



YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF
CARE AND THEIR INFORMAL CARERS

National report:

An Overview of the Situation of Informal Caregivers and Younger Adults in Need of Care in Italy



Co-funded by
the European Union

The YoungCare project is co-funded by the European Union's Erasmus + KA220-ADU – Cooperation partnerships in adult education programme under grant agreement no. 2022-1-DE02-KA220-ADU-000086558. The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

ABOUT THIS PUBLICATION

This report summarizes the national overview of informal care services and caregivers of individuals aged 18 to 65, outlines the needs and challenges encountered by the YoungCare target group, and provides practical support along with examples of good practices. Erasmus+ project **YoungCare: Relief for Younger People in Need of Care and their Informal Carers** (Grant agreement: 2022-1-DE02-KA220-ADU-000086558). **PROJECT WEBSITE:** <https://youngcare.eu/>

PARTNERS AND CONTACTS

The Erasmus+ project YoungCare started in December 2022 and runs until July 2025. The project involves partner organisations in five European countries:

ISIS INSTITUT FÜR SOZIALE INFRASTRUKTUR GEMEINNÜTZIGE GMBH

Germany
(European Coordinator)

Jesper Schulze

✉ schulze@isis-sozialforschung.de

🌐 <https://isis-sozialforschung.de/en/>

AFEDEMY, ACADEMY ON AGE-FRIENDLY ENVIRONMENTS IN EUROPE BV

The Netherlands

Willeke van Staalduinen

✉ willeke@afedemy.eu

🌐 <https://www.afedemy.eu/>

SHINE 2EUROPE

Portugal

Carina Dantas

✉ carinadantas@shine2.eu

🌐 <https://shine2.eu/>

VYTAUTO DIDZIOJO UNIVERSITETAS

Lithuania

Rasa Naujaniene

✉ rasa.naujaniene@vdu.lt

🌐 <https://www.vdu.lt/lt/>

CADIAI

Italy

Michela Patuzzo

✉ m.patuzzo@cadi.ai

🌐 <https://www.cadi.ai/>

PARITÄTISCHE Projekte gemeinnützige Gesellschaft mbH

Germany

Anne Marie Duscha

✉ annemarie.duscha@paritaet-projekte.org

🌐 <https://www.paritaet-projekte.org/>

AUTHORS

CADIAI

Gloria Verricelli

✉ g.verricelli@cadi.ai

Elisabetta Bartolucci

✉ E.bartolucci@servizioset.it

Barbara Zanna

✉ B.zanna@servizioset.it

CADIAI
COOPERATIVA SOCIALE

CONTRIBUTORS

Michela Patuzzo, **CADIAI**

Copyright © 2023 YoungCare



This publication is licensed under a [Creative Commons Attribution-NonCommercial 4.0 \(CC BY-NC 4.0\) International License](https://creativecommons.org/licenses/by-nc/4.0/).

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Education and Culture Executive Agency (EACEA). Neither the European Union nor EACEA can be held responsible for them.



TABLE OF CONTENTS

1. Aims of the National Report.....	5
2. Methodology	5
2.1 Desk Research	6
2.2 Interviews	6
3. RESULTS	7
3.1 OVERVIEW OF THE NATIONAL SITUATION.....	7
3.2 OVERVIEW OF THE POLITICAL, PUBLIC AND SCIENTIFIC DISCUSSION	10
3.3 NEEDS, CHALLENGES, SOLUTIONS AND GOOD PRACTICE EXAMPLES	15
3.4 PORTRAITS	16
4. REFERENCES	24



1. Aims of the National Report

The project "YoungCare - Relief for younger people in need of care and their informal carers" aims at improving the situation of younger people in need of care. This is a group of younger adults up to the age of 65 who have become dependent on care as a result of a drastic event such as an accident or serious illness and can no longer manage their everyday lives without help. In most cases, these people are neglected in care services and have problems receiving care tailored to their needs. In most cases, therefore, they are cared for at home. The partner organizations from Germany, Italy, Lithuania, the Netherlands and Portugal want to draw attention to the sometimes precarious situation of young adults in need of care and the people who care for them.

The national report is supposed to be an important part in assembling a European compendium. The compendium is meant to provide a scientifically based but practice-oriented and easily accessible overview of the situation of younger people in need of care and their informal carers. It is aimed primarily at these informal carers and people in need of care who are confronted with disease and care for the first time or who feel the need to improve their situation. It is part of Work Package 2 of the YoungCare project, which is intending to collect evidence on the perspectives of the target group, creating an extended knowledge base and developing solution strategies. The results of this work package are also meant to contribute to the development of the digital learning opportunities and for the development of the publicity strategy in the following work packages. In order to accomplish the task of the European compendium being the main output of this Work Package the national reports from all the partner-countries (Germany, Portugal, Italy, Lithuania and the Netherlands) are an important piece of input and information.

Although the main aim is to be a fundamental piece towards completing the European compendium the publication of the national reports also gives an overview of the situation of YoungCare in each of the countries represented by a partner organisation. It is important because it sheds a light on the daily struggles and hurdles young people in need of care and their informal carers must face locally. Also, the political, public and scientific discussion will be elaborated. Particularly because of the scarcity of data and information, it is important to use the national reports to provide an insight into the everyday lives of young people in need of care and their informal caregivers.

2. Methodology

Before describing the methods applied to achieve the above-mentioned aims, it is important to specify the target groups summarized as "younger adults in need of care". The main criterion for the differentiation is the question if need for care has already existed since birth or was acquired during life (between 18 and 65 years of age). We intentionally use the term "younger adults" for the project to describe the age group that



can neither be described as children and young people, nor as senior citizens. This is done with the knowledge that this age group encompasses a large age variation.

