

Healthcare for people with intellectual and developmental disabilities in Italy

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Abstract

The Italian healthcare system is public and freely available to the population. With a few exceptions, there are no distinctions between the healthcare services and practices (e.g., primary care) designed for the general population and those for individuals with intellectual and developmental disabilities (IDD). Prevalence data on adults with IDD are lacking and most disability policies and resources are designed for people with disabilities broadly defined, without specification based on disability type or severity level. Recent legislation provides specific supports for individuals with severe disabilities or autism spectrum disorder. This paper describes the legislation and health policies developed for people with disabilities, the organization of the Italian healthcare system, and the organization of disability support services and healthcare services. Strengths (e.g., availability of many financial resources, adoption of biopsychosocial approach to disability, presence of innovative projects to address the healthcare needs of people with IDD) and weaknesses (e.g., lack of distinction among disability types, territorial differences, lack of disability training of healthcare providers) of the current healthcare practices are reported and discussed.

KEYWORDS

health, ID, medical care, policy, system of supports

ITALIAN HEALTHCARE SYSTEM

Statistics on intellectual and developmental disabilities population

Specific terminology distinguishes between ID, developmental disability (DD), and intellectual and developmental disabilities (IDD). ID is defined as significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills that manifest during the developmental

period (APA, 2022; Schalock et al., 2021a). DD (a) is defined as a severe, chronic disability that is attributable to a mental or physical impairment or a combination of mental or physical impairment; (b) is manifested before 22 years old; (c) is likely to continue indefinitely; (d) results in functional limitations in three or more major life activity areas; and (e) reflects the individual's long term need for a combination and sequence of special, interdisciplinary, or generic services and individualized supports (Developmental Disabilities Assistance and Bill of Rights Act Amendments

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of 2000). The term IDD is used to refer to people with ID and/or DD (Schalock et al., 2021b).

The prevalence of ID is often found to be around 1% globally and varies widely (range: 0.05%–1.55%; Maulik et al., 2011; McKenzie et al., 2016), depending on study settings, methodologies, age groups, and case definitions (McKenzie et al., 2016). Among Italian school children, ID was the most common type of disability in elementary and middle school, impacting 42% of students receiving special education (National Institute of Statistics, 2020). Moreover, 51% of students with ID have multiple disabilities (National Institute of Statistics, 2020). The prevalence of autism spectrum disorder (ASD) among 7–9 year olds was found to be 1 in 87 in 2016 (Narzisi et al., 2020) and 1 in 77 in 2021 (Ministry of Health, 2021a) with a male to female ratio of 4.4.

Among Italian adults, however, neither ID nor DD prevalence research has been conducted. The only population-level disability estimate comes from the reports of the National Institute of Statistics, that includes only the so-called *Global Activity Limitations Indicator* as disability identifier: “Having limitations due to health issues, for at least six months, that limits daily living activities.” The National Institute of Statistics estimated that approximately 5% of Italian adults had a disability according to this definition (National Institute of Statistics, 2019). For this reason, in this paper, we will refer to individuals with disabilities, except where otherwise noted.

Characteristics, organization, and financing structures of the healthcare system

The Italian national healthcare system (“Servizio Sanitario Nazionale” [SSN]) was established with Law 833 (1978) and later implemented with Legislative Decree 502 (1992). It guarantees health as a fundamental right for all citizens (Italian Constitution, Article 32). SSN is public and based on three fundamental principles (Ministry of Health, 2019a): universality (health is a community resource and healthcare services are for the whole population), equality (all citizens must access to the SSN services regardless of individual, social, or financial differences), and equity (healthcare services must be high-quality, effective, adequate, and transparent for all).

Three basic types of assistance are guaranteed: collective prevention and public health, health and social programs, and hospital care (Ministry of Health, 2019b; Prime Minister Decree 65, 2017). The SSN is organized into two primary levels: central state level (i.e., Italy and its governmental institutions, like the Ministry of Health)

and regional. The Central State establishes goals and standards for each of the 20 Regions to achieve (Ministry of Health, 2019a). Regions are further divided into 110 Local Healthcare Units (“Azienda Sanitaria Locale” [ASL]), each of which covers a specific geographical area (e.g., Tuscany has three ASLs: Center, North-West, and South-East) (Ministry of Health, 2019a). In accordance with Law 833 (1978), which requires services be offered as close as possible to people’s places of living, ASLs are further subdivided into districts to provide services in areas of limited dimensions (a surface area of 440 km² and a population of 85000 on average) through hospitals and health facilities.

