

# ANED 2014 Task 3 - Accessibility to Healthcare

**Country:** Spain

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The <u>Academic Network of European Disability experts</u> (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the synthesis report on <u>Access to healthcare</u> in European Countries.







### **Discrimination**

A recent report of the EU Agency for Fundamental Rights (FRA) groups discrimination in the context of health care into six categories: delay of treatment; refusal of treatment; lack of dignity and stereotyping; malpractice and poor quality of care; lack of informed consent; and harassment. An additional dimension could be liability to violence or physical harm. All of these could potentially be applied to people with disabilities.

1. Does non-discrimination law prohibit discrimination in the context of access to healthcare and disability? If so, is there an obligation to provide a reasonable accommodation to individuals with a disability? Please provide references to relevant legislative provisions and, if available, case law. Other sources, such as guidance notes and Codes of Practice may also be relevant with regard to addressing discrimination, and should also be mentioned. In addition, you should include reference to (and brief explanations of the findings of) any studies or reports relating to disability based discrimination in the context of health care.

General accessibility requirements have been mandatory since the Law 51/2003 of 2 December<sup>2</sup> on equal opportunities, non-discrimination and universal accessibility for people with disabilities. Every patient has the right to receive information on their health and access to medical records, as well to obtain a copy of the data. The State and the Autonomous Communities should guarantee access to these records to users with disabilities (Law 41/2002).<sup>3</sup> Law 14/1986 of 25 April, on General Health<sup>4</sup> states that every patient has the right to receive information about the health services they can access and the necessary requirements for use. The information must be made available in appropriate formats, following the rules set by the design for all principle,<sup>5</sup> so that they are accessible and understandable to people with disabilities

 $\frac{http://www.grupofundosa.es/sites/pregrupofundosa.epresentaciones.net/files/Resumen\%20explicativo \\ \underline{\%20LIONDAU\_en.pdf}.$ 





<sup>&</sup>lt;sup>1</sup> European Union Agency for Fundamental Rights (FRA), Inequalities and multiple discrimination in access to and quality of healthcare, 2013.

<sup>&</sup>lt;sup>2</sup> English summary at: <a href="http://www.grupofundosa.es/sites/pregrupofundosa.es-presentaciones.net/files/Resumen%20explicativo%20LIONDAU\_en.pdf">http://www.grupofundosa.es/sites/pregrupofundosa.es-presentaciones.net/files/Resumen%20explicativo%20LIONDAU\_en.pdf</a> Full Spanish version is available at: <a href="https://www.boe.es/buscar/act.php?id=BOE-A-2003-22066">https://www.boe.es/buscar/act.php?id=BOE-A-2003-22066</a>.

<sup>&</sup>lt;sup>3</sup> Available at: https://www.boe.es/buscar/act.php?id=BOE-A-2002-22188.

<sup>&</sup>lt;sup>4</sup> Available at: https://www.boe.es/buscar/act.php?id=BOE-A-1986-10499.

<sup>&</sup>lt;sup>5</sup> The concepts of "design for all" and "universal design" are quite similar. Law 51/2003, of December 2, on equal opportunities, non-discrimination and universal accessibility for people with disabilities, considers "Design for All" as: a process through which spaces, processes, goods, products, services, objects, instruments, devices and tools are conceived and planned from the outset to be used by all people and as widely as possible. That law defines "Universal accessibility" as: a condition to be met by all places, processes, goods, products and services, together with all objects, instruments, tools and devices, so that they are understandable, usable and practical for all, safely and comfortably in the most autonomous and natural form possible. This presupposes a design strategy for all and should be understood without prejudice to the reasonable adjustments that should be made. An English summary version of the Law can be accessed from:



(art.10). There are no laws specific to the accessibility of medical records, other than the general laws on Universal Accessibility requirements. However, since the interface for the HCDSNS (Electronic Health Record System) is the Internet, the existing Web accessibility standards apply as well. Since access to medical records is through web pages and there are already rules for Web accessibility, there are no specific accessibility rules just for medical records.

According to Spanish Law, complaints and claims can be submitted to the Permanent Specialised Office, the Ombudsman, and their counterparts at regional level, as well as to competent public authorities in regard to equal opportunities, nondiscrimination and universal accessibility for people with disabilities. In addition, and according to the General Law on Health,6 each Autonomous Community has its own Patient Advocate who is responsible for defending the rights of people in relation to their health.