The distinction between the need of care since birth and a later acquisition seems to make sense in the context of the YoungCare project's objective to develop a practical educational tool. The thesis is that the first group (from birth) is already introduced into the social and care system through the offers in the child and youth sector. Even if problems arise with the transition to adulthood and care services (presumably) deteriorate, this group has experience with the issues of care and the social system. In the second group, there is a need to acquire this knowledge in an extreme situation.

People in need of care are defined as those persons who are dependent on help in managing their daily lives. All people who informally help other people to cope with their everyday life are defined as carers.

The following methods were applied during the finalisation of this National Report:

2.1 Desk Research

The partners conducted the desk research in their countries with a special focus on the national situation and focussed on the following topics:

- Facts and figures on care services, care needs, types of illnesses and types of care provided
- Scientific work on the topic
- Political and practical debates on the topic
- Obstacles and difficulties for the YoungCare target group in the provision of care and services
- Suitable offers and good practice offers for the YoungCare target group
- Suitable practical support for those affected and their carers (first aid)

2.2 Interviews

In each country, interviews with an open structure were conducted. They were conducted primarily with informal carers but if possible, depending on the individual situation of the persons concerned, persons in need of care were also interviewed. A short amount of the interviews was conducted with experts to improve the understanding of the overall situation.

In Italy, 8 persons were interviewed: 5 adults with acquired disability, 1 person with disability from birth, 1 informal caregiver and 1 institutional expert. Most of the interviewed caregivers are family members.

3. RESULTS

3.1 OVERVIEW OF THE NATIONAL SITUATION

ISTAT - the National Institute of Statistics, a technical body of the state that deals with general censuses of the Italian population - and the Presidency of the Council of Ministers in 2019 released data on persons with disabilities, identifying 3.150 million persons with disabilities in Italy (5.2 % of the population).

Almost one and a half million people over the age of 75 (22% of the population in that age group) have disability and one million of them are women. The 'geography of disability' sees the Islands in first place, with a prevalence of 6.5%, against 4.5% in the Northwest. The Regions where the phenomenon is most widespread are Umbria and Sardinia (6.9% and 7.9% of the population, respectively). Lombardy and Trentino Alto Adige are, instead, the Regions with the lowest prevalence: 4.1% and 3.8% respectively.

29% of people with disabilities live alone, 27.4% with their spouse, 16.2% with their spouse and children, 7.4% with their children and no spouse, about 9% with one or both parents, the remaining 11% live in other types of households.

The ability to move freely is very limited among people with disabilities. Mobility data for 2019, states the document released by ISTAT in March, show that only 14.4% of people with disabilities travel by urban public transport, compared to 25.5% of the rest of the population. These differences vary greatly with age.

Physical or sexual violence experienced by women reaches 31.5% over a lifetime, but for women with health problems or disabilities the situation is more critical. Physical or sexual violence reaches 36% among those who say they have poor health, 36.6% among those with severe limitations.

Family in Italy plays an important role in caring for and combating the risk of social exclusion. The families of people with disabilities enjoy on average a lower level of economic well-being: according to the latest available estimates, their average annual equivalent income (including transfers by the State) is 17,476 euros, 7.8% lower than the national average.

The resources needed by the family to play the role of social shock-absorber are not only economic, but also relational: 32.4% of families with at least one person with disability receive, in fact, support from informal networks (a share almost double that of the total number of families 16.8%). The range of aid provided by the network includes personal assistance, accompaniment and hospitality, household activities, completion of bureaucratic procedures and health services.

The inclusion policies implemented over the years have favoured a progressive increase in school attendance: in the year 2019/2020 the number of pupils with disabilities attending Italian schools was almost 300 thousand, over 13 thousand more than the

previous year. These pupils are taken care of by approximately 176 thousand support teachers, 1.7 per teacher; however, it should be noted that 37% have no specific training.

Moreover, policies and interventions for school integration still suffer from a lack of technological tools: computer stations are insufficient in 28% of schools. Another critical aspect is the presence of architectural barriers: only one school in three is accessible for pupils with motor disabilities.

The opportunities for pupils with disabilities to participate in school have been limited due to the pandemic necessitating distance learning. Between April and June 2020, more than 23 % of pupils with disabilities (approximately 70,000) did not participate in lessons (the other pupils who did not participate made up 8 % of those enrolled).

In Italy, regulations aimed at fostering the employment of persons with disabilities have existed for some time; the main one is represented by Law 68 of 1999, which introduced the institution of targeted employment, overcoming the previous compulsory employment that was merely a compensation tool for persons with serious health problems. Despite this far-sighted legislation, the disadvantage of persons with disabilities in the labour market remains significant. In fact, in 2019, considering the population aged between 15 and 64, only 32.2% of those with severe limitations are employed, compared to 59.8% of people without limitations.

Welfare and the system of social transfers aimed at compensating the reduced income capacity of persons with disabilities play a fundamental role, often constituting a significant share of disposable household income. Indeed, thanks to disability-related social transfers, the incidence of poverty risk among households with disabilities does not exceed that observed at national level. 48.9% of these households receive monetary transfers, with 18.7% benefiting from at least one social transfer and 39.5% from at least one welfare transfer. Monetary transfers prove capable of alleviating economic hardship; this is evidenced by the fact that the risk of poverty of households with people with disability, at national level, drops from 34.4% in the absence of transfers to 18.9% thanks to economic transfers.

However, transfers are not sufficient to guarantee these households the same living conditions as the rest of the population, and this because of the additional medical and health costs induced by disability. Therefore, higher incomes are needed for them to enjoy the same (material) living conditions as other households. The overall material deprivation indicator highlights the greater hardship of households with people with disability: 28.7% are in material deprivation while the national average figure is 18%. The most relevant signs of deprivation are the following: 67% of the households in which at least one person with disability lives cannot afford a week's holiday a year away from home; 53.7% cannot afford an unforeseen expense of EUR 800; more than one-fifth cannot sufficiently heat their homes or eat an adequate meal at least once every two days.

