
- c) Quality of assistance based basically on:
  - Safety: ABI care must include diagnostic and therapeutic measures considered safe for the

individual clinical situation in which each patient is.

- Effectiveness: the diagnostic and therapeutic measures to be applied to patients should be based as far as possible on those interventions considered as effective (Evidence-Based Medicine) and at the same time it is considered that they are applicable in clinical practice, waiting of its application a clinically beneficial effect.
- Integration of assistance / Continuity of care / Coordination / Organization. Care
  for people affected by ABI is a complex process and generally prolonged over time, in
  which many people intervene and in different areas and places of care. The integration
  of care, continuity of care and coordination among the entire group of professionals,
  devices and care settings is a necessary element for this care to be successful and
  satisfactory for all participants.

The Care Integration corresponds to the coordination in the transversal and longitudinal axes, as well as among the agents and devices in the health field (integration of the health resources), in addition to the coordination between agents, devices, areas and resources between different care sectors by example between health and social, training and employment, education, etc ... In this context, coordination between health and social or community resources is especially relevant: families, patient associations, municipal corporations and voluntary associations.

#### **Portugal**

#### Good practice 1: Estrategia Nacional de Saude para o doente oncológico

One of the good practices found is the way in which several areas are integrated and treat the sick person with cancer, integrating all the specialists involved in treatments, social rights and other entities that help the patient and family, putting them in permanent contact and with a common goal defined by the patient with the support of doctors and family.

This practice was designed and implemented by public health and implies the existence of a responsible for each case/cancered person, never leaving that person without support in any area of their life.

#### Good practice 2: Serviço de Apoio e Mesas Redondas Novamente

The existing good practice related to TBI and family has been the mission of association Novamente and its greatest support service to the family: since the accident, **Novamente talks to the family offering information** about what is TBI, how to deal with the coma phase, how to manage the rest of the family, jobs and contracts that the person with TBI had, deal with insurance, how to talk to medical specialists, how to get in the transition from one

medical department to another, in a hospital to a rehabilitation centre, coherence and communication among professionals, how to deal with the person victim of severe TBI in each phase, how to manage crises and family breakdowns and avoid them, how to prepare for the return home and how to live with a person with a disability and train them as much as possible to be autonomous and participative in society.

This practice includes and encourages **dialogue with specialists** in rehabilitation and reintegration with the TBI person and the family. Awareness to professionals about the impact of TBI on the family and the role that a professional can play in reducing this impact, training on the importance of networking and with common objectives (rehabilitation and reintegration into a holistic method). It implies sensitization and awareness to civil society about the impact of a TBI so that this TBI persons can be better understood by anyone in the society.

In this good practice, there is the work of Novamente focussed in the creation of a network of stakeholders and the enhancement of existing solutions. There is thus a gap: there is a lack of products that do not exist in the country, such as the existence of a specialized coach to accompany the return to active life, the professional career coach, a personal assistant, support to the family in terms of health, life training and hygiene support when the person with TBI is very dependent and returns home.

#### **Turkey**

In the rehabilitation process of individuals with TBH, it is necessary to raise the awareness of the family or caregiver and to provide the necessary support. Trainings should be provided to the family or caregiver to make arrangements for individuals with TBI to facilitate their daily lives and maintain their lives. In addition, it is necessary to give information about the legal rights and similar applications of TOOLS4BRAIN that they can benefit in health.

In Turkey, specific studies for individuals with TBI, are handled under the heading of people with disabilities in a wider perspective, and in all studies or projects, individuals with TBI are included in the subtitles.

Good practice 1: Ministry of Family, Labour and Social Policies, Disability Support Program (EDES)

**Goal:** Training of disabled care personnel and improving the care conditions of the elderly and disabled people within the scope of EDES, conducted by the Ministry of Family, Labour and Social Policies, General Directorate of Disabled and Elderly Services (EDES).

**Content:** EDES creates an opportunity in the field of disability to solve the problem at its source and contributes to the development of the cooperation between public institutions and

organizations, local administrations, and non-governmental organizations in the region. EDES is a program that is prepared and implemented by public institutions at the local level, especially in provincial administrations, municipalities, universities, and professional institutions that are public institutions, and that provides local ownership on disability.

**Effect:** Raised awareness about disability by activating local dynamics, Aimed to contribute to the psycho-social and medical rehabilitation of the disabled and the prevention of disability. http://kirsehir.meb.gov.tr/www/engelliler-destek-progra-mi-edes-kapsaminda-7-proje-kabul-gordu/icerik/703

Good practice 2: The first "Accessibility to History Without Barriers" project of the Presidency under the coordination of Çanakkale Governorship within the scope of the "Support Program for the Disabled" developed by the Ministry of Family, Labour and Social Policies, General Directorate of Disabled and Elderly Services

**Goal:** The purpose of this project is to enable individuals with disabilities to access history without disabilities. Çanakkale Visually Impaired Association, was one of the stakeholders of the social responsibility project, was realized under Çanakkale Family, Labour and Social Policies Provincial Directorate coordination with the participation of Çanakkale Provincial Directorate of National Education.

**Content:** To ensure that all the personnel in the relevant institutions are subjected to necessary training and receive awareness and sensitivity training. Social inclusion activities were carried out with these trainings.