LAW 41/2002, of 14 November, regulating patient autonomy and rights and obligations of clinical information and documentation, mandates that (fourth Additional Disposition): The State and the Autonomous Communities, shall adopt detailed regulations to guarantee patients or users with special needs related to disability, the rights to autonomy, clinical information and documentation covered by this Act.

Law 16/2003 of 28 May on Cohesion and Quality of the National Health System provides in Article 28 that the accessibility of schools, health services and benefits for the disabled is a quality criterion to be guaranteed by the National Health System. The newly created health centers must comply with the rules in force in the promotion of accessibility and the removal of barriers of all types that apply to them. The government must promote the removal of barriers in centers and health services that present obstacles for users with mobility or communication issues.

Paragraph 2 of Article 3 of Law 16/2003, has been changed according to the Law 26/2011 of 1 August, for adaptation of laws for the International Convention on the Rights of Persons with Disabilities. Now, the paragraph states that the government will focus their actions on health by incorporating active measures to prevent discrimination of any group of people who for cultural, linguistic, religious, social or disability reasons, be particularly difficult to effective access to health services of the National Health System.

Royal Legislative Decree 1/2013, of 29 November, <sup>7</sup> approving the revised text of the General Law on the Rights of Persons with Disabilities and its social inclusion. Its Article 10, Right to protection of health, states that the Government must develop the necessary actions to promote access for persons with disabilities to services and health-related benefits equal to other citizens.

<sup>&</sup>lt;sup>7</sup> Available at: <a href="https://www.boe.es/buscar/act.php?id=BOE-A-2013-12632">https://www.boe.es/buscar/act.php?id=BOE-A-2013-12632</a>.



<sup>&</sup>lt;sup>6</sup> Available at: <a href="https://www.boe.es/buscar/act.php?id=BOE-A-1986-10499">https://www.boe.es/buscar/act.php?id=BOE-A-1986-10499</a>.



As detailed by Pérez Bueno (2004). *Plan integral de Salud para las personas con discapacidad* [Comprehensive Health Plan for People with Disabilities]. Madrid: CERMI. Under the agreement the Inter-Territorial Council of the National Health System, the Ministry of Health and health officials of the Autonomous Communities, in 2004, approved the Comprehensive Health Plan for people with disabilities. The Plan specifies the following goals (1) Research, (2) Improving the quality of public health care and public health benefits for people with disabilities. (3) Adequacy of training of human resources of the National Health System (NHS) to meet the needs of people with disabilities, (4) Adaptation of the health information system with the inclusion of specific information on persons with disabilities from the perspective of health: rights and responsibilities, self-care practices, health care utilization and ability to make suggestions about the above. (5) Participation of people with disabilities and their families in the NHS

Despite the above, it is worth mentioning a recent study by Muñoz, Fernández, Belinchón, Sellán, Días, Hernando, & Muñoz, (2014). *Intellectual disability and health:* rights, inequality, evidence and proposals. Madrid: FEAPS.

The study by Muñoz et al., (2014) states "People with severe intellectual disabilities have more barriers to accessing health care services and have worse health issues than general population". The study reveals that there are alarmingly low rates of visits to medical specialists by this group of people. Taking as an example the ophthalmologist, it was found that more than 40% of the people in the sample used glasses but only 13% went to the ophthalmologist. The data indicate that this also applies to other medical specialties such as psychiatry and that, although there is a sufficient number of public and private health services in Spain to serve people with intellectual disabilities (ID), as well, these services also: (1) are not accessible for people with cognitive or physical disabilities (especially those with more severe degrees of disability). (2) Services do not guarantee the absence of discrimination. Authors claim that there are countless examples of direct and indirect discrimination by public health services and by the health state laws. Economic decisions arising from the current crisis, and especially actions such as pharmaceutical co -payment, are beginning to limit the accessibility to health services for economic reasons (which

España"((http://www.mspsi.gob.es/profesionales/saludPublica/prevPromocion/promocion/desigualdad Salud/docs/Propuesta\_Politicas\_Reducir\_Desigualdades.pdf).