These conditions of hardship particularly characterise households in southern Italian regions.

Italian social protection system assigns a central role to local authorities (Framework Law No 328 of 2000), in particular to municipalities, which provide interventions and services aimed at guaranteeing care and support for social integration.

Expenditure incurred by municipalities for social interventions and services aimed at the disabled, from 2003 to 2018, increased from approximately EUR 1.22 billion in 2003 to over EUR 2.5 billion in 2018. This growth is mainly due to the establishment of the National Fund for non-self-sufficiency. Within the sphere of dedicated services, the main items of expenditure include day care centres (approximately 312 million) and residential facilities (approximately 366 million), which provide assistance to the disabled and support to families either during the day or on an ongoing basis. In 2018, more than 27,000 persons with disability make use of municipal day care centres, and another 16,500 or so benefit from municipal subsidies to make use of private contracted centres. There are more than 30,000 users of both municipal and private contracted residential facilities.

The ISTAT report does not highlight the incidence of acquired disabilities on the Italian population. The figure remains limited to regional and/or municipal realities.

Specifically, in the Emilia-Romagna region - where YoungCare partner CADIAI is located - there is a need to provide concrete and timely responses to the needs of families with people who are victims of road accidents or accidents at work, or who suffer from progressive degenerative diseases, such as multiple sclerosis, muscular dystrophy, and amyotrophic lateral sclerosis. The issue is also the focus of the territorial area plans and has priority importance. It is a universe that is often misunderstood by most.

The families who today turn to associations for problems related to acquired disability present fragilities attributable to numerous factors:

- the psychological impact of acquired disability (whether due to a chronic degenerative pathology or to a traumatic event such as road or work accidents or sudden events such as aneurysms, strokes or ischaemia) on the individual person with disability (who was used to living an almost completely normal life) and on the family unit to which he or she belongs (exposing it to very strong emotional and relational tensions as well as to an extremely high burden in terms of care work);
- the often total extraneousness of the acquired person with disability and his or her family members from the world of social and health services (in many cases, these are people who have not previously had major health problems and who suddenly find themselves completely bewildered in the face of a diagnosis and a severely limiting prognosis, precisely because they know nothing of the labyrinth of services and their articulation)



- the need (sometimes impelling and manifest, sometimes unconscious) to find psychological support and to relate with other people and families who have gone through or are going through the same type of experience in order to feel less alone and to begin to follow a path of acceptance, which must not, however, translate into resignation, but rather into a courageous search for a better or possible autonomy.

According to data published in 2018 by ISTAT, there are more than 7 million (about 15 percent of the population) Italians engaged in informal caregiving, that is, for the benefit of their own family members. Most are over 50 years old, one in five over 60. These are people who take on daily caregiving tasks, involving physical and emotional commitment, sacrifices in terms of personal renunciations, time and life choices.

There are also numerous young caregivers, teenagers or young adults who, despite their young age, find themselves assisting or caring for a family member suffering from a physical or mental illness, with a disability or addiction. Caring for someone is not easy; it affects mental and physical balance and personal well-being. And if this is true at any age, for a young person the impact is strong, even with repercussions in school or university, professional and social life.

According to ISTAT in Italy, young caregivers are about 7 percent of 15–24 year-olds, or about 400.000 young people. The phenomenon of young caregivers has always existed, but awareness is relatively new. There are no structured services, we need to slip into the folds of what exists and involve the various services such as school, university, social, health or mental health services. It happens that the children themselves develop psychological distress that needs to be attended to, and so it is complicated to bring all these subjects together.

3.2 OVERVIEW OF THE POLITICAL, PUBLIC AND SCIENTIFIC DISCUSSION

Disability is protected, first and foremost, by the Constitution, which deals with it in various provisions, in a more or less specific manner. In particular, Article 2 can be taken as the basis for the protection of disability in the part that states that 'The Republic recognises and guarantees the inviolable rights of man' and does so regardless of the personal, social and health conditions of the individual. Article 3, on the other hand, upholds disability by stating that 'All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social conditions' and that 'it is the duty of the Republic to remove obstacles of an economic and social nature, which, by limiting the freedom and equality of citizens, prevent the full development of the human person'. Finally, Article 32 states that 'The Republic protects health as a fundamental right of the individual and an interest of the community'.



The International Day of Persons with Disabilities was proclaimed in 1981 and falls on 3 December each year in order to promote the rights and welfare of persons with disabilities.

The CRPD - United Nations Convention on the Rights of Persons with Disabilities - is the ultimate expression of the political and cultural change affecting persons with disabilities. The convention is an international treaty that establishes inalienable principles and guidelines, which can be translated into a national law that must be contextualised and dropped into the reality of individual countries. The convention contemplates multiple levels of involvement for the promotion and protection of the rights of persons with disabilities. Not only the various institutional spheres starting with the state, but also society as a whole with its articulations. The Convention on the Rights of Persons with Disabilities was adopted on 13 December 2006 by the United Nations General Assembly. The CRPD entered into force on 3 May 2008 after its 20th ratification. It consists of a preamble and 50 articles. It is the first human rights convention ratified by the European Union and entered into force on 22 January 2011. On the basis of the CRDP, the European Disability Strategy 2010-2020 was developed. Countries adhering to the Convention undertake to develop and implement policy programmes, laws and administrative measures to guarantee the rights recognised by the Convention and to abolish laws, regulations and practices that constitute discrimination. The CRDP is therefore binding and initiates a democratic process that must involve all sectors of society civil society, guide good behaviour and promote the reporting of violations.

