



FUNDACIÓN SIN DAÑO

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FUNDACIÓN SIN DAÑO is Spanish non-profit organization that aims to develop research and study of unexpected brain injury treatment prevention, especially during childhood and youth, it also aims to assist and help people that has been affected and their families.

The Fundación carries out actions that help to improve the life of those who suffer from unexpected brain injury, especially during childhood and youth, as well as in their family environment, promoting programs that help them in every aspect: cultural, educational, sanitary, hygienic, familial, social and any other that may be beneficial for the people mentioned.

The scientific committee is composed of 9 health professionals that constitute a team, they work in different public hospitals in Madrid: the Neuropediatricians María Luz Ruiz Falcó (Niño Jesús Hospital of Madrid), Pedro de Castro (Gregorio Marañón Hospital) and Rogelio Simón (12 de octubre Hospital); the doctors encharged of the neuro rehabilitation Mercedes Martínez Moreno (La Paz Hospital), Olga Arroyo Riaño (General University Hospital Gregorio Marañón) and Inés Folgado Torranzo (Beata María Ana Hospital); the Neuro-therapist Beatriz Gavilán Agustí (Beata María Ana Hospital), Sergio Lerma Lara physiotherapist and Dean of La Salle Faculty of Health Sciences and Ignacio Martínez Caballero orthopedic surgery specialist. (Niño Jesús Hospital).

Fundación Sin Daño is part of the following organizations:

La fundación es miembro de las siguientes organizaciones:

- DCA PLATFORM <https://www.plataformadca.org> which aims to raise awareness between all social agents to bring about structural changes that favour the appropriate care and treatment of people with unexpected brain injury (DCA in Spanish).
- CHILDREN'S PLATFORM <http://plataformadeinfancia.org/>. Alliance of non-profit entities that works to achieve full compliance with the rights of children and adolescents.
- FEDACE Spanish Federation of Cerebral injury <https://fedace.org/> Groups 41 entities with more than 10,100 members, defends the rights of people with unexpected brain injury and their families.

THE RIGHT TO HEALTH OF CHILDREN WITH BRAININJURY AND RELATED DISEASES

Organization of the Spanish National Health System

1. Article 43 of the Spanish Constitution of 1978 establishes the protection of the health and health care of all citizens.
2. The Spanish Constitution of 1978 designed a territorial organisation of the State that has made it possible for the Autonomous Communities to assume competences in matters of health.
3. Under the protection of the constitutional provisions and the respective Statutes of Autonomy, all the Autonomous Communities have assumed powers in matters of health planning, public health and management of health services.
4. It is the responsibility of the General State Administration to establish the bases and general coordination of health, foreign health and international health relations and agreements, as well as legislation on pharmaceutical products.
5. The National Health System is the coordinated set of the Health Services of the State Administration and the Health Services of the Autonomous Communities that integrates all the health functions and benefits that, in accordance with the law, are the responsibility of the public powers.
6. This organizational model must be a mean of bringing health care management closer to the citizen, thereby providing guarantees of equity and quality.
7. Coordination and cooperation between public health administrations must be strengthened as a means of ensuring citizens' right to health protection.
8. The Convention on the Rights of the Child considers the full and harmonious development of childhood as a collective responsibility of all public institutions.
9. This international convention indicates the primary interest of children in all actions carried out by social welfare institutions, courts of law, administrative authorities or legislative bodies.
10. The International Convention on the Rights of Persons with Disabilities provides a clear mandate for the maximum development of the potential, personality, talents and creativity of children with disabilities or at risk of disabilities.
11. This Convention establishes a direct mandate on the right to health of persons with disabilities by stating that "health services specifically needed by persons with disabilities as a result of their disability shall be provided, including early detection and intervention where appropriate, and services designed to prevent and minimize the onset of new disabilities, including children and older persons".

12. Act No. 1/2013 of 29 November on the rights of persons with disabilities and their social inclusion contains in several of its articles mandates aimed at the prevention of impairments and the intensification of disabilities (article 11), care, treatment and psychological guidance (article 15), comprehensive care (article 13), habilitation and rehabilitation (article 14), social protection (articles 49 and 50) and affirmative action measures (articles 67 and 68).