<sup>&</sup>lt;sup>8</sup> The application of current pharmaceutical copayment Spain entered into force in July 2012 (RD 16/2012, of 20 April: <a href="http://www.boe.es/diario">http://www.boe.es/diario</a> boe/txt.php?id=BOE-A-2012-14695). There are some variations in the forms of payment across Autonomous Communities. From 1 January 2014 the maximum payable by pensioners and their beneficiaries for drugs were updated. Pensioners must pay 10 percent of the price of drugs. Meanwhile, active workers pay a percentage depending on their incomes. The different Autonomous Communities have implemented far differently; some communities have waived their application while others applied it in a wrong way and are returning the money raised by this measure. There are very critical voices on the grounds that such measures are increasing social inequalities in health

<sup>(</sup>https://www.diagonalperiodico.net/blogs/javierpadillab/gobierno-espana-aumentando-desigualdades-sociales-salud.html). These voices claim that such actions are contrary to the report prepared in 2010, of the Commission to Reduce Social Inequalities in Health in Spain "Moving towards equity: proposal of policies and interventions to reduce social inequalities in health



especially negatively affect individuals and families with a member with disability). Also, -they continued-, there is clear evidence of direct discrimination by private insurers, as proposed in the document "Evaluation of Discrimination of Persons with Disabilities in relation to the insurance sector" (Pérez Bueno, 2004). Access to information for people with ID is often not guaranteed. Also, their right to confidentiality is often violated (e.g., patient clinical information is usually given to anyone, even when the patient is legally competent, without their prior authorization). (3) Health professionals recognize that they are not adequately trained to work with this population, so that health services do not meet the quality standards for people with ID.

In this document, the authors made a series of recommendations for overcoming inequalities: Towards a model of good health care for people with ID.

Recommendations include the following: (1) promoting effective equality of opportunity for people with ID and the elimination of discriminatory situations, consistent with the UN Convention on people with disabilities. (2) Promoting a comprehensive health plan for people with ID. This plan must involve a comprehensive response to their needs in the field of health and effective equality of opportunity and accessibility. In addition, this plan should be developed with the active participation of organisations representing the collective. Muñoz et al., (2014) also mention that although, in 2004, the Spanish Committee of Representatives of People with Disabilities (CERMI) developed a "comprehensive health plan for people with disabilities," that included 17 actions to improve health care for people with disabilities, the specific needs of people with ID were not well reflected. Instead, Muñoz et al., (2014) propose that the plan should include things like:

- Detailed analysis of the situation of women with ID as they may be subject to multiple forms of discrimination on grounds of gender, disability and ill-health.
- Detailed review of the state of health care for people with ID in rural areas and designing effective interventions to achieve equal opportunities for them, wherever they live.
- Designing a Comprehensive Policy on Universal accessibility and removal of architectural, attitudinal, cognitive and communication barriers for people with ID in healthcare. This policy should promote the effective development of specific actions.
- Elimination of administrative and bureaucratic mechanisms and provision of facilitators for people with ID (technical, specific professional support, etc.)
   Restrictions.
- Guarantee access to health information, which involves: (a) ensuring both the presentation of information in an understandable format for people with ID and the removal of barriers of all kinds in the centres and procedures in the health field. (b) Facilitating the training of administrative and medical staff on universal accessibility, communication and understanding. (c) Ensuring access to any information relating to rights as patients and users of the health system, medical history, and documents and procedures to provide informed consent.







- Ensure initial and continuing education of health professionals and social services on the health of people with ID, in order to prevent disease or to recognise them as soon as they appear and properly treat them.
- Raise awareness of health professionals about the idiosyncrasies and peculiarities of people with ID in order to eliminate prejudices and stereotypes.
- Design a universally accessible system for emergency services that allows anyone with ID or their families have easy access and communicate with them.
- Promote public awareness campaigns for the general population, through education campaigns aimed at eliminating prejudices, stereotypes and other attitudes that undermine the right of people to be equal, thus promoting respect for and coexistence with people with ID.
- Encourage research on the health of people with ID in both its epidemiological and clinical aspects.
- Incorporate proper attention to diversity, particularly people with disabilities, as a criterion of quality of the health system.

A recent, and relevant, study published in the Revista Española de Discapacidad by Leturia, Diaz et al. (2014) *Health care for people with disability* (available at: <a href="http://sid.usal.es/idocs/F8/ART20432/leturia.pdf">http://sid.usal.es/idocs/F8/ART20432/leturia.pdf</a>) concludes that: "Most people with disabilities need more intense and frequent health care. This is explained by a higher prevalence of some medical conditions as well as a higher risk of comorbidity among people with disabilities. At the moment there are many problems concerning accessibility, under-diagnosis and over-treatment. National health systems should be able to offer all their services adapted to disabled people in order to obtain results for this group that are similar to those of the rest of the population. To achieve this objective it is necessary to improve professional competencies and skills and develop some specific health programmes."