Italy ratified the CRDP on 3 March 2009 and it is consequently a law in force and binding. In compliance with the convention, an observatory (OND) was also established, supported by a technical secretariat and a scientific committee with the following functions:

- promotion of the implementation of the UN Convention on the Rights of Persons with Disabilities
- preparation of a two-year action programme for the promotion of the rights and integration of people with disabilities;
- promotion of the collection of statistical data and the carrying out of studies and research on the subject;
- preparation of the report on the state of implementation of disability policies.

There are some parts of the convention that are relevant to the role of caregiver. These must then be contextualised by each state that has ratified the CRDP and translated into laws.

In Italy, on 7 August 2019, the parliamentary process was presented and started for the Bill n°1461 containing the "Provisions for the Recognition and support of the figure of the family caregiver". A complex and delicate project, still being discussed and fine-tuned, which with its 11 articles will recognise and define the role of the informal caregiver, normalising it, making it 'visible', in order to protect over 8 million citizens called by necessity to have to reconcile or give up a job and part of their lives.

"..., whether a spouse, a parent or a relative within the third degree, in order to carry out his or her duties of supporting a Person with Disability, is granted 3 days of paid monthly leave, extraordinary leave, and the possibility of early retirement". Moreover, again under Law 104 with Order No. 6150 of 2019, the Court of Cassation reaffirmed the "right of the caregiver to a work transfer to the location closest to the assisted person's home".

In recent years, in fact, the legislator has wanted to recognise the social and economic value of the non-professional care activity of the family caregiver and has done so for the first time through the establishment, by the 2018 Budget Law (paragraph 254 of Law no.205 of 2017), at the Presidency of the Council of Ministers of a Fund for the support of the title of care and assistance of the family caregiver with an initial allocation of 20 million euros for each year of the three-year period 2018- 2020.

On 16 October 2020 at the Unified Conference, a favourable opinion was expressed by the regions, UPI (Union of the provinces of Italy) and ANCI (National Association of Italian Municipalities) on the decree allocating the Fund to the regions, which completed the parliamentary approval process that began in 2017, so that the text becomes effective. The decree of distribution provides that the resources, allocated to the Regions and subsequently distributed to the municipalities and territorial authorities, must be used primarily to support caregivers of persons with very serious disabilities, caregivers of those who have not had access to residential facilities due to emergency regulations proven by appropriate documentation, and accompanying programmes aimed at de-institutionalisation and reunification of the caregiver with the person being cared for.

The previously mentioned notion of family caregiver, posited by Article 1, paragraph 255, of the 2018 Budget Law (Law No. 205 of 27 December 2017), remains in place. Subsequently, the legislator confirmed the attention paid to efforts to recognise the role of family caregivers by establishing, through the 2021 Budget Law, a Fund for the financial coverage of legislative interventions aimed at recognising the social and economic value of the non-professional care activities of family caregivers.

The so-called caregiver Fund, provided for within paragraph 334 of the Budget Law, is intended for the financial coverage of legislative interventions for the recognition of the non-professional activity of the family caregiver, as defined by Article 1, paragraph 255, of the Budget Law for 2018 (Law No. 205/2017), with an allocation of 30 million for each year of the three-year budget planning period 2021-2023. This Fund, unlike the pre-existing Fund for the support of the care and assistance role of the family caregiver, will be entered in the estimate of the Ministry of Labour and Social Policies.

Presidential Decree No. 616 of 1977 implemented the decentralisation of administrative functions and, in particular, assigned to municipalities the functions of organising social services. Further innovations were introduced in the 1990s and in particular with the first Bassanini law (Law No. 59 of 1997), which introduced the principle of subsidiarity, according to which decisions are taken by the government body closest to the citizens, i.e., the one that is best able to interpret the needs and resources of the territorial community of reference.

The principle of vertical subsidiarity is a criterion for allocating the competences of bodies of different territorial levels, in which the care of the citizen's interest is entrusted to the closest body and the intervention of the body at a higher level is justified where the action of the former is inadequate. This declination of the principle of subsidiarity must be distinguished from horizontal subsidiarity, enhanced by Article 118, fourth paragraph, of the Constitution, which regulates the relationship between private initiative and public intervention. This provision has made explicit in the constitutional text the system implications deriving from the recognition of the 'profound sociality' that characterises the human person (cf. Constitutional Court, sentence no. 228 of 2004) and its possibility of achieving 'positive and responsible action' (cf. Constitutional Court, sentence no. 75 of 1992).

This principle has led to the development of organisational-institutional models that attribute to the municipalities the ownership of administrative functions concerning social services and that enhance collaboration between the public and private sectors. This redefinition of the State-Regions-Local Authorities relationship was completed through the introduction of Law 328 of 2000 and the Reform of Title V of the Constitution (Law 3 of 2001).

Law No. 328 of 2000, the framework law for the implementation of the integrated system of interventions and social services, redefined the profile of social policies by introducing a number of new elements. First of all, it marked the transition from the concept of the user as the bearer of a specialised need to that of the person in his or her entirety; hence the transition from a traditional meaning of assistance, as a place where merely reparative interventions of hardship are carried out, to one of active social protection, a place where the causes of hardship are removed but above all a place of prevention and promotion of the person's inclusion in society through the enhancement of his or her abilities.

Legislative Decree No. 117 of 3 July 2017 (the so-called Third Sector Code) provides that public administrations, in the exercise of their programming and organisation functions at a territorial level of interventions and services in the areas of activity of third sector entities, shall ensure their active involvement through forms of co-programming and co-designing and accreditation, implemented in compliance with the principles of Law No. 241 of 7 August 1990, as well as with the rules governing specific procedures and in particular those relating to area-based social programming.