First, its main purpose is to enable individuals with disabilities to access history without facing any barrier. Considering the fact that each individual does not have enough budget to visit the historical area, besides, considering that the cost of coming with a sign language translator and accompanying is high, various studies are carried out within the scope of this exemplary pilot project. In this context, with the introduction videos, some disabled people were provided with some sign language interpreters, Braille alphabet embossing techniques and audiobooks.

impact: With this project, the target audience with disabilities has been included in social life and communication, interaction and awareness have been increased with the target group without disabilities. In this context, training workshops and social inclusion activities continue. <a href="https://catab.ktb.gov.tr/tr-196345/engelsiz-erisim.html">https://catab.ktb.gov.tr/tr-196345/engelsiz-erisim.html</a>

## Good practice 3: Regulation on the organization and duties and procedures of the Ministry of Family, Labour and Social Policies, Directorate General for Disabled and Elderly Services

#### Goal:

- To carry out and coordinate the Ministry's preventive, preventive, educational, developer, guidance, and rehabilitative social work activities for the disabled and the elderly.
- To coordinate efforts to prevent disability, education of the disabled, employment, rehabilitation, participation in social life by benefiting from human rights without discrimination and determination of policies and strategies at national level on other issues, to implement, monitor and evaluate the determined policies and strategies.
- To investigate the problems and solutions of disabled people, to prepare and implement suggestions and programs for the development of the application in this regard.
- To make researches and research on disability related issues, to prepare and implement projects.
- To carry out the works related to the disabled identity cards prepared to be used exclusively for the rights granted to the disabled and the services provided.
- To determine and comply with the principles, procedures and standards regarding social service activities carried out by public institutions and organizations, voluntary organizations, and real and legal persons towards the disabled and the elderly.
- To organize scientific events at national and international level, to prepare publications that enlighten the society, to conduct educational activities and projects, to organize national and international congresses, seminars, councils, and similar events.

**Effect:** With the prevention of disability, the education, employment, rehabilitation of people with disabilities, their participation in social life by benefiting from human rights without discrimination, and the determination of policies and strategies at national level on other issues were coordinated, determined policies and strategies were implemented, awareness was raised, and monitoring and evaluation of the studies were provided. <a href="https://kms.kaysis.gov.tr/ho-me/goster/24606?aspxautodetectcookiesupport=1">https://kms.kaysis.gov.tr/ho-me/goster/24606?aspxautodetectcookiesupport=1</a>

## 4 Fact Sheets. Summary in data

#### **Spain**

https://drive.google.com/open?id=1nO1IUY6urDD4NMZFVM6hD-NC8qiCKMY9

https://drive.google.com/open?id=1X7OfwlVb3rkR1U66nGxwMpsncAJyl2PD

- Daño Cerebral Sobrevenido en España: Un acercamiento epidemiológico y sociosanitario (Informe del Defensor del Pueblo, 2005). State report prepared by the Defensor del Pueblo that analyses the situation of the ACD in Spain. It offers an epidemiological approach contributing to the incidence and prevalence of the different etiologist that can cause brain damage. In addition, it analyses the preventive measures that are being carried out, as well as the socio-sanitary assistance received by those affected in both acute and subacute and chronic phases.
- Modelos de Atención a las Personas con Daño Cerebral (IMSERSO, 2007). Report prepared under the protection of IMSERSO in order to facilitate the community of professionals and agents involved in the design of policies and the provision of services to people with brain damage an important instrument to achieve standardized care models in the whole Spanish state.
- Guía Clínica de Neuro-Rehabilitación en Daño Cerebral Adquirido (IMSERSO, 2013). It is an evidence-based clinical guide that has been developed by a multidisciplinary team of professionals dedicated to the neurorehabilitation of people with acquired brain damage (ACD) under the financing of IMSERSO. The work of review of the scientific literature, analysis of the recovered evidence and elaboration of the recommendations has been carried out in a coordinated manner between the authors between January 2012 and June 2013.

#### **Portugal**

Studie about the TBI impact on families and victims in Portugal, statistics, resume of stakeholders' meetings related to the TBI state of the art in Portugal (mesas Redondas) and Guides (GUIA) to help people that live with brain damage, families and formal caregivers.

- TBI Statistics ApresentaçãsoGiria final
- Statistics modificada 24092016
- Statistics Relatorio ESP
- Mesa Redonda I
- Mesa Redonda II
- Mesa Redonda III.
- Mesa Redonda IV
- Mesa Redonda V
- Mesa Redonda VI

- Mesa Redonda VII
- Mesa Redonda VIII
- Mesa Redonda IX
- · Guia Reabilitação após dano cerebral
- Guia para as familias
- · Guia regresso à vida

https://drive.google.com/open?id=1a7jjohEVOD1QWtNhYtQmnahzyUOA wp4

#### **Turkey**

- · Prime Ministry, Regulation on Disabled People.
- Official Newspaper including the Regulation on the organization and duties and procedures of the Ministry of Family, Labour and Social Policies.

https://drive.google.com/open?id=1k9M2-msZ0jU-VEecVxCjjljhSD86DMaN









SERVICIO DE NEURORREHABILITACIÓN





