



Health care for people with intellectual disability in Spain

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Abstract

We describe the healthcare system for people with intellectual disability (ID) in Spain. First, we provide general population statistics before focusing on the most recent prevalence data related to people with disability in general, and with ID in particular. We also discuss how health care is organized. Most of the Spanish population is covered by the public healthcare system, which is structured into primary care (first-level health services; easily accessible and capable of tackling the most common ailments) and specialized care (second-level health services; comprising the most complex and costly diagnostic and therapeutic resources). We then explain Spain's primary legislation that promotes the rights of people with disabilities, highlighting the importance of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which is enshrined in the Spanish General Law on the Rights of People with Disabilities and their Social Inclusion (Royal Legislative Decree 1/2013). Second, we describe the organization of Spanish disability support and health services, whose regulation is highly complex given that the autonomous regions set their own rules about coverage, services, and financing. Third, we present some recent studies that allow a better understanding of health care for people with ID in Spain, including a summary of the ongoing #Rights4MeToo project. We report specific data on the right to habilitation/rehabilitation. People with ID and professionals providing them with supports agreed that the most problematic aspects of health care for people with ID were the lack of: coordination across services, user-friendly information to maintain or improve their health, psychological treatments, preventive medical check-ups, and knowledge about disability among health professionals. There is a need to give people with ID priority access to services, reduce waiting times, increase the length of medical appointments, and create protocols and prevention campaigns targeting them.

Abbreviations: ID, Intellectual disability; CRPD, United Nations Convention on the Rights of Persons with Disabilities; SNHS, Spanish National Health System; CERMI, Comité Español de Representantes de Personas con Discapacidad (Spanish Committee of Representatives of Persons with Disabilities).

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KEYWORDS

Convention on the Rights of Persons with Disabilities, health, health care, intellectual disability, mental health

INTRODUCTION TO THE GENERAL HEALTHCARE SYSTEM

General population statistics

Statistics from the Spanish Ministry of Health (2022a) indicate that Spain has approximately 47 million inhabitants, of whom 19% are over 65 years of age. Life expectancy is around 83 years, and 72 of these years are expected to be lived in a healthy way for the general population. The main causes of death in Spain are similar to those in countries with comparable socioeconomic environments: cardiovascular diseases, stroke, and cancer. According to a 2020 macro-survey on disability in Spain (National Institute of Statistics, 2022), 4.38 million people (9.5%) residing in households stated they had a disability. Mobility problems are the most frequent type of disability reported.

Although almost 10% have limitations and state they have a disability, in Spain only those who have been recognized with a degree of disability equal to or greater than 33% are legally recognized as persons with disabilities. Disability recognition is an essential prerequisite to have access to the social safety net (e.g., protected employment, financial support for studies, adaptations at home). The assessment and recognition of a disability is a long and decentralized administrative procedure carried out by a specialized team (made up of a doctor, a psychologist, and a social worker) that, upon request, establishes the diagnosis, evaluates the disability, and assesses the degree thereof. If the team assesses the degree of disability to be equal to or greater than 33%, then the person is legally considered as a person with a disability. People who met these criteria and therefore were considered as persons with a disability accounted for 7% of the population in 2020, and those who had intellectual disability (ID) as the main cause of their disability accounted for 0.6% (Institute for Older Persons and Social Services, 2022).

Among people with ID in Spain, the pyramid of the population by age is distributed as follows (Institute for Older Persons and Social Services, 2022): 3% were under 7 years old, 15% were between 7 and 17, 28% between 18 and 34, 45% between 35 and 64, 7% between 65 and 79, and 2% were 80 years or older. Most of them were living in the regions of Andalusia (23%), Catalonia (17%), Community of Madrid (12%), and Community of Valencia (9%). It is noteworthy that the rate of people with a recognized degree of disability with ID as the main cause fell by 0.2% between 2019 and 2020.

Beyond those with a legally recognized disability, the availability of data is highly insufficient as no existing sources provide comprehensive and updated information about the number and characteristics of people with ID and their care service use (Salvador-Carulla & García-Gutiérrez, 2009). Plena inclusión (2023) estimates that ID affects 1% of the Spanish population, taking into account that some people may not know that they have ID, and others have a diagnosis of ID but not a legally recognized disability.