The SSN is partially funded by the following sources: (a) a percentage of two taxes paid by the population (income tax and a tax on companies), (b) revenue of the ASL, (c) national budget (including the “National Health Fund”), (d) other minor sources. In addition, individual citizens pay a portion of healthcare costs (the so-called “ticket”), according to a sliding fee scale, for the following services: some medicines, specialist visits and exams, and non-urgent interventions performed in the Emergency Department to people over 14 years old. Italian citizens may be exempted from paying the “ticket” based on age (i.e., citizens under 6 and over 65 with an annual income not exceeding 36151.98€), family income, disability (Law 104, 1992) status (e.g., health impairments acquired during previous military service), presence of specific health conditions (e.g., pregnancy) or healthcare services performed (cancer or HIV screening). Although most healthcare facilities are public, a small number of private healthcare facilities also exist, most (93%) of which are accredited and paid by SSN (meaning that patients pay only the “ticket”).

Legislation and policy regarding people with disabilities

The Italian Constitution states that all citizens must have equal rights and be protected from discrimination. Law 104 (1992) codifies these principles concerning rights, social inclusion, and assistance of citizens with disabilities. Law 104 (1992) defines disability as “physical, mental or sensory impairment, stabilized or progressive, which causes difficulties in learning, relationships or work integration and is associated with social disadvantage or marginalization” (Law 104, 1992, art. 3). Disability certification is needed to access financial, education, and other resources. Law 104 (1992) covers various topics (e.g., prevention and early diagnosis, treatment and rehabilitation, school and work inclusion, guardianship). In terms of healthcare, Law 104 pursues the social and

functional recovery of individuals with disabilities and assures services and supports for preventing, treating, and rehabilitating impairments.

Additional supports were codified in Legislative Decree 502 (1992), Presidential Decree 87 (1994), and Law 162 (1998), which established Personalized Support Plans (“Piani Personalizzati di Sostegno”) for people with severe disabilities (see the section *Disability and Support Services, Organization and Resources* of this paper).

Legislative Decree 502 (1992) and Prime Minister Decree 65 (2017) direct the establishment of a preventative service department in each regional district to function as an institutional guarantor of health promotion, prevention of diseases and disabilities, and individual quality of life improvement through the provision of rehabilitation services.

Presidential Decree 87 (1994) provides for the healthcare needs of children with disabilities, specifically: (a) formulation of a functional diagnosis (i.e., description of functional impairments) by a multidisciplinary team that collects psycho-social and clinical information in cognitive, affective-relational, linguistic, sensory, motor, neuropsychological and autonomy areas (Presidential Decree 87, 1994) and that considers all the factors having a role for the development and manifestation of the disorder (Balboni & Cubelli, 2011); (b) formulation of a functional dynamic profile (e.g., describing the child's strengths and weaknesses and the potential development in the short and medium term); (c) individualized educational plan for the child with a disability (a document describing the interventions prepared for the child in a given period of time, in order to realize their right to education and training). These directions were explicitly extended later to individuals with ASD (Law 134, 2015), whose multidisciplinary healthcare team are required to receive education and clinical experience on ASD and neurodevelopmental disorders.

In March 2007, Italy signed the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) and, in May 2009, the Italian Parliament ratified the CRPD and the related Optional Protocol with Law 18 (2009), which also established the National Observatory on the Condition of People with Disabilities. In 2016, the National Observatory on ASD was also established (Ministry of Health & Italian National Institute of Health, 2016). These provisions develop programs for the promotion of the rights, health, social inclusion of individuals with disability and ASD, respectively, and to promote research to identify priority areas of actions and interventions relevant to the field.

