

TOWARDS PERSON-CENTERED INTEGRATED CARE IN ITALY

INCEPTION REPORT



OECD Directorate for Employment, Labour and Social Affairs &
OECD Trento Centre for Local Development

Towards patient-centered integrated care in Italy Inception report (Output 1)

The aim of this inception report is to summarise the current situation and discussions in Italy on the integration of health and social services at home for dependent persons. Three sources were used for this. First, we reviewed the current scientific literature to evaluate the effect of policies promoting the integration of health and care services. Secondly, we analysed laws and guidelines at national, regional and autonomous province levels through a documentary study. Finally, to enhance the collected information, we conducted semi-structured interviews with a range of stakeholders. These included national and local authorities, institutions, civil society groups, trade unions, universities and research centres.

The report is the first output of a Technical Support Instrument project (no. 23IT26). The action was funded by the European Union via the Technical Support Instrument, and implemented by the OECD, in co-operation with the Directorate-General for Structural Reform Support of the European Commission.

This document was produced with the financial assistance of the European Union. The views expressed herein can in no way be taken to reflect the official opinion of the European Union

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Executive summary

In recent decades, Italian authorities have endeavoured to implement an integrated model of health and social care. However, successful initiatives have been sporadic and confined to a handful of areas. As a result, each region has used its specific expertise to adopt its own strategy. This has increased the notable differences and disparities within the country.

To address this division and offer a unified care strategy, the Italian Parliament passed Decree no 77 on 23 May 2022 and the National Plan for Dependency 2022-2024. The first sets out models and standards for developing local care within the Italian National Health Service (SSN). The second outlines the Essential Levels of Social Benefits (LEPS) for the first time, stating that home care, assistance and support services must be provided for older individuals who are dependent or have limited autonomy. Other key measures related to dependency include Law no. 227/2021 “Government delegation of powers on disability”, Law no. 33/2023 “Government mandate on policies supporting older people,” and the National Recovery and Resilience Plan approved by the European Commission on 22 April 2021. This plan outlines six missions, two of which are relevant for improving the integration of social and health services: mission 5 (cohesion and inclusion) and mission 6 (health).

The implementation of the project “Towards person-centered integrated care in Italy” contributes to the ongoing reform on strengthening integrated care at community level to better address the health and social needs of persons with severe limitations that prevent them from carrying out usual activities (i.e. dependent people) in Italy. This project aims to enhance the quality and availability of care for dependent people who receive home support in the long run.

The aim of this inception report is to summarise the current situation and discussions in Italy on the integration of health and social services at home for dependent persons. Three sources were used for this. First, we reviewed the current scientific literature to evaluate the effect of policies promoting the integration of health and care services. Secondly, we analysed laws and guidelines at national, regional and autonomous province levels through a documentary study. Finally, to enhance the collected information, we conducted semi-structured interviews with a range of stakeholders. These included national and local authorities, institutions, civil society groups, trade unions, universities and research centres.

This inception report emphasises:

- The ambiguity that characterises the definition of a dependent person
- The low intensity of services offered at home to dependent persons
- The weak link between formal and informal care
- The challenge of making home health and social care services more appealing to workers who care for dependent people
- The unique opportunity offered by the current legislative framework

1 The target population of the project

To assess the current state of care services for dependent people, we must define the target population. This involves identifying potential beneficiaries and quantifying them.

1.1. Defining the perimeter of dependency

A precise, internationally agreed definition of the dependent population that can be used to identify persons entitled to access integrated social and healthcare services does not yet exist. Box 1 gives the definition of long-term care and disability. These two ideas are often used in social and healthcare services. They help to explain the Italian legislation and put them in a wider international setting.

In Italy, the 2022-2024 National Plan for Dependency (PNNA) targets older people with high or low care needs and those with serious or severe disabilities (Ministero del Lavoro e delle Politiche Sociali, 2022^[1]).

This inception report is part of the “Towards person-centered integrated care in Italy” project. It focuses on Italy’s dependent population. In this context, therefore, the dependent population is defined as described in the PNNA, including:

- Dependent older persons (≥65 years) with low or high care needs;
- Individuals with serious or severe disability, including those classified as civil invalids, people with disabilities or handicapped as per Italian law and listed in Table 1.