Organization of the healthcare system

The healthcare system in Spain is both public and private. Private health care usually requires medical insurance and plays an important role in provision, especially for those people and treatments not eligible to be treated by the public system. Although there is a growing reliance on the private sector, most of the Spanish population is covered by the public healthcare system. Article 43 of the Spanish Constitution establishes the right to health protection and health care for all citizens. The Royal Decree-Law 7/2018 guarantees the universality of assistance and the right to health protection and health care, under the same conditions, to all people who are in the Spanish State. Eligibility is linked to residency, although people who do not habitually reside in Spanish territory may have their right to health care recognized in Spain by another legal title. This would be the case, for example, for those who have the right to health care under the protective action of social security, for Spanish residents abroad, and for returnees.

Since 1989, health care has been universal and funded through different taxes and payments, via contributions deducted from the monthly salary of residents. Health responsibility is devolved to each of the 17 autonomous regions, which each have their own health department—responsible for all the health centers, services, and facilities in that particular region. The central government provides this service directly in the autonomous cities of Ceuta and Melilla; it also carries out general and basic coordination tasks between the different regions.

The Spanish National Health System (SNHS) is structured into primary care and specialized care. Primary care (first-level health services) is easily accessible and capable of tackling the most common ailments. It makes basic services available within a 15-min radius from any place of residence and it is the first and major face-to-face access

point to health care. The main facilities are healthcare centers, staffed by multidisciplinary teams comprising general practitioners (family doctors), pediatricians, nurses, administrative staff, and, in some cases, social workers, midwives, and physiotherapists. Specialized care (second-level health services) comprises the most complex and costly diagnostic and therapeutic resources. Citizens obtain access to these resources by referral from primary-care doctors. The patient, along with their clinical information, is subsequently referred back to the primary-care doctor, who obtains a comprehensive clinical overview and ensures the provision of continuous care.

The basic services consist of preventive, diagnostic, therapeutic, rehabilitation, and health maintenance and promotion activities. The primary-care level covers general medicine, pediatrics, disease prevention, health promotion, health education, and rehabilitation, while specialized care includes all medical and surgical specialties. There is also a 24-h care mechanism for emergency health care. In case of a medical emergency, people can go straight to a hospital if they are physically able or call 112 to get an ambulance and be treated in a public hospital. Most emergency healthcare services are received at hospitals and healthcare centers, but exceptionally they can be received at home. In order to treat complex or rare pathologies, or indeed any pathology requiring a high degree of technological and professional specialization, there are referral centers, services, and units.

The SNHS provides supplementary services, as well as pharmaceutical, orthopedic and prosthetic services, nonurgent healthcare transportation, and diet therapy treatments. The pharmaceutical service is funded by the public healthcare system and covers the vast majority of medicinal products authorized in Spain, along with certain medical devices. A number of products are expressly excluded, such as homeopathic medicines, cosmetic products, dietary supplements, nonprescription medicines, or medicines from nonfunded therapeutic groups for the treatment of minor symptoms.

According to the Ministry of Health (2022b), the SNHS comprises 158 000 doctors, 198 000 nurses, and 330 000 other healthcare professionals. They provide care in 3000 centers, 10 000 doctors' offices, and 2000 outpatient accident and emergency services. The SNHS has 3000 ambulances, 464 hospitals with 114 000 beds and 19 000 outpatient hospital places, and 297 reference centers. Spain spends €81.6 billion a year on public health care and €33.8 billion a year on private health care (i.e., a total of €115.4 billion each year). Satisfaction with the public healthcare system is 6.6 on a 10-point scale (Ministry of Health, 2022b). The perception of good coordination between healthcare levels is less than 50%. Most people state that they participate in decision-making

regarding their health condition and treatment in both primary care (78%) and specialized care (74%).