2. Are there legal or other guarantees in place to prevent the discriminatory denial of health care or health service, or the denial of food and fluids on the basis of disability? Are hospitals and medical practitioners required to establish any ethical or monitoring bodies in this respect? Please provide references to relevant legislative provisions and, if available, case law; as well as to any reports or studies on this issue – or campaigns e.g. by disabled people's organisations.

The Law 14/1986 of 25 April, on General Health states that every patient has the right to receive information about the health services they can access and the necessary requirements for use (art. 10). The information must be given in appropriate formats, following the rules set by the design for all principle, so that they are accessible and understandable to people with disabilities.







The Arbitration System on Disability,<sup>9</sup> regulated by Law 51/2003, is the instrument that the government made available to persons with disabilities to effectively resolve complaints and claims arising in the field of equal opportunities, non-discrimination and universal accessibility.

3. Does the law prohibit or allow discrimination / different treatment of persons with disabilities in the context of health insurance? Please provide references to relevant legislative provisions and, if available, case law; as well as any studies or reports on this issue, or campaigns e.g. by disabled people's organisations.

Article 10, Right to protection of health, of the Royal Legislative Decree 1/2013, of 29 November, approving the revised text of the General Law on the Rights of Persons with Disabilities and its social inclusion, states: the government will promote the necessary measures to facilitate access for people with disabilities to services and health-related benefits equal to other citizens. However, as indicated González Carrasco (2013) in her paper: "Discrimination on grounds of disability in the private healthcare insurance - available at: http://www.revista.uclm.es/index.php/cesco - " Article 10 sets out in a general way, the principle of non-discrimination in access to health services, imposing on public authorities a duty to take steps to improve access for people with disabilities to services and services relating to their health on equal terms with other citizens. A specific regulation of the right of access to health insurance or assistance, according to the principle of non-discrimination is required. González Carrasco states that: "the situation of disabled people in relation to access to health insurance is particularly complex because the insurance market tends to confuse the existing situation regarding the "health" of the applicant with the situation of "disability" (p. 447). Article 23, Basic conditions of accessibility and nondiscrimination, establishes the requirement for accessibility of buildings and environments, instruments, equipment and technologies, and goods and products used in the field or area. In particular it addresses the removal of barriers to facilities and the adaptation of equipment and instruments, as well as appropriate signage thereof.

The previously mentioned example can be extended to accessibility requirements to medical equipment. That is, more specific regulations are required.

The study "La discriminación por motivos de discapacidad" [Discrimination based on disability] (A. Jiménez & A. Huete, 2003; <a href="http://riberdis.cedd.net/bitstream/handle/11181/3855/La%20discriminaci%C3%B3n%20por%20motivos%20de%20discapacidad.pdf?sequence=1&rd=0031652377041215">http://riberdis.cedd.net/bitstream/handle/11181/3855/La%20discriminaci%C3%B3n%20por%20motivos%20de%20discapacidad.pdf?sequence=1&rd=0031652377041215</a>) examined a total of 1980 answers (people with disabilities or family members) to a questionnaire about discrimination based on disability that was promoted by the Spanish organisation CERMI. 14,3% (283) of the total people interviewed mentioned "healthcare" discrimination. Most of the concerns were related to physical and

http://www.msssi.gob.es/en/ssi/discapacidad/proteccionDerechos/sistemaArbitral.htm.



<sup>&</sup>lt;sup>9</sup> Information available at:



psychological barriers. In accordance to answers given to open questions, discrimination in healthcare was very serious, related to disrespectful treatment by health professionals and also by their limited knowledge of the reality of disabilities.

4. What opportunities do people with disabilities have to make complaints if they feel they have been discriminated against in the provision of healthcare, e.g. through courts, equality bodies, ombudsman, health authorities? Please identify the option or options available. Please indicate what kind of sanction or remedy can be imposed in cases of discrimination. If available, please give statistics about the number of complaints relating to alleged disability discrimination. In addition, please provide details of any studies or reports on this issue.