With the exception of the definitions of persons with civil invalidity, disability or handicap given in Table 1, the assessment of care needs (low or high) and of disability (serious or severe) is left to the regional level, through the use of multidimensional assessment tools (e.g. SVAMA, SVAMDI, VALGRAF).

Box 1. Definitions of *long-term care* and *disability* in Italy and OECD countries

Internationally, two concepts often mentioned in relation to care services for dependent people are long-term care and disability care services.

Long-Term Care (LTC)

The OECD describes long-term care services as medical, personal care and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people with a degree of long-term dependency, assisting them with their personal care (through help for activities of daily living, ADL, such as eating, washing and dressing) and assisting them to live independently (through help for instrumental activities of daily living, IADL, such as cooking, shopping and managing finances) (OECD/Eurostat/WHO, 2017^[2]).

While the OECD does not limit long-term care by age, some countries do. For example, Japan sets a minimum age for long-term care. In contrast, Lithuania offers these services to all ages. Furthermore, most people getting long-term care in OECD countries are over 65. On average in 2019, only 25% of

long-term care service users in OECD countries were under 65 years old (OECD, 2021^[3]). Looking at *long-term care* services at home, in 2021 on average in OECD countries 69% of people receiving *long-term care* at home were aged 65 years or older (OECD, 2023^[4]). The high demand for long-term care in those over 65 is partly due to more chronic diseases in old age and an ageing population, leading to a higher percentage of people aged 65 and over.

Italian law still does not define long-term care or specify who should receive these services. The idea of disability, however, has been frequently revisited and honed by Italian law in recent decades.

Disability

Under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), a person with disabilities is someone with long-term physical, mental, intellectual or sensory impairments that may limit their full and active participation in society. Disability is therefore defined as a social construct, stemming from the interaction between individuals with disability and their environment. This definition also acknowledges that the CRPD recognises disability as a concept that changes over time. Assessing disability and comparing nations can be complex due to the changing nature of its definition (OECD, 2022^[5]).

Italian law currently recognises three distinct definitions of disability. Each one determines eligibility for different support services: civil invalidity, handicap and disability. Table 1 summarises the definitions of these terms, as stated in current law. Law no. 227 of 2021 outlines a process to revise and restructure the definition and laws related to disability. The law seeks to match the Italian disability definition with the CRPD's proposal. To achieve this, the Minister for Disabilities established a drafting committee on 9 February 2022 to review and restructure the current disability provisions.

Table 1. Types of disability under Italian law

Types of disability	Reference legislation	Definition
Civil invalidity	Law no. 118 of 1971	Civil invalids are citizens with congenital or acquired disabilities, including progressive ones. This includes those with mental disabilities due to organic or metabolic issues, and those with mental deficiencies from sensory and functional defects. They have a permanent work capacity reduction of at least a third, or if under 18, they have ongoing difficulties performing age-appropriate tasks and functions. War, work or service invalids, as well as the blind and deaf-mute covered by other laws, are excluded.
Handicap	Law no. 104 of 1992	A "handicapped" person is someone with a physical, mental or sensory impairment, whether steady or worsening, that hinders learning, social interaction or work integration, leading to social disadvantage or marginalisation.
Disability	Law no. 68 of 1999	The following are defined as people with disabilities: (a) People of working age with physical, mental or sensory disabilities, and those with intellectual disabilities, who have a work capacity reduced by more than 45%, as confirmed by the relevant disability assessment boards; (b) People unable to work due to a disability level over 33 per cent, confirmed by the National Institute for Work Accident Insurance (INAIL) following current rules; (c) persons who are blind or deaf; (d) People disabled by war, civilian war casualties and service-disabled individuals.