Recently, several laws were passed, mainly concerning allocating financial resources to the healthcare services intended for people with disabilities (e.g., Council

of Ministers, 2021). With the Next Generation EU program, the European Union provided resources to each state member for the three-year term 2021–2023 to cover a variety of financial demands consequent to the COVID-19 pandemic. The Italian National Recovery and Resilience Plan (“Piano Nazionale di Ripresa e Resilienza”) is part of this program. The Plan allocates funding for six missions to foster the wellbeing of people with disabilities. For example, Mission 1 (“Digitalisation, innovation, competitiveness, culture and tourism”) concerned interventions to remove the architectural and sensory barriers in museums and libraries. Specifically regarding the healthcare of people with disabilities, Mission 5 (“Inclusion and cohesion”) provided investments in social infrastructures, community, home, social, and health services aimed to improve the independence of people with disabilities, while Mission 6 (“Health”) regarded the implementation of interventions to improve health assistance and services (e.g., the use of telemedicine) to promote truly universal access to public health (e.g., dismantling territorial differences in healthcare services and access) (Council of Ministers, 2021). In this sense, within Mission 6, the strengthening of home assistance and the upgrading of territorial structures and facilities are envisaged. For example, there is a project to create 1288 Community Houses (e.g., easily identifiable and accessible community care points with a “hub” that provides primary care, social, and welfare supports, with a multidisciplinary team of physicians, pediatricians, nurses, social workers, and other health professionals). The Community Houses were especially designed for those citizens with particular frailties, such as the elderly, people with disabilities, and people with chronic diseases and others with high support needs, to decrease the risk of their institutionalization and guarantee the needed healthcare services in a context that is independent and socially appropriate (Council of Ministers, 2021).

Law 227 (2021) updated existing legislation to be compliant with the guidelines of the CRPD (United Nations, 2006) and the Strategy for the Rights of Persons with Disabilities 2021–2030 (European Commission, 2021). In addition to updating disability laws and provisions, it revised its definition of disability to align with the International Classification of Functioning, Disability, and Health (World Health Organization, 2001) and the biopsychosocial approach. Moreover, this Law established the presence of a national disability guarantor for the protection and promotion of the rights of people with disability.

Finally, given the evidence about the importance of sport activities for the health of people with ID (Special Olympics, 2020) and to encourage the inclusion of individuals with ID through sport, Law 208 (2015) allocates

funds to the international program of sport training and competitions “Special Olympics Italy”. In addition to social inclusion, the Special Olympics program promotes the healthcare and self-care of athletes with ID, thanks to volunteer health professionals (nutritionists, podiatrists, ophthalmologists, dentists, audiologists) and medical students who offer athletes free screening of the highest quality.

THE ORGANIZATION OF HEALTHCARE FOR PEOPLE WITH DISABILITIES

Disability support services

Historical context

Deinstitutionalization in Italy began in 1978 with the Italian Mental Health Act (i.e., Basaglia Law or Law 180, 1978) that reformed the Italian psychiatric system. This Law required all Italian asylums (that hosted individuals with mental health and with disabilities, particularly ID) to close and be replaced with community-based care services. Recently, the Law “after us” (Law 112, 2016) reaffirmed that institutionalization must be avoided and provided assistance for people with severe disabilities to support their life course (e.g., support for services in one’s own home, programs to develop skills for managing daily life as independently as possible) in the absence of family support (e.g., after the death of their parents/guardians). Institutional care should be used only temporarily and only in emergencies (e.g., to access healthcare services that are not available with home-based care, or in case of a behavioral health crisis).

Organization and resources

Individuals with disabilities and their families receive some services from the public or institutional sectors (e.g., municipality, ASL, or cooperatives). However, the public resources are not enough to cover all the needs. Indeed, 49% of the families of people with disabilities do not receive any public support whatsoever. In addition, the number of resources available vary by territory (National Institute of Statistics, 2019). Thus, people with disabilities resort to private service support or informal support. In this framework following the dispositions of the SSN (Law 833, 1978) and Law 180 (1978), many social service companies provide social, health, educational services (Type A cooperatives), and job placement (Type B

cooperatives) to people with disabilities and other minorities (Montanari & Ruzzante, 2021).

Financial support is provided by the Italian government to people with disabilities and/or their families (Ministry for Disabilities, 2022). Parents of individuals with disabilities receive financial assistance lifelong (the so-called “assegno unico”) that differs based on several factors (e.g., income, number, and age of offspring). Single or unemployed parents may qualify for additional financial support (Ministry for Disabilities, 2022). Funds supporting healthcare include:

1. Fund for non-self-sufficiency (established with Law 296, 2006): aims to enhance care, services, and independent living for people with high levels of support needs and their caregivers.
2. Fund for assistance to persons with severe disabilities deprived of family support (established with Law 112, 2016): aims to avoid institutionalization and support people when leaving the family of origin. Interventions may support home care in family-type houses and co-housing settings similar to a family home, or interventions to support home-based care and to improve daily living skills and independence.
3. Fund for family caregivers (established with Law 205, 2017): provides financial support for non-professional care work performed by family caregivers.
4. Fund for the care of individuals with ASD (established with Law 208, 2015): aims to strengthen direct support staff by providing them with education and training on ASD, improve residential and semi-residential facilities, and enhance ASD research.