13. However, in spite of these legal bases, the right to full development of minors with disabilities is a right still to be reached at its most guarantee level, which commits us to vindicate, work and innovate, in a continuous way, in knowledge, practices and devices at the service of child development throughout its vital stage of growth and throughout all the natural contexts of participation.

14. In relation to the recommendations on the establishment of an inter-ministerial committee or a high-level governmental working group on human rights (131.10, 131.11 and 131.12 - A/HRC/29/8), consideration should be given to the participation of representatives of autonomous communities and municipalities, as they have important competencies in the areas of education, health and social policy, among others.

15. Full implementation of recommendations 131.130 (Continue efforts to fully guarantee the economic and social rights of all vulnerable groups, including immigrants and persons with disabilities); 131.136 (Ensure access to health care and effective health coverage for all persons, without discrimination); 131.140 Facilitating access to health services and education for children belonging to the most vulnerable groups; 131.152 (Ensuring that all persons with disabilities are protected against discrimination and have equal opportunities regardless of their level of disability); and 131.155 (Intensifying its efforts to further improve the situation regarding the protection of the rights of persons with disabilities) requires taking and implementing measures to ensure that all persons with disabilities have access to health and education services; 131.152 (Ensuring that all persons with disabilities are protected against discrimination and have equal opportunities regardless of their level of disability); and 131.155 (Intensifying its efforts to further improve the situation regarding the protection of the rights of persons with disabilities).

I. Pharmaceutical Copayment

16. The current model of pharmaceutical copayment and pharmaceutical products should be changed to expand the group of groups that currently do not have access to free health care, with the aim of guaranteeing their human right to health.

17. It is proposed to amend Articles 101 and 102 of Royal Legislative Decree 1/2015, of 24 July, approving the consolidated text of the Law on Guarantees and Rational Use of Medicines and Health Products in order to expand the group of groups exempt from pharmaceutical contribution.

18. The exemption from pharmaceutical and health product co-payments must include at least the following groups: 1) persons with disabilities who are not exempted for other reasons; 2) persons with an income of any nature that does not exceed a minimum

threshold to be determined on the basis of poverty risk indicators; 3) persons with chronic illnesses, with special reference to minors, including rare or rare illnesses, degenerative illnesses and oncological pathologies; 4) persons in other exceptional circumstances that merit individualized recognition of the exemption benefit.

II. Minors and adults that suffer from unexpected or congenital brain injury. Right to cognitive and behavioural rehabilitation.

19. According to the Spanish Federation of Brain injury statistics there are 420.000 people (nearly 1% of Spanish population) affected by unexpected brain injury. Every four minutes in Spain there is an admission for brain injury, of which, more than 300.000 will be affected forever. In children the incidence of unexpected brain injury is 191 out of 100.000. On the other hand, the number of people with Cerebral Palsy (congenital brain injury) in Spain is 120,000, with Cerebral Palsy being the most common cause of disability in children. (Source: FEDACE and Fundación AINDACE, Ayuda a la Investigación del Daño Cerebral).

20. Taking into account the statistical data on numbers of people affected by brain injury and the exponential increase in cases, the cognitive and behavioural rehabilitation of people -both minors and adults- with brain injury should be included in the portfolio of common services of the National Health System.

21. In order to adequately care for people with brain injury, the cognitive and behavioral rehabilitation included in the portfolio of common services of the National Health System should explicitly define the professionals and therapists needed in the field of neuropsychology and clinical psychology.

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20. Taking into account the statistical data on numbers of people affected by brain injury and the exponential increase in cases, the cognitive and behavioural rehabilitation of people -both minors and adults- with brain injury should be included in the portfolio of common services of the National Health System.

21. In order to adequately serve people with brain injury, the cognitive and behavioral rehabilitation included in the portfolio of common services of the National Health System should explicitly define the necessary professionals and therapists in the field of neuropsychology and clinical psychology.

III. Right to health of minors with brain injury. Pediatric neurorehabilitation units

22. In order to guarantee comprehensive care for children with brain injury and related diseases, regardless of the autonomous community in which they reside, paediatric neurorehabilitation units for children should be established to cover the entire national territory.