Source: OECD Secretariat

1.1.1. Figures on dependency in Italy

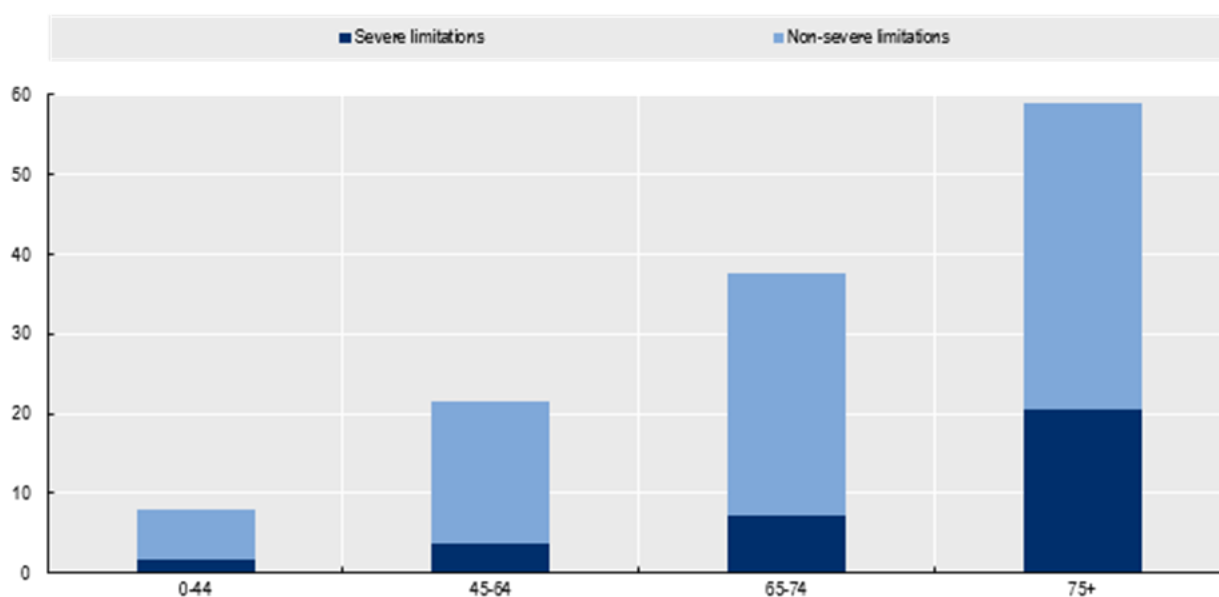
In Italy, varying definitions of dependency create a disjointed view of the dependent population and the health and social services they use.

The National Institute of Statistics (ISTAT) routinely releases estimates of the Italian population with major and minor limitations. These estimates are worked out using a globally accepted measure that is part of the European statistics system: the Global Activity Limitation Indicator (GALI)¹. The indicator displays the proportion of people who report health issues hindering their ability to carry out normal activities. People living in residential facilities are excluded from this indicator.

In 2021, 5% of the population reported severe limitations, while 16.4% reported non-severe ones. This result indicates that 12,767,000 Italians, living in their own homes, report health problems that limit their daily activities. Limitations vary greatly among different age groups. In the under-45 population, 7.9% report limitations (both major and minor). This figure jumps to 59.1% in those over 75 (Figure 1) (ISTAT, 2023^[6]). It is important to note that this figure might underestimate the actual service need. It relies solely on data from people living at home who took part in the survey.

Figure 1. Almost 60 per cent of the population over 75 years of age say they have limitations

Persons with major and minor limitations in their usual activities (percentages), by age, 2021



Source: (ISTAT, 2023^[6])