The model configured by Article 55 of the Third Sector Code is based on the convergence of objectives and the aggregation of public and private resources for the joint planning and design of services and interventions aimed at raising the levels of active citizenship. This model of sharing the public function is reserved for the Third Sector, to entities that fall within specific typified organisational forms that pursue, on a non-profit basis, civic, solidarity and socially useful purposes through the performance, exclusively or principally, of one or more activities of general interest in the form of voluntary action or the provision free of charge of money, goods or services, or mutuality or the production or exchange of goods or services, and that entered in the single national register of the Third Sector.



Then there are more specific disciplines for the protection of disability.

First of all, the one dictated by law number 104/1992, i.e., the 'framework law for assistance and social integration and the rights of persons with disability'. This provision, with multiple sub-provisions, aims to guarantee respect for human dignity and the rights of freedom and autonomy, as well as full family, school, work and social integration. It also aims to ensure the services and benefits necessary for the prevention, care, rehabilitation and legal and economic protection of the disabled. Law 104 is known, above all, for the recognition of specific permits to workers with serious disabilities and to employees who provide assistance to family members with serious disabilities. These are extraordinary, paid leaves, to be enjoyed for three days a month or one or two hours a day, depending on working hours.

Law 68/1999 regulates the targeted employment of persons with disabilities by providing for the establishment of services for their employment at regional and provincial level. These services provide for the planning, implementation and verification of interventions to promote the entry of persons with disability into the world of work. To this end, the employment services avail themselves of a provincial office to which specific technical committees refer. These committees are called upon to assess the abilities and work potential of the disabled, to define the tools for job placement and targeted placement, to prepare a tutoring plan for job placement, to guide the disabled and employers, to organise workplace inspections, and to collaborate in drawing up training and vocational retraining programmes for workers with disabilities.

By virtue of the provisions of Law 68/1999, then, public bodies, political parties, trade unions, non-profit organisations and private companies and bodies, must compulsorily employ:

- one person with disability, if they have between fifteen and thirty-five workers
- two persons with disability, if they have between thirty-five and fifty workers
- a number of people with disability equal to 7% of the total number of employees, if they have more than fifty workers.

Despite the regulatory protections mentioned above, Italy lacks policies to support family caregivers of people with disabilities, and in particular lacks an ad hoc law for caregivers. The United Nations Committee has also spoken out on this issue, noting that the lack of financial and social support for families of people with disabilities constitutes a violation of human rights. The Italian legal system does not provide any legal protection for family caregivers with regard to welfare pensions, allowances or sickness, there are no protections, compensation or financial support for people who have had to leave work to care for their loved ones. In the context of Article 28, the UN Convention on the Rights of Persons with Disabilities recognizes the right of family caregivers to state protection, "provided that this recognition is inextricably linked to the protection of the rights of family members with disabilities": the UN Committee urges Italy not only to provide adequate compensation to such persons, but also to take measures so that the family has

access to appropriate individualized support services, and to provide for interventions to prevent similar violations in the future.

3.3 NEEDS, CHALLENGES, SOLUTIONS AND GOOD PRACTICE EXAMPLES

The Action Programme for the promotion of the rights and integration of persons with disabilities provides for some lines of action, namely:

- recognition of the condition of disability, multidimensional assessment aimed at supporting the system of access to services and benefits and personalised planning
- policies, services and organisational models for independent living and inclusion in society
- health, right to life, habilitation and rehabilitation
- school inclusion and training processes
- work and employment
- promotion and implementation of the principles of accessibility and mobility
- international cooperation and international projection of disability policies
- development of the statistical system and monitoring of policy implementation.
- In some cases, people with disabilities are granted civil invalidity, which entails the recognition of additional rights. Civil invalids are considered to be
- persons aged between 18 and 65 who have a physical, psychic and/or intellectual disability, congenital or acquired, even progressive, as a result of which their working capacity is reduced by more than 33%
- minors who have persistent difficulties in performing tasks and functions proper to their age
- citizens aged 65+ with difficulties in performing tasks and functions proper to their age.

Overcoming disability-related difficulties also involves further provisions. Specific rules are laid down in the fields of health, education, transport and overcoming architectural barriers. All are aimed at inclusion. In addition, many tax benefits are reserved for the disabled, such as those incurred for the purchase of necessary means of accompaniment, walking and lifting or for the purchase of technical and computer aids.

In the interviews below, a varied picture of critical issues, challenges, needs and examples of good working practices emerges, reported by the people CADIAI identified for the interviews.



Caregiving requires different skills, in giving care, in organizing care, in providing care even with relevant technical aspects, in dialoguing with formal services, and in reconciling living and caring times. The caregiver is forced to constantly learn new things and have new experiences. He therefore needs information and help, confrontation and dialogue, and requires resources, personal, environmental, economic. The absence of sufficient resources puts everyone involved at risk because it exacerbates poverty, induces despair, and causes a breakdown in the balance that holds caregiving together. There are also often underestimated repercussions: 8 % of those caring for a person with disability experience a decrease in income, 5,5 % lose their jobs, and 2 % request retirement.

The majority of caregivers argue that the most appropriate care model, in order to meet the needs of the person with disability, should leverage the creation or enhancement of a network of public services on the ground, and secondarily the adoption of economic interventions that include an increase in the accompanying allowance.

3.4 PORTRAITS

The interviews were carried out by CADIAI thanks to the collaboration of operators, workers and users belonging to the Social Service for Disability of the Municipality of Bologna.

3.4.1 INTERVIEW WITH PROFESSIONAL CAREGIVER

The head of the disability service of the Municipality of Bologna, a social worker and formal caregiver, exposes the strengths and weaknesses of the Bologna model. She confirms the lack of articulate and specific data on the subject of disability in Italy. She also hopes that reconnaissance and analysis can be carried out at municipal and regional level to provide a careful and complete overview of the population affected by disability.

In particular, it would be opportune to conduct a statistical survey aimed at identifying the types of disability, cognitive physical and mixed, the etiology and the onset, thus detecting the incidence of acquired disability, a situation that has a strong impact on families and the personal services system.