According to Spanish Law, complaints and claims can be submitted to the Permanent Specialised Office,<sup>10</sup> the Ombudsman,<sup>11</sup> and their counterparts at regional level, as well as to competent public authorities in regard to equal opportunities, non-discrimination and universal accessibility for people with disabilities. In addition, and according to the General Law on Health, each Autonomous Community has its own Patient Advocate who is responsible for defending the rights of people in relation to their health. In exercising its functions, the Health Advocate may make proposals, recommendations and suggestions.

To our knowledge, annual reports from the Permanent Specialised Office and the Ombudsman do not report any discrimination complaint related to the provision of healthcare.

In the 2013 Report on Questions Answered by the Legal Advisory body of the CERMI (the Spanish Committee of Representatives of People with Disabilities), <sup>12</sup> only 8 questions were about the Health System, and most of them were related to accessibility of services. Other questions were asking for information.

## **Informed Consent and Consent for Medical Experimentation**

5. Please briefly summarise the law relating to informed consent. Does legislation relating to the need for informed consent to treatment refer to people with disabilities in any way, e.g. does it specifically address informed consent of people with intellectual disabilities or people with psychosocial disabilities? Please provide references to relevant legislative provisions and, if available, case law; as well as any relevant studies or reports or campaigns.

Law 41/2002 of 14 November, regulates patient autonomy, rights and obligations to information and clinical documentation governing informed consent. A fourth additional provision relating to disability stipulates that "The State and the

http://www.oadis.msssi.gob.es/en/creacionFunciones/home.htm.

<sup>&</sup>lt;sup>12</sup> Available at: http://www.cermi.es/es-ES/Novedades/Paginas/Inicio.aspx?TSMEIdPub=1684.





<sup>&</sup>lt;sup>10</sup> Currently known as "Office of Attention to DisabilitY", at:

<sup>&</sup>lt;sup>11</sup> Available at: <a href="http://www.defensordelpueblo.es/en/Quienes/Que/index.html">http://www.defensordelpueblo.es/en/Quienes/Que/index.html</a>.



Autonomous Communities should make precide statements to ensure patients or users with special needs related to disability are provided with the rights to autonomy, information and clinical documentation regulated under this Act "

Reports from the Documentary Center of FEAPS.<sup>13</sup> (<a href="http://www.feaps.org/archivo/centro-documental/search\_result.html">http://www.feaps.org/archivo/centro-documental/search\_result.html</a>) deal with the issue of informed consent, as explained below:

- Muñoz, J., Maeso, P., Díez-Picazo, G., Mosquera, A., Pérez, R., Belinchón, M. y Tamarit, J. Claves para solicitar el consentimiento informado a una persona con discapacidad intelectual. Guía para profesionales [Keys to obtaining informed consent from a person with intellectual disability. Guide for Practitioners.]. Madrid: FEAPS. (available at: <a href="http://www.feaps.org/archivo/centro-documental/cat\_view/85-salud.html">http://www.feaps.org/archivo/centro-documental/cat\_view/85-salud.html</a>). This report shows professionals how to communicate with people with intellectual disabilities. The importance of addressing them directly is emphasised; use of graphic material (photographs, drawings) is suggested for patients who have more difficulty communicating; spending more time, being patient and communicating by using simple language, are also some of the suggestions. It is further stated that informed consent can be verbal, but it must be presented in writing in cases of: (a) surgery, (b) diagnostic or therapeutic invasive procedures, (c) diagnostic or therapeutic procedures that involve risks and drawbacks, which may impact significantly in everyday life (p.6).
- (2009). Consentimiento informado. Guía para personas con discapacidad intelectual [Informed consent. Guide for people with intelectual disabilities]. (available at:
   http://www.uam.es/centros/psicologia/paginas/cpa/paginas/doc/documentacion/Materiales/CONSENTIMIENTO\_INFORMADO\_secuencialectura.pdf) The document explains in Easy reading format, the fact that people with disabilities have the right to give their informed consent, even if legally incapacitated.
- 6. Can a person with disabilities be subject to medical or scientific experimentation without giving his or her consent? If so, under what circumstances and subject to what guarantees? Please provide references to relevant legislative provisions and, if available, case law; as well as to any relevant studies or reports or campaigns.