Legislation and policy regarding people with ID

In Spain, the legal framework for ensuring the rights of people with disability is derived from national and international norms and declarations of principles, which have led to the progressive promulgation, adaptation, and improvement of specific laws and policies at the national and local levels (Citarella et al., 2020). Article 49 of the Spanish Constitution states the rights of people with disability and explicitly acknowledges the role of preventive care, rehabilitation, and treatment, and delegates the role of legislating for these purposes to the public authorities. At the supranational level, Spain signed and ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD; United Nations, 2006), which states in Article 25 that “all persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (p. 20). Since 2008, this international regulatory text has been part of the Spanish legal system.

The most recent Spanish legislation specifically dedicated to people with disability is the General Law on the Rights of People with Disabilities and their Social Inclusion (Royal Legislative Decree 1/2013). This General Law aims to guarantee the right to equal opportunities and treatment, as well as the full and effective exercise of rights by people with disabilities on equal terms with respect to other citizens. This Law prescribes a variety of services for guaranteeing health assistance to people with disability and, for this purpose, public administrations must establish programs of lifelong learning for all professionals working in the healthcare system (Citarella et al., 2020).

THE ORGANIZATION OF HEALTH CARE FOR PEOPLE WITH ID

Although there are general rules for the State, not to mention funds to provide social services, the regulation of care services in Spain is highly complex. This is because the autonomous regions have legal responsibility and can therefore set their own rules about coverage, how to provide services, and how to finance them. The public system of social services is financed mainly from the budgets of the autonomous regions, from contributions of the general budgets of the State and, in some

cases, also by users' contributions (i.e., copayment). The main model of care is public-private collaboration (García-Sabater, 2020). Access to these services for people with disability is a priority for public authorities operating in health, education, and social services, but also for third sector organizations (e.g., *Plena inclusión* (2023), *Down España*). The latter are coordinated by the Committee of Representatives of Persons with Disabilities (CERMI), an umbrella organization representing the interests of people with disabilities in Spain and guaranteeing their equal opportunities, human rights, and full inclusion in society.

In Spain, no specific policy to promote life in the community for people with ID has been developed. The support needs of people with disabilities are usually addressed in residential institutions and day centers. There are currently approximately 50 000 people with ID living in residences and many more are on lengthy waiting lists. Those with more extensive support needs especially face many situations of social exclusion and violation of rights: 16 591 people with ID and extensive support needs continue to live in institutions: the support they receive is mainly focused on residential care (32%) and day-care centers (28%), with other resources to promote inclusion in community living being vestigial (Esteban et al., 2021). Although the number of people in large residential institutions is decreasing (Martínez-Leal et al., 2011), data reflect the institution-based model that prevails in Spain for people with more significant disabilities, to the detriment of other services that are more inclusive and consistent with the content of Article 19 of the CRPD, such as personal assistance and independent living.

The Law for the Promotion of Personal Autonomy and Care for Dependent People (Law 39/2006 of December 14) regulates social protection resources through economic benefits and services (i.e., prevention of situations of dependency and promotion of personal autonomy, telecare, home help, day and night centers, and residential care). These resources are allocated depending on whether they support older people or people with different types of disability (e.g., day center for people with ID, day center for people with physical disability). Also, independent living support systems are part of a catalog of services and benefits intended to support daily living for people with a legally recognized dependency (e.g., personal assistant services, sheltered housing).

Although there should be no differences in the health care received by people with and without disability (and also between people with different types of disability, including those with ID), several studies show that people with disability do not receive the required level of

provision. Meseguer et al. (2010) observed major differences by gender and by disability status: 18% of women and 8% of men with a moderate or severe disability declared that on at least one occasion they had not received medical assistance when it was needed, as compared with 4% of women and 2% of men without disability. The most common cause, in around a third of the cases, was that there was a long wait, they were unable to secure an appointment, they were impeded by family obligations or work, they were too nervous, or they had no transport. With the goal of adapting to the demands and characteristics of this population, some autonomous regions are issuing a card that grants priority care to people with ID and allows them to bring a companion to most medical appointments (*Plena inclusión*, 2023).