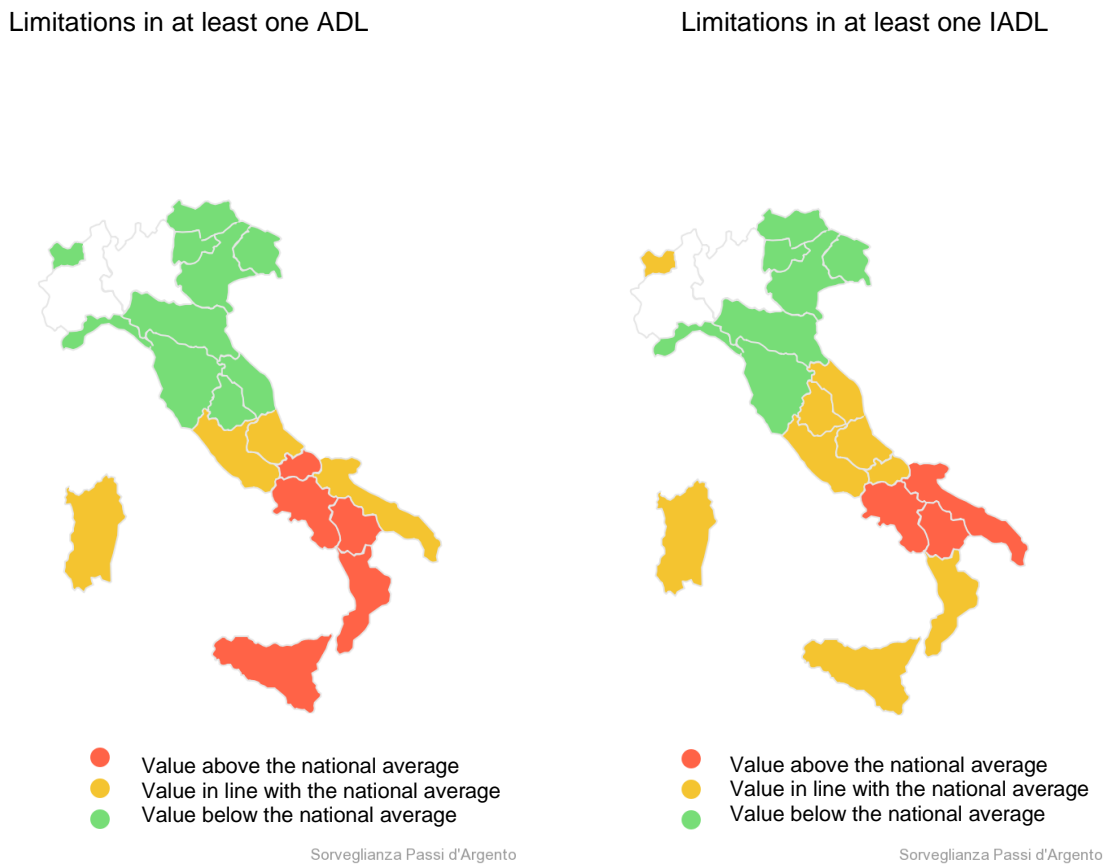
Given the high number of individuals with limitations to their independence among older people, a detailed study of those aged 65 and over could help provide a clearer understanding of care needs in Italy. The “PASSI d’argento” study from the Istituto Superiore di Sanità (ISS) provides data on the health and autonomy of older people², aged 65 and above. Data from 2021-2022 reveals that roughly 13% of people

¹ The indicator is based on the following question: How much have health issues, lasting at least six months, limited your usual activities? (Severe Limitations, Mild Limitations, No Limitations) The question is asked to people living in homes, not including those in residential facilities.

²The analysis does not include people in institutions, such as the older people in assisted living (RSA), nursing homes (RSSA), or retirement homes.

aged 65 and over have at least one limitation in their Activities of Daily Living (ADLs). This means they struggle with basic tasks like eating, dressing, washing, moving around the house, maintaining continence, and using the toilet. 17% of older people (65 years or older) have at least one limitation in performing complex daily tasks, such as cooking, housekeeping, taking medication, moving about, managing money or using a phone. These tasks are known as Instrumental Activities of Daily Living (IADLs). Once again, the data reveal a notable rise in limitations with increasing age. Among individuals aged 85 and above, 41% and 34% respectively require assistance with at least one ADL and IADL. The dependent population is distributed unevenly across the country. The south and islands have a higher rate of people with limitations, while the north has a lower rate (Figure 2).

Figure 2. The prevalence of individuals aged 65 years and above with limitations in Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) varies between regions



Source: (ISS, 2023_[7])

2 Social care services for dependent people in Italy

Dependent people in Italy may receive support in the form of cash transfers, formal services in residential or semi-residential facilities, formal services provided at home and informal support from family members, friends or personal helpers.

Among cash transfers, the most common is the support allowance from INPS for those certified as fully disabled. The allowance is €515 per month and there is no income requirement to get it. In some cases, municipalities also provide money transfers (like care allowances or vouchers). The rules for getting these, how much you get, and how you can use them, differ across municipalities.

Semi-residential and residential services provide day and round-the-clock care to dependent people, respectively. Access conditions, service offerings and their costs differ by region.

Finally, dependent people can access home services.

This report analyses home care services, as defined by Legislative Decree no. 299/1999, which include:

- Healthcare services with strong medical integration, provided at home. This includes all activities with significant therapeutic importance and intensity, mainly related to maternal and child care, care for older people, disability, mental health issues, and addiction to drugs, alcohol and substances. It also covers illnesses due to HIV and terminal diseases, as well as inability or disability resulting from chronic degenerative diseases.
- Health services of social importance offered at home, i.e. activities aimed at health promotion, prevention, detection, removal and containment of degenerative or disabling outcomes of congenital and acquired diseases. These activities, considering environmental factors, aid in social involvement and personal expression.
- Certain home-based health and social services are provided to support individuals in need. These services are designed to help those facing health issues due to disability or social exclusion. They include help with everyday tasks like eating, washing and dressing (Activities of Daily Living – ADLs), as well as assistance with household chores like cooking, shopping and managing money (Instrumental Activities of Daily Living – IADLs).