As previously noted, people with disabilities have the right to offer their informed consent. However, there are cases in which the rights of this group are violated. As an example, according CERMI (2011)<sup>14</sup> in the Spanish legislation forced admission to internment on grounds of disability ("mental disorder") is permitted. A constitutional court declared the violation of the right to individual freedom of a disabled person to

<sup>&</sup>lt;sup>14</sup> See: http://semanal.cermi.es/noticia/internamientos-forzosos-libertad-personal-CERMI.aspx.



<sup>&</sup>lt;sup>13</sup> Spanish Federation of Associations in favour of individuals with intellectual disabilities (<a href="http://www.feaps.org/">http://www.feaps.org/</a>).



be hospitalised against their will to receive psychiatric treatment. CERMI (2012) claims that there is an urgent need to change Spanish legislation on forced internment to meet the International Convention on the Rights of Persons with Disabilities.

Another issue raised by CERMI (2011) is that of forced sterilisation. Luis Cayo, President of the Spanish Committee of Representatives of People with Disabilities (CERMI) has asked for the repeal of forced sterilisation included in Article 156 of the Penal Code<sup>15</sup> that allows this for "disabled people who suffer from severe mental impairment." CERMI calls for the abolition of this article, as required by the UN Convention on the Rights of Persons with Disabilities in 1985. Spanish law states that "decriminalisation of sterilisation of people who lack capacity to consent will be made under court order and a process with maximum guarantees".<sup>16</sup>

7. Can a person with disabilities decide for him or herself whether to participate (and withdraw) from clinical trials even if somebody else (e.g. a guardian) takes a contrary view? Please include references to any relevant legislative provisions and, if available, case law; as well as relevant studies, reports and campaigns.

People with disabilities must give their informed consent in all cases. There are documents that try to spread the importance of these notions among relatives of people with intellectual disabilities. One example is the paper by Muñoz, Rivière, Perez, Tamarit, and Belinchon, (2008). Health Guide for families of people with intellectual disabilities. Madrid: Centre for Applied Psychology (CPA) of the Autonomous University of Madrid. [Guía de Salud Para familiares de personas con discapacidad intelectual]. This guide is aimed at family members who accompany their relatives with intellectual disabilities. The authors state that they should be aware that their job is to mediate between them and their health professionals. To do this, some suggestions are included: promote to communicate as much as they can, and tell the doctor what is their preferred form of communication and the meaning of certain things (for example if they use signs to communicate, relatives must provide a description of the signs or they should translate them when being used). During the visit, the authors insist on the importance of: Offering your son /daughter all the possibilities to communicate with the doctor, and promote him/her in taking the initiative if communicating.

On this subject, it is worth mentioning the paper by Muñoz (2004), aimed at people with intellectual disabilities. The document, entitled: *Programa para el apoyo y la mejora de la atención a personas con discapacidad intelectual en el ámbito de la salud, Yo también digo 33* [Program for the support and improvement of care for people with intellectual disabilities in the field of health, 33 Madrid. Centre for Applied Psychology (CPA) of the Autonomous University of Madrid], offers, among other information, the results after having used the Delphi technique to gather the views of

<sup>&</sup>lt;sup>16</sup> More info at: <a href="http://miraloqueestanhaciendo.wordpress.com/2012/07/28/los-discapacitados-piden-a-gallardon-que-elimine-la-esterilizacion-forzosa/">http://miraloqueestanhaciendo.wordpress.com/2012/07/28/los-discapacitados-piden-a-gallardon-que-elimine-la-esterilizacion-forzosa/</a>.



<sup>&</sup>lt;sup>15</sup> Available at: <a href="http://noticias.juridicas.com/base\_datos/Penal/lo10-1995.l2t3.html">http://noticias.juridicas.com/base\_datos/Penal/lo10-1995.l2t3.html</a>.



experts on care for people with intellectual disabilities. Concerning health care issues, some actions, among other measures, are proposed: Improving training for health professionals, developing programmes adapted for primary care and establishing the position of specialists in intellectual disabilities, among many others.

To mention another issue, according to the report by FEAPS: mental health disorders in people with intellectual disabilities, FEAPS Statement and Technical Report, 17 none of the existing laws relating to persons with disabilities refer to the needs of the group with Intellectual Disability –Mental Health problems. Unlike what happens in other countries, mental health lacks a specific legislative framework in Spain.