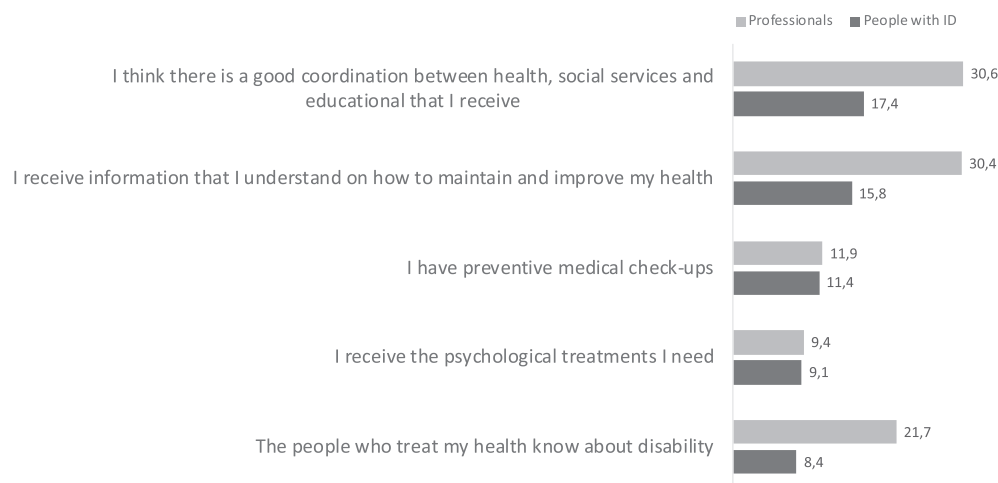
Despite Spain having generally satisfactory and adequate health and social care systems, the threat posed by COVID-19 revealed that they are not egalitarian. The severity of the disease and the consequences of the lockdown did not affect everyone equally. As observed by Navas et al. (2021), although people with ID generally received the assistance they needed, those living in specific settings (facilities for people with ID depending on organizations) had fewer natural supports, while those living with their family relied heavily on relatives. In addition, Amor et al. (2021) found that a significant proportion of people with ID (20%) who were living in disability-related services had to change their living context because of the pandemic and lockdown, which had a deleterious effect on their emotional well-being and occupations.

Studies have also shown that people with ID tend to have lower levels of access to mental health services (Gómez et al., 2021; Salvador-Carulla et al., 2013; Salvador-Carulla & Symonds, 2016). The individual autonomous regions are responsible for incorporating the necessary specifications for the specialized care of people with ID in their mental health plans. This leads to a large degree of heterogeneity across regions, with some making considerable progress in mental health-care systems, but most of them are focused on the principles of deinstitutionalization rather than on alternative community-based mental health services (Salvador-Carulla et al., 2010). For example, in Madrid, Girona, and Barcelona there is a specialized mental health service for adults with ID, accessible by referral from primary care or social services. Elsewhere in Spain, however, there is a general lack (especially in rural areas) of specialized and accessible mental health services for people with ID, insufficient monitoring and evidence about the deinstitutionalization process, and an urgent need to improve coordination within and across social and health care and to reduce geographical disparities

TABLE 1 Recent publications about health care and people with ID in Spain.

Authors (year)	Type of study and topic
Alonso-Sardón et al. (2019)	Cross-sectional study involving 162 institutionalized people with ID. The measurement tool was a structured questionnaire completed during an individual/family interview. The study showed that mental health was rated worse than physical health. People with ID and a higher degree of personal autonomy determined by institutional and family support reported better health and quality of life.
García et al. (2020)	Cross-sectional study involving 362 informants about 1040 people with ID (ad hoc survey) and 12 172 people without ID (secondary data analysis). Chronic constipation, urinary incontinence, thyroid disorders, and obesity were the most prevalent chronic diseases among people with ID, who were affected by these health conditions more frequently than people without ID.
Muñoz and de Araoz (2021)	Given the saturation of healthcare facilities and the scarcity of resources during the COVID-19 pandemic, many decisions were made without taking into consideration the rights of people with ID. This is a theoretical article in which the authors reflect on the situation created during the pandemic and relevant conclusions are drawn for the preservation of the right to health.
Navas et al. (2019)	Cross-sectional study involving 369 professionals (58%) and family members (42%) who replied to two open-ended questions about the improvements they believed should be introduced to ensure optimal access to health care for older people with ID. They emphasized the need to improve disability training for healthcare practitioners and highlighted the urgent need for flexibility in the structure of a healthcare system that has overlooked the specific needs of people with ID.
Vilaseca et al. (2017)	Cross-sectional study involving 2160 families with a family member with ID in Catalonia. Their answers to an ad hoc questionnaire showed that specialized healthcare services were the first need for people with ID.