The Disability Service, in a network with other services, has the mandate to provide assistance to the 'new' person with disability, through interventions that allow a readjustment to the new living conditions. It would be desirable to supplement the accompaniment with specialised psychological support, aimed at the person with disability and the members of the family nucleus, especially the informal caregiver, who daily takes care of the relative at various levels, experiencing feelings of helplessness and loneliness. It would be useful to create permanent supervision paths within the services, in order to support the caregivers in their efforts to find the most suitable and customised solutions possible.

Another missing piece of data concerns the incidence of disability among non-EU persons present in Italy. In recent decades, the migratory phenomenon has brought with it the hope of being able to find assistance and care in Italy, a challenge with which the social and health system has struggled to find solutions respecting cultural diversity. With this in mind, it is necessary to identify tools and possible solutions that, through participatory cultural mediation, can enable people to redefine their expectations within an inclusive reception context.

Another current critical issue concerns the rapidly increasing digitalisation of the society. In daily life and in relations with public institutions, in fact, in order to access services, IT skills are increasingly necessary, which, unfortunately, are not present in large sections of the population. In fact, it is estimated that only 21% of Italians possess a level of digital literacy sufficient to independently disentangle themselves in their relations with institutions. Particularly for people with disabilities and their families, it is hoped that a service would be set up to provide practical support for people who show little or no digital skills. It would therefore be useful to have a back-office desk to which people can go for bureaucratic needs that would facilitate the acquisition of digital skills.

Another sore point concerns the economic support of people with disability and families. More economic support could help people's autonomy. But the discussion and identification of economic intervention strategies must be analysed at the political level. With more economic resources, the service could continue to provide or increase the coordination functions of the care and educational interventions that the disabled and their families receive, guaranteeing adequate levels of autonomy and self-determination.

Even the house where the person with acquired disability lives can become a major obstacle to restoring acceptable living conditions. In the field of private building, the service provides specific technical advice to adapt the home to the new needs that disability brings. It is necessary to redesign the living space to be barrier-free. The person with disability and the family are then supported in the various bureaucratic procedures. In social housing, there are rather long waiting times to be able to change accommodation.

Workers with disability, given their proven difficulty in entering the labour market, are assigned to a compulsory targeted employment scheme, the purpose of which is to promote their social integration, the full development of their person, and the creation of job opportunities.

The Disability Service of the Municipality of Bologna, in synergy with the targeted employment centre, provides training and retraining courses to make people with various types of disabilities employable. In the field of acquired disabilities, the enhancement of residual abilities and the identification of customised projects aimed at reintegrating the person into a productive context, when possible, can stimulate acceptance of the new living condition and promote adequate personal autonomy. In addition to having an identity function, work also protects against depressive moods that have repercussions not only on the individual but also on his or her family system.



3.4.2 INTERVIEW WITH A PERSON WITH A DISABILITY FROM BIRTH

C., 37 years old, was adopted at the age of 3 and from early on physical and cognitive developmental problems became apparent. C. lives with her retired parents, both of whom take care of her with the support of public services.

Initially the situation was very compromised, C. only expressed herself with screams. From the very beginning the nucleus was able to make use of the services provided; the interventions until the age of majority concerned psycho-physical rehabilitation and school support. Numerous professionals were involved. The school career was particularly positive: the girl had personalised and competent support from nursery school to high school. Difficulties arose with the transition to adulthood because the support pathway changed, and resources diversified by changing social services of reference. The mother reports of a "world that disappears and another one full of holes opens up" with a clear separation between health and social services.

When C. was taken into care as an adult, she was able to benefit from a great deal of support in the employment area by doing an apprenticeship in a supermarket, which was very useful and appreciated; what is missing, according to the family, is a strong reference structure and the mother's perception is that she has few references. There is a lack of a customised project from the institutions, aimed above all at social integration, which is often instead offered by private voluntary associations, at the expense, however, of the families. Important help is recognised at the legislative level with the "Dopo di Noi" ("after us") law and the institution of the figure of the support administrator, but this does not give greater serenity to the family, which continues to feel worried about the future.

3.4.3 INTERVIEW WITH SUBJECT WITH ACQUIRED DISABILITY

C., 27 years old, 100% disabled with accompaniment due to road trauma brain injury.

The accident, which occurred in 2016 and was very serious, completely turned the whole family's life upside down. The hospital/health care pathway is recognised as well-functioning, both in terms of care and personnel, while some shortcomings in long-term care are complained of. The father, caregiver, tells of entire nights spent in the hospital and of not having received enough guidance to be able to support his son's return home; he speaks of this with great suffering and a sense of bewilderment.

Once at home, the continuation of rehabilitation is arranged through Centro Byron where physiotherapy, speech and occupational therapist services are offered.

C. succeeds in resuming employment in the same dealership where he worked before the trauma. A traineeship project is implemented by agreeing on a possible job description with the therapists. This placement, which is still in place, envisages the presence of the father, who uses Law n. 104 permits in this way, until retirement.



The same centre has ordered the transfer to the territorial public services due to discharge and consequent interruption of rehabilitation, which can only continue in private form, with payment. A big fracture between health and social care is reported, since after the strong support offered by hospital services, the transition to the territory is impoverished, as are the resources.

It is also not easy to obtain and maintain support measures (civil allowance and L. 104), because if it is initially arranged by the hospital social worker, then it is the family who has to deal with it. The wish, with respect to this issue, would be for the family to be relieved/supported. The protections exist but it is still complicated to obtain them.

C. needs to be constantly monitored, all family members are involved in the help and care process. C. always needs to be reassured, to have someone by his side, and this is a huge burden. Little or no psychological support was provided, only and hardly during hospitalisation.