23. These paediatric neurorehabilitation units must attend to all minors with functional sequelae, both physical and cognitive and behavioural, derived from neurological diseases or injuries, whether of congenital or acquired origin.

24. Pediatric neurorehabilitation units shall be equipped with the necessary material means and a transdisciplinary team composed at least of a neuropaediatrician, rehabilitation physician, physiotherapist, speech therapist, occupational therapist and neuropsychologist or clinical psychologist. IV. Atención temprana

25. There are currently significant differences between autonomous communities in terms of early care and availability of resources. A law should therefore be adopted at the national level to ensure access to universal, free, comprehensive and quality early care for all children in need and their families.

26. As stated by the Ombudsman in his annual report for 2018, the implementation of appropriate instruments and protocols for coordination between the health, educational and social spheres is necessary for the processing of the assessment and allocation of these resources, including those over six years of age, so that, after assessment, they can continue to have access to the resource.

27. The demand for early care is greater than the resources available, so early care resources should be increased to serve the entire population from 0 to 6 years in need.

V. Rights of critical pediatric patients in states of minimal consciousness or unresponsive wakefulness syndrome.

28. The progress of the medical sciences leads to a greater survival of patients with pathologies that until now were considered unviable. Among them are to be considered those that present clinical pictures of unhappy prognosis.

29. A model of comprehensive care for minors with unresponsive wakefulness syndrome and minimal awareness should be implemented in order to achieve basic levels of specialized care that ensure a quality of life adjusted to their reality.

30. The objective of the therapeutic intervention will be to establish a correct diagnosis and achieve the maximum level of stabilization and recovery, including the improvement of consciousness and function.

31. The demand for care that does not focus exclusively on the physical well-being of the patient, but also addresses their psychological and social needs. The undoubted negative effects on the child of isolation from his or her environment indicate that care for the critical child must be extended to the family nucleus.

32. This implies the physical and functional structuring of units in an environment adapted to the child's psychology, where natural light guarantees the preservation of basic circadian rhythms, allowing an open regime of visits so that parents can stay as long as possible with their children, as well as the provision of dignified spaces for relatives that provide a minimum of privacy.

33. A programme of hospitalisation or home therapeutic care should be implemented and provided by medical staff and home helpers. VI. Paliativos pediátricos

34. In recent years, numerous regional palliative care plans have been published. Consensus has been reached on a care model based on comprehensive care for the needs of patients and families and also on an organizational model, with a basic level aimed at all patients and a specific level for those with greater complexity.

35. The map of palliative care structures and resources shows an increase in recent years. However, there is still a significant heterogeneity of structures and resources, with differences in accessibility and equity, and a comprehensive plan for paediatric palliative care should be approved at the national level.

36. In addition, the necessary specific resources (human, structural, organizational) should be implemented to respond to the needs for home and hospital care of the entire child population in all the autonomous communities under conditions of equity, equality and quality.

Transition to Adult Units

37. Transitional consultations should be created in all paediatric services of public hospitals to ensure an adequate therapeutic relationship with the different adult specialties with special attention to the transition from oncological, neurological and serious mental health disorders.

VIII. Eating Disorders Units

38. Resources for eating disorders should be expanded to ensure better access to both outpatient and inpatient benefits.

IX. Rare and neurodegenerative diseases

39. It is estimated that in Spain there are more than 3 million people with rare diseases, according to the Spanish Federation of Rare Diseases.

40. An average of 5 years has elapsed since the first symptoms appeared and the diagnosis of a rare disease was obtained.

41. Research into rare diseases, neurodegenerative diseases and orphan drugs should be encouraged, financial resources increased and coordinated.

An action protocol should be developed, in coordination with all public administrations involved, to facilitate a comprehensive assessment of the socio-health needs of people affected by a rare disease and their families.

X. School nursing

43. It is essential to extend the presence of specialised health professionals in all educational centres, who work in a coordinated manner with primary and hospital care, in order to attend not only to the health needs of students with disabilities, but also to those with chronic and permanent ailments or who require continuous health care over time.

XI. Caregivers

45. social policies must be designed to provide comprehensive care for the health of dependent disabled persons and the health and quality of life of their carers, in order to avoid reducing an increasingly social problem to the family and individual level.