In Italy there are two types of home services for dependent people: The Integrated Home Care (ADI) and the Home Care Service (SAD). ADI primarily involves nurses providing healthcare services. Services are accessed based on the level of care needed. SAD services are social benefits often supplied by the third sector, given after assessing income and needs.

Data show a high demand for health and social care services nationwide, which the current formal care services for dependent individuals cannot meet. Nearly everyone aged 65 and over with at least one limitation in ADLs and IADLs reports getting help (98.8% and 99.3% respectively). However, most of them get informal help from family, acquaintances, friends, or personal carers, as shown in Table 2.

Table 2. Informal care is the primary support for older people who cannot do their usual activities due to limitations (i.e. dependent people).

Proportion of older people with one or more limitations in ADLs and IADLs receiving formal and informal care services

Type of assistance received	Older people with at least one limitation in ADLs	Older people with at least one limitation in IADLs
Family members	94.8%	96.1%
Acquaintances, friends	10.8%	13.4%
Voluntary associations	2.5%	1%
Person identified and paid on their own (e.g. carer)	38.5%	21.1%
Home care by public service providers e.g. AUSL, municipality	11.1%	2.4%
Day care centre	2.2%	0.4%
Financial contributions (e.g. care allowance, accompaniment)	25.9%	6.8%

Notes: More than 100% of older people with at least one ADL limitation use the services listed. This is because the services are not exclusive. In other words, a dependent person can use home care services and also get informal help from family or paid personal helpers.

Source: (ISS, 2023^[7])

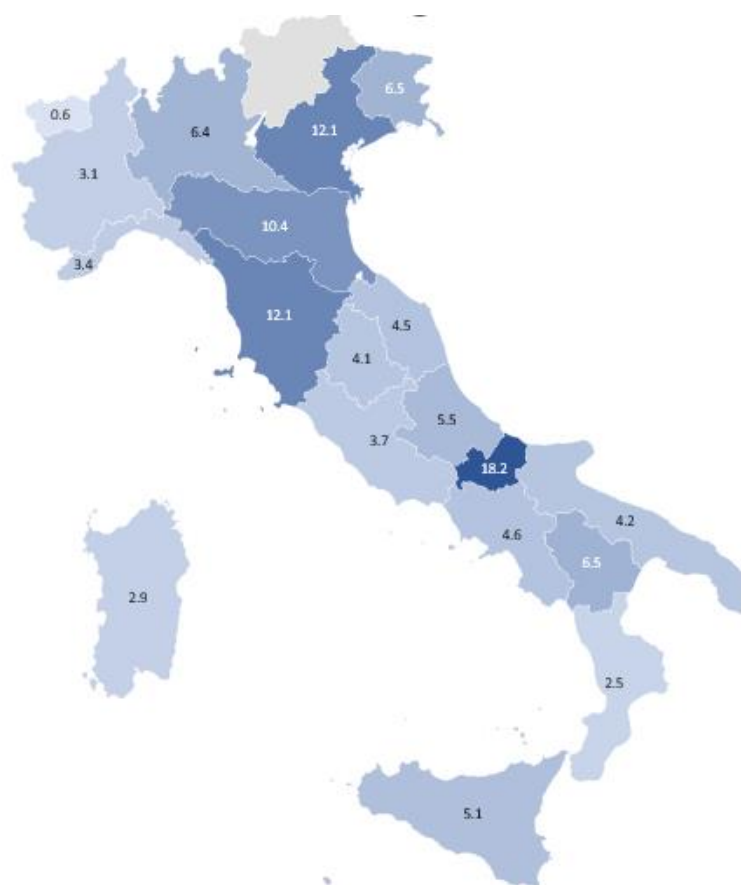
Home services currently make up a tiny portion of social and healthcare for dependent people. In 2021, Italy had 99 active integrated home care services, two less than in 2019 (Ministero della Salute, 2023^[8]). (Cinelli G., 2021^[9]) states that nearly half (48%) of the 2.9 million dependent older people who need care do not get public help. They only rely on their family and personal carers. The remaining 52% of dependent older people receive public services that do not meet their needs, primarily as cash allowances (in 63% of cases). Only 31% of older dependent people receiving public aid can access home services (ADI and/or SAD)³. In 2021, nearly 1.2 million cases were treated with ADI, as recorded by the Health Ministry. In the population aged 65 and over⁴, 6.3% used ADI services, though this varied by region. The lowest figure was recorded in Valle D'Aosta, with 0.6% (424 cases), while Molise recorded the highest figure, with 18.2% (16 708 cases) (Figure 3).