3.4.4 INTERVIEW WITH SUBJECT WITH ACQUIRED DISABILITY

C., 59 years old, acquired disability due to myelopathy, caregiver his 57-year-old partner.

C. retraces in great detail what she calls the 'ordeal' from the moment of surgery until her return home. It is a tale of great loneliness, exacerbated by the fact that it took place during the pandemic with all that it entailed. It was precisely because of this that it was not possible to receive any psychological support from the facility and subsequently from anywhere else. The new condition brought great nervousness to the couple; C. often felt mistreated by her partner who poured his anger on her.

The return home was particularly tiring, a good support was provided by the Byron Centre and also by the general practitioner who became an important reference point. The transition to the territorial services worked effectively, all the paperwork for economic support and aid was activated. The services collaborated to prepare necessary changes to the accommodation, through the CAD (specialised centre). C. obtained the recognition of incapacity for work and retirement, although no financial support has yet been received.

The disability services have provided a care allowance to support the care work of the partner. On the other hand, the lack of monitoring by the rehabilitation health facilities is underlined. Once the cycle is over, everything is the responsibility of the patient, both the cost of the therapies and the search for competent facilities.

3.4.5 INTERVIEW WITH SUBJECT WITH ACQUIRED DISABILITY

A., 60 years old, graduated several times in art and literature. Diagnosed with multiple sclerosis at the age of 40. 100% disability with accompaniment, he receives more than 1,000 € per month from the State.



For the past two years he has been living in a nice flat in social housing, which has been renovated and furnished thanks to the help of the disability service workers and some friends.

The Disability Service of the Municipality of Bologna supports him thanks to the intervention of three operators: a case manager, a social worker and an educator of the territorial educational service.

Social workers are coordinated for cleaning, meal preparation, support for bureaucratic practices, participation in leisure activities, accompaniment to specialist visits at the multiple sclerosis service.

When the diagnosis was announced, A.'s world collapsed. Thanks to the support of colleagues, he came to the multiple sclerosis centre and during the first years of the disease, which was already at an advanced stage, he was adequately supported medically, he had problems with vision, swallowing and walking. The counselling and courses given in the health sector to learn strategies to compensate for the physical changes were very effective.

Subsequently, help was provided by the Disability Service of the Municipality of Bologna for the disability paperwork and the search for accommodation suited to the new needs. A. states that he is supported by the Services in everything.

Currently, with the worsening of symptoms and living conditions, the work of formal caregivers allows him to lead a sufficiently adequate existence. A. reports the great humanity and empathy conveyed by the formal caregivers, he feels listened to and safe.

3.4.6 INTERVIEW WITH SUBJECT WITH ACQUIRED DISABILITY

M. is 50 years old and 10 years ago, due to a viral fever, he suffered a hemiparesis with consequent walking and cognitive problems, which have now been resolved. He has been granted 100% disability without accompaniment, with an allowance of approximately EUR 300 per month.

The acquired disability has completely disrupted his life. After his hospitalisation, when he returned home to his family, a severe state of depression led to his marital separation.

Afterwards, having returned to live with his parents, he started a rehabilitation and social pathway at a specialised centre, and then entered the Disability Service of the Municipality of Bologna.

A pathway to return to work was activated with inclusivity and training apprenticeships. M. tries to have his own economic autonomy to be able to participate in the expenses related to the maintenance of his daughter who lives with his ex-wife.

A certain concern emerges with regard to the possibility of finding employment inherent to the training he is concluding, although hopes remain strong and present. The motivation to get back into the game is high.



On the other hand, he emphasises the absolute inadequacy of the disability allowance. Had it not been for his family, his wife and older parents who supported him financially, he would probably have had to make drastic choices, such as selling his flat.

The family has also been instrumental in his return to an almost normal condition, providing him with the necessary support for daily activities.

In particular, he still needs to be accompanied to training and medical appointments. He is not always able to use public transport for travel, due to long waits and poorly organised connections. In conclusion, M. declares that he received medical care and subsequent socio-rehabilitative interventions that were extremely adequate to his needs.

He also emphasises the fundamental role played by his family and hopes instead that the public service can put in place more incisive interventions so that he can be reintegrated into the world of work.

3.4.7 INTERVIEW WITH SUBJECT WITH ACQUIRED DISABILITY

G., aged 52., has a 75% disability. In 2014, following a scooter accident, he had his right leg amputated. He worked as a security guard. He lived together with his partner in a flat. He considers the hospitalisation, health care and subsequent rehabilitation with the prosthesis to have been excellent. While he was still in hospital, the department's social worker contacted the homologator of the Disability Service of the Municipality of Bologna, who, after carrying out an inspection at G.'s home, arranged for the stair lift to be installed.

The institute where he worked had to dismiss him, because, having also suffered a head injury, it considered that he no longer met the conditions to act as a security guard. G. preferred not to appeal and has been unemployed ever since. Following the amputation, the couple's relationship also broke down, as the partner, who acted as an informal caregiver, could no longer cope with G.'s depressive-aggressive state. With the support of an acquaintance, G. managed to get a social housing allocation.

He declares that his life could proceed well if only he had a job suited to his new conditions. The allowance recognised by the National Social Security Institute is a little more than 400 euros per month. The Disability Service of the Municipality of Bologna has placed him in a training course where he is employed at a school with secretarial duties. He has been a member of the Centre for Targeted Placement for some time but complains of its lack of support in actively looking for a job. With regard to travel, he uses public services, but only those of the urban network, as the means of transport of non-urban routes have architectural barriers.

3.4.8 INFORMAL CAREGIVER INTERVIEW

A., 82, is the mother of S., 50, who suffers from "hemiparesis due to cerebral haemorrhage from neonatal suffering. Phobic-obsessive disorder", with a disability of 80%.