Abbreviation: ID, intellectual disability.

**FIGURE 1** #Rights4MeToo Scale items with the highest percentages of disagreement with the statements.

(Gómez & Navas, 2021; Gómez et al., 2021; Salvador-Carulla et al., 2010).

RECENT STUDIES

Table 1 summarizes recent publications about healthcare provision in Spain for people with ID, highlighting some of the areas of discrimination faced by this group.

Currently, a research project titled #Rights4MeToo (Gómez et al., *in press*) is being conducted in Spain. In

this ongoing project involving 555 people with ID (46% women), aged between 18 and 67 years old ($M = 39.4$; $SD = 12.6$), 20% of participants showed challenging behaviors and 4% exhibited conduct disorders. More than half (59%) were taking medication, including 20% who were taking antiepileptics and 19% who were taking antipsychotics. These results accord with those from another recent study conducted in Spain: In a sample of 991 people with ID over 45 years old, García et al. (2022) found that behavioral problems were the most frequent mental health condition (54% in their sample) and antipsychotics

were the most widely used psychotropic medication (28% in their sample).

The aim of the #Rights4MeToo project is to use the quality of life framework to monitor the implementation of the Articles ratified in the CRPD (Gómez, Morán, Navas, et al., 2022; Gómez et al., 2021). Within the framework of this project, the #Rights4MeToo Scale (Gómez, Morán, Al-Halabi, et al., 2022; Gómez et al., *in press*) has been developed and is currently being validated with a broad Spanish sample. The field-test version of this scale comprises 153 items distributed across eight quality of life domains and CRPD articles. All items are answered using a 4-option Likert-type response format (from *totally disagree* to *totally agree*). Instructions, items, and answer format were validated with easy reading standards by people with ID (UNE 153101:2018 EX).

One of the CRPD articles explored in the #Rights4MeToo Scale is the right to habilitation/rehabilitation (Article 26), which is evaluated through 14 items. On the one hand, these 14 items were completed by 438 people with ID (47% women; 18–67 years old), who gave their opinion about the health care they receive. On the other hand, professionals supporting people with ID answered the same questions with their opinion about the care provided by healthcare staff to another 484 people with ID (47% women; 18–67 years old). Both groups of respondents highlighted the same five key areas in which the system was lacking: coordination across services; user-friendly information to maintain or improve their health; psychological treatments; preventive medical check-ups; and knowledge about disability among health professionals (Figure 1).

DISCUSSION

Although the right to health is recognized and protected by national legislation, people with ID seems discriminated against by the Spanish health system. Despite presenting more health problems than the general population, they consult health services less frequently due to innumerable barriers, such as lack of accessibility, underdiagnosis, and overtreatment (Leturia et al., 2014). The barriers that people with ID face and the reasons behind this discrepancy between health needs and care must be investigated as a matter of urgency. In Spain, to adequately care for people with ID, public and private health services must be physically and cognitively accessible, guaranteeing access to information and data confidentiality. Provision should incorporate a flexible, integrated and comprehensive care approach (socio-health care) throughout the life cycle. Furthermore, these services should be provided by health personnel who are

adequately trained in disability. There is a need to increase the length of medical appointments, reduce waiting times, create protocols and prevention campaigns targeting people with ID, and provide preferential access to services (Navas et al., 2019). Furthermore, to ensure the right to health for people with ID, natural supports need to be developed for those living in accommodations owned by disability organizations, while the provision of professional supports should also reach people residing in their homes (Navas et al., 2021).

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

ETHICS STATEMENT

This research was authorized and supported by the Ministry of Social Rights and Welfare of the Principality of Asturias, as well as the Research Ethics Committee of the University of Oviedo (17_RRI_2021). All participants provided their informed consent. Confidentiality and anonymity of the responses were guaranteed by not collecting personal data that could identify the participants.

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