³The estimates from Cinelli G. (Cinelli G., 2021^[9]) draw on data from INPS, the Italian NHS statistical yearbook, municipal social spending data, and ISTAT surveys.

⁴ The figure relates to all people aged 65 and over, both with and without limitations on independence.

Figure 3. The percentage of the older population receiving ADI services in 2021 varies between 0.6% and 18.2%

Percentage of population aged 65 and over receiving ADI services in 2021, by region

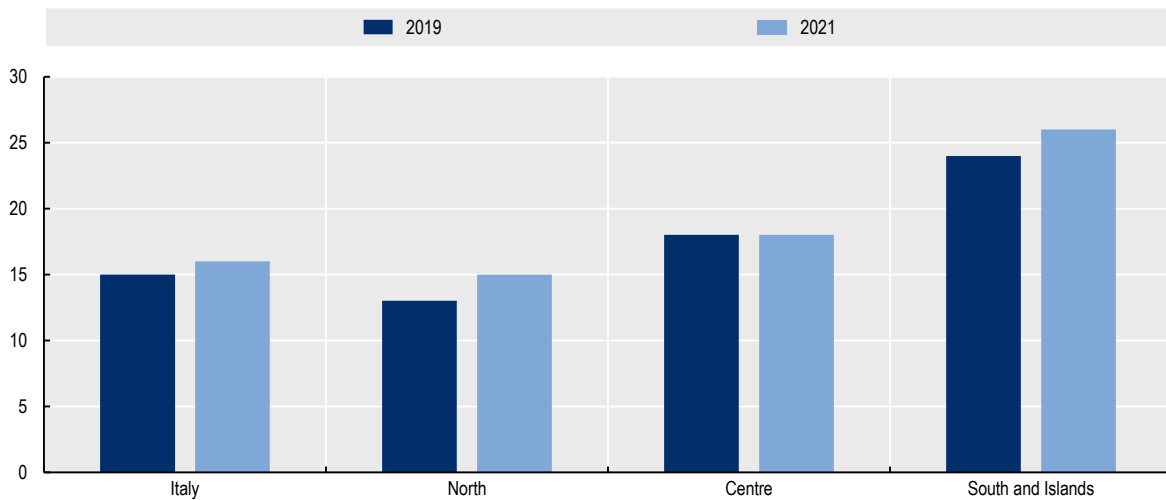


Notes: Autonomous Province of Bolzano: 1%, Autonomous Province of Trento: 6.3%
Source: (Ministero della Salute, 2023^[8])

Furthermore, the intensity of ADI services is not enough to give proper support to dependent people. According to Health Ministry data, in 2021, each older dependent person reliant on ADI will typically receive 16 hours of care annually. Nurses will provide 10 hours, rehabilitation therapists 3 hours, and other professionals will cover the remaining 3 hours. The figure has stayed quite steady in recent years, but with significant regional differences (Figure 4). Northern Italy has a larger older population but provides less intensive services, at 14 hours per case in 2021. Conversely, Southern Italy serves fewer older people with ADI services, but with more intensive care, at 30 hours per case in 2021. At present, therefore, ADI is limited to supporting dependent persons in their transition from a residential or hospital setting to a home setting.

Figure 4. On average in Italy, an older person receives 16 hours of ADI per year, with regional variations

Total ADI hours per older (65+) case, by geographical macro-areas, 2019 and 2021



Notes: North includes Piedmont, Valle D'Aosta, Lombardy, Autonomous Province of Trento, Autonomous Province of Bolzano, Veneto, Friuli Venezia Giulia, Liguria, Emilia Romagna. Centre includes: Tuscany, Umbria, Marche, Lazio. South and islands includes Abruzzo, Molise, Campania, Apulia, Basilicata, Calabria, Sicily, Sardinia