A., an extremely reserved person, worked as a clerk until her retirement, taking care of her daughter in the time she had left, delegating, in spite of herself, the education and care of S. to her grandmother.

At the age of 18, after being discharged from the Child Neuropsychiatry Service, S. was taken into care by the Disability Service of the Municipality of Bologna, which started her on a work bursary at a Catholic institute with secretarial duties. A position she still holds as part of an inclusion traineeship. For several years, S. has also been involved in numerous socio-educational and rehabilitation activities (workshops, occasional outings, stays, gentle gymnastics).

Due to her daughter's behavioural and emotional characteristics, she has been completely devoted to her since her retirement, accompanying her everywhere and indulging her every whim.

Her caring role has been rather tiring and lonely, not least because of the sense of guilt that has always accompanied her. In fact, she has always felt responsible for her daughter's disability and afraid of exposing her to social stigma, due to an experience of personal and family shame.

She has never thought of being psychologically supported, but realises that it would have been definitely useful, also because her husband has never taken care of S. and she has always been the one to take on all the management of her daughter, silently experiencing feelings of anguish, discouragement and worry.

She feels that over the years the Disability Service has improved her daughter's quality of life and thus supported the entire family unit.

Ms A. is currently undergoing treatment for a severe illness and her concern is for her daughter's future when she is no longer there. Who will take care of her? Where will she live? The anguish is strong, and she confides that she often bursts into tears without being noticed by her husband and daughter. Despite her age and illness, she continues to be completely available to her daughter.

On several occasions, the Service has proposed to her a support administration and an approach to the "Dopo di Noi" ("after us"), but her husband has always refused to consider these hypotheses.

The need to carry out bureaucratic procedures in digitised form has led her to have to ask for help from the service's operators, to whom she turns in case of need, obtaining computer assistance in carrying out the procedures.

Last year she benefited from a project of the municipality of Bologna called 'Caregiver Project', which provided a package of hours to relieve the family member who cares for her child with disability through educational and assistance interventions, which she used to transport her daughter to the traineeship site. She is currently waiting for this project to be authorised again.



3.4.9 INFORMAL CAREGIVER INTERVIEW

Mrs. F., 40, is the wife of R., 50, a traffic accident victim in 2021 with a 100% disability. An extremely outgoing person, they ran a private business together that they had to sell after the tragedy. F. is engaged 24/24 in caring for her husband; they live on his disability pension and earnings from selling the bar. All supports and health care are provided by the national health care system.

The social disability service has proposed to the couple the opportunity of attendance at a day care centre when the physical condition stabilizes, in the meantime it supports them in the bureaucratic process. R.'s cognitive ability has been severely impaired. F. says he is taking care of a "child," they who have been unable to have children.

F. is also using psychological support, the cost of which is covered by friends of the family. If the day care centre project materializes, perhaps, F. can think about resuming a part-time job.



4. REFERENCES

- Agenzia delle Entrate. (2022). *Agevolazioni per le persone con disabilità* [website]. Retrieved from https://www1.agenziaentrate.gov.it/web_app_entrates/agevolazioni_disabilita.html#indice
- Codacons. (n.a.). *Sportello Disabili* [website]. Retrieved from <https://codacons.it/sportello-disabili/>
- Convenzione delle Nazioni Unite sui diritti delle persone con disabilità (2006). *Convenzione delle Nazioni Unite sui diritti delle persone con disabilità* [Treaty]. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Costituzione della Repubblica Italiana* (1947). [Constitutional law]. Gazzetta Ufficiale, n. 298, Serie generale. Retrieved from <https://www.senato.it/documenti/repository/istituzione/costituzione.pdf>
- Decreto Legislativo recante "Codice del Terzo settore"* (2017). Decreto Legislativo n. 117 (Gazzetta Ufficiale n. 160, 12 July 2017).
- Istituto Nazionale di Statistica (ISTAT). (2021, March 24). *Audizione dell'Istat presso il Comitato Tecnico Scientifico dell'Osservatorio Nazionale sulla condizione delle persone con disabilità* [PDF]. Retrieved from https://www.istat.it/it/files/2021/03/Istat-Audizione-Osservatorio-Disabilit%C3%A0_24-marzo-2021.pdf
- Legge istitutiva della protezione civile*. (2001). Legge n. 3 (Gazzetta Ufficiale n. 15, 18 January 2001).
- Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali*, Legge 8 November 2000, n. 328. (2000). [Law]. Gazzetta Ufficiale, n. 270, Serie generale.
- Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate*, 5 February 1992, n. 104. (1992). [Law]. Gazzetta Ufficiale, n. 42, Serie generale.
- Ministero della Salute. (n.a.). *Buone pratiche per la sicurezza delle cure sanitarie* [website]. Retrieved from https://www.salute.gov.it/portale/news/documenti/eventi/sicurezzaCure/buone_pratiche_sanita.pdf

Misure per la tutela giudiziaria delle persone con disabilità vittime di discriminazioni, 1 march 2006, n. 67. (2006). [Law]. Gazzetta Ufficiale, n. 54, Serie generale.

Norme per il diritto al lavoro dei disabili, Legge 12 march 1999, n. 68. (1999). [Law]. Gazzetta Ufficiale, n. 71, Serie generale.

Regione Emilia-Romagna. (n.a.). *Assistenza domiciliare - Assegno di cura* [website]. Retrieved from <https://salute.regione.emilia-romagna.it/socio-sanitaria/assistenza-domiciliare-assegno-di-cura>

Testo unico delle norme in materia di pensioni di guerra, Decreto del Presidente della Repubblica 23 december 1978, n. 915. (1978). [Decree]. Gazzetta Ufficiale, n. 22, Serie generale.

Unione Europea. (2010). *Strategia europea sulla disabilità 2010-2020* [Strategic document]. Retrieved from <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:it:PDF>