Law 162 (1998) provides funding to the Municipalities for Personalized Support Plans that provide social-welfare interventions for individuals with severe disabilities (e.g., personal and/or home assistance, educational assistance, day centers). The aim is to build on the person’s strengths to maximize independence, especially in managing daily activities and free time. These individualized interventions are designed by the families in conjunction with professionals, based on the person’s specific needs (e.g., physical therapy, daycare services, transportation, supported employment and housing, sport and social activities). Family members or guardians can request the Personalized Support Plan from their Municipality and, once determined eligible, they are redirected to specific associations (e.g., National Association of Families of People with Intellectual and/or Relational Disabilities) or cooperatives deputed to the provision of these services.

Italian municipalities allocate most of their financial resources to support the living arrangements of people with disabilities, including daycare and residential (or semi-residential) facilities, which are mostly used by individuals with higher support needs, followed by home-based care services, aimed to make adults with disability independent within their own home environment (Ministry of Health, 2019b; National Institute of Statistics, 2019). Residential facilities provide both social and healthcare services, and may be offered in community-based facilities. Although data on the use of independent living settings by people with ID is not reported, small community-based residential placements are less common and generally limited to individuals with mild or moderate ID without higher support needs (Academic Network of European Disability Experts, 2019).

Disability healthcare services

The Italian healthcare system provides the same services for people with and without disabilities. The SSN guarantees the inpatient, outpatient, and home-based care of all people with acute or chronic diseases according to the best practices and patient's needs (Prime Minister Decree 65, 2017). In Italy, healthcare services and social-support services are hardly distinguishable. As described, services provided to people with disabilities in their residential, semi-residential facilities, or home-based settings may include both healthcare services and support services. This happens because health, social services, and interventions (including rehabilitation and psychotherapy services) must be provided in an integrated manner (Law 328, 2000), enhancing the individual's abilities, minimizing the overall impairment, and involving family and community contexts (Prime Minister Decree 65, 2017).

In terms of primary care, citizens older than 14 years with or without disabilities are entitled to the following services, free of charge, from a family physician (Ministry of Health, 2021b): outpatient and home-based care visits for preventive, diagnostic, and therapeutic purposes, prescriptions for medicine and specialist services, requests of hospitalization, home-based care, some types of vaccinations, issuance of some medical certificates (e.g., excused absence from work/school). These same services are guaranteed for children by the pediatrician. Children are guaranteed pediatric services from birth to 6 years of age. For minors aged 6–14 years old, parents (or guardians) can choose whether to keep their pediatrician or switch to a family physician. Only minors with disabilities or certified chronic illness are allowed to stay

with their pediatrician until the age of 16. In addition, pediatricians provide preventive and screening examinations, checking for linguistic, socio-relational, psychomotor, and other developmental delays that may indicate the presence of IDD or ASD.

In addition to primary care, citizens with disabilities are entitled to specialized care, if needed, that can be public or private. The use and access to the Emergency Department services including the use of the universal telephone number “118” is available to people with and without disabilities (Ministry of Health, 2021b). For specialist visits in public services, the citizen must obtain a prescription from the family physician, schedule the service, and pay the “ticket,” unless exempt.

All individuals who need rehabilitation services must have an Individual Rehabilitation Plan. It is composed of one or more rehabilitation services to meet their individual needs, strengths, and weaknesses (Ministry of Health, 1998). The SSN guarantees the implementation of rehabilitation activities at outpatient clinics, home, hospital (ordinary hospitalization for people who require at least 24-h medical-nursing surveillance), accredited residential and semi-residential social-health facilities for people discharged from acute or rehabilitation hospitalization who need ongoing treatment to further recover their abilities but who no longer need medical care during the night hours (Ministry of Health, 2019c).

These residential and semi-residential social-health facilities offer intensive rehabilitation services (i.e., 3 h/day and 6 day/week interventions for no more than 45 days aimed at recovering important, complex, modifiable limitations) or extensive rehabilitation services (i.e., 1 h/day and 6 day/week interventions for no more than 45 days for patients with disabilities who have the potential to recover function and cannot benefit from intensive rehabilitation treatment). In both cases, the services are free of charge for patients. A third type of intervention in social-health residential and semi-residential social-health facilities is treatment to maintain the functional skills of people with higher support needs and stable physical, mental, and/or sensory disabilities. However, this latter type of treatment is only partially funded by the Health Service (Prime Minister Decree 65, 2017).