### Rehabilitation

8. Does legislation or policy guarantee a minimum right to rehabilitation following the onset of a disability? If so, please provide further information, e.g. length, funding, nature of rehabilitation. Are these or other rehabilitation services also available to people who have always had a disability? Please provide details of any relevant studies and reports which consider the appropriateness of the nature and/or availability of these services.

The Law on Social Integration of the Disabled, LISMI,<sup>18</sup> imposes on the State the obligation to ensure and promote the prevention of disability and medical and psychological care and rehabilitation, among others.

Royal Legislative Decree 1/2013, of 29 November, approving the revised text of the General Law on the Rights of Persons with Disabilities and its social inclusion has been approved. This Law establishes the creation of multidisciplinary teams to share guidance on habilitation and rehabilitation, with full respect for the autonomy of the disabled person, to establish their needs, skills and chances of recovery, monitoring and review. It also indicates that comprehensive care programmes may include those relating to medical Enabling or functional rehabilitation. In addition, Article 14 on Enabling or medical-functional rehabilitation, states:

- Enabling or medical-functional rehabilitation aims to achieve maximum functionality of the physical, sensory, mental or intellectual capacities. This process begins with the detection and identification of deficiencies and psychosocial needs of each person and continuing until achieving and maintaining the highest possible development and personal autonomy.
- 2. For this purpose, any person with a disability, shall be entitled to benefit from the enabling processes or medical rehabilitation needed to improve and achieve the maximum personal independence possible and to achieve the necessary support, personal development and full and effective participation in society on an equal basis with others.

<sup>&</sup>lt;sup>18</sup> Available at: https://www.boe.es/buscar/act.php?id=BOE-A-1982-9983.



<sup>&</sup>lt;sup>17</sup> Availble at: <a href="http://www.feaps.org/biblioteca/documentos/trastorno\_salud\_mental.pdf">http://www.feaps.org/biblioteca/documentos/trastorno\_salud\_mental.pdf</a>.



- 3. Enabling or rehabilitation process to start in specific services will be developed in close connection with intervention centers and continue, if necessary, as home treatment or in the environment in which the disabled person develops his life, with existing community resources.
- 4. Habilitation and rehabilitation programmes will be complemented by the provision, adaptation, conservation and renovation of assistive technologies, prosthetics and orthotics, devices, vehicles, and other aids for disabled people whose personal circumstances require this.

In our opinion, one of the more urgent needs of the system in Spain, for many years has been to establish good coordination between the health and social system services for improving rehabilitation outcomes. In addition, there is no continuity or follow up after initial health rehabilitation services. Beyond physical rehabilitation, the system should assess and treat individuals with a holistic, multidimensional, approach focusing on improving quality of life (personal outcomes) (Schalock and Verdugo, 2012: A leadership guide for today's disabilities organisations: Overcoming challenges and making change happen. Baltimore: Paul H. Brookes. ISBN: 978-1-59857-181-3) (SCHALOCK, R.L. & VERDUGO, M.A., 2013: The transformation of disabilities organizations. Intellectual and Developmental Disabilities, 51(4), 273-286. ISSN: 1934-9491).

State and Regional (Autonomous Communities) budget cuts in recent years are reducing sharply the rehabilitation options for many people with disabilities, especially for those with higher levels of impairment and with poor economic conditions of life (CERMI, 23/7/2014: http://www.cermi.es/es-ES/Noticias/Paginas/Inicio.aspx?TSMEIdNot=5563), (CERMI, 9!1/2014: http://noticias.lainformacion.com/asuntos-sociales/condiciones-sociales/discapacidad-el-cermi-pide-al-gobierno-que-destierre-los-recortes-en-discapacidad\_Tf5usJei3ebuFMYP9I3U82/)

## **Training / Awareness Programmes**

9. Do action programmes or training requirements related to healthcare professionals seek to raise awareness of the human rights, dignity, autonomy and needs of persons with disabilities in healthcare, including through the promulgation of ethical standards? If so, please provide details.

More training awareness, in curricula and other training programmes are required, as explained earlier. This is also a conclusion of Leturia et al. (2014).<sup>19</sup> "Most people with disabilities need more intense and frequent health care. ....To achieve this objective it is necessary to improve professional competencies and skills and develop some specific health programmes."

<sup>&</sup>lt;sup>19</sup> Available at: http://sid.usal.es/idocs/F8/ART20432/leturia.pdf.