By law, healthcare services intended for Italians with disability should be provided by a multidisciplinary team of healthcare professionals who are experts and have had previous experience with the patient's condition (Law 104, 1992; Law 134, 2015; Prime Minister Decree 65, 2017). Yet, disability training programs are not required for health professionals, even among the continuing education programs that are required of all Italian health professionals. Disability training is only



available at the postgraduate level, always on a voluntary basis, and generally behind a paywall.

Furthermore, regarding healthcare facilities, today only a few offer a priority access to patients with disabilities needing outpatient services, adequate space in the Emergency Department, and specific rooms for the care of people with ID (Elisei et al., 2021; National Observatory on the Health in the Italian Regions and Spes contra Spem, 2016). However, some innovative projects have been implemented to address these needs and improve healthcare accessibility for people with ID and other disabilities (Elisei et al., 2021; Frondizi et al., 2021), including during the COVID-19 pandemic (Buono et al., 2021).

DISCUSSION

The Italian healthcare system is public and available to all Italian citizens, including individuals with disabilities for whom specific resources have been provided since the 1970s. Despite this extremely positive benefit, Italian healthcare services are generally not tailored to the particular needs of individuals with disabilities. Indeed, despite the availability of specific services for people with severe disabilities and higher support needs of individuals with ASD, disability is understood as a single condition, associated with limitations in daily living activities due to health issues that have persisted for at least 6 months. However, there are many types of disabilities, each of which has specific healthcare and support needs. Moreover, different types of disability may be associated with comorbidities, interacting in complex ways. For example, ID represents a heterogeneous group of etiologies, with a wide range of severity levels and comorbid physical and mental healthcare conditions. Consequently, people with different types of disabilities or with different levels of the same disability have different needs and require diverse types and levels of support. Furthermore, there are complex disabilities, such as rare neurodegenerative and neuromuscular pathologies, which also have specific needs currently not taken into consideration and specified in the legislation in force in Italy.

Making visible the invisible by knowing the prevalence of these disability subgroups represents the first step to understanding the ID population's health status, health determinants, and health needs, and accordingly developing adequate policies and practices to predict and meet these needs (Krahn, 2019). This is particularly relevant because there are large territorial differences in resource allocation and access. Many families of people with disabilities, especially those from Southern Italy, need to use private support services and healthcare services at their own expense (National Institute of Statistics, 2019).

Notwithstanding, promising changes that will lead to more equitable health are in progress, where the preferences of patients with disabilities are considered, valuing self-determination and independence (Law 227, 2021). Finally, disability is no longer viewed with a medical approach. The living context of the person with disability can be sources of health barriers or facilitators (World Health Organization, 2001).

Clearly stating that patients with disabilities must fully participate in all the decisions concerning their health (Law 227, 2021) implies that healthcare providers must be trained to properly care and interact with people with disability (and patients with ID specifically). Therefore, specific disability education should be introduced, standardized across the country, and required for all healthcare professionals, either as part of the degree programs or as mandatory courses in the continuing education programs (Bacherini et al., 2021, 2022). Research conducted in Italy echoes international findings that healthcare providers (including psychiatrists) for adults with disability (including ID and ASD) felt unable to meet the specific needs of these populations. Moreover, they are generally reluctant to care for these patients due to a severe lack of knowledge and training about neurodevelopmental disorders, but are generally willing to learn (Elisei et al., 2021; Italian National Institute of Health, 2021). A similar situation is observed in the field of oral healthcare for people with ID (Dellavia et al., 2009; Fernández Rojas et al., 2021).

In conclusion, to improve healthcare equity, access, quality of care provided to individuals with ID, and to decrease the healthcare disparities that this population face, the two most important future directions are: to develop a clear roadmap to collect better data on prevalence and health surveillance of people with ID at a national level, and establish education and training programs mandatory for all healthcare providers. Certainly, a prerequisite for these changes is the adoption of a clear definition of ID, distinguished either from IDD or DD (Havercamp et al., 2019; Schalock et al., 2021b).

AUTHOR CONTRIBUTIONS

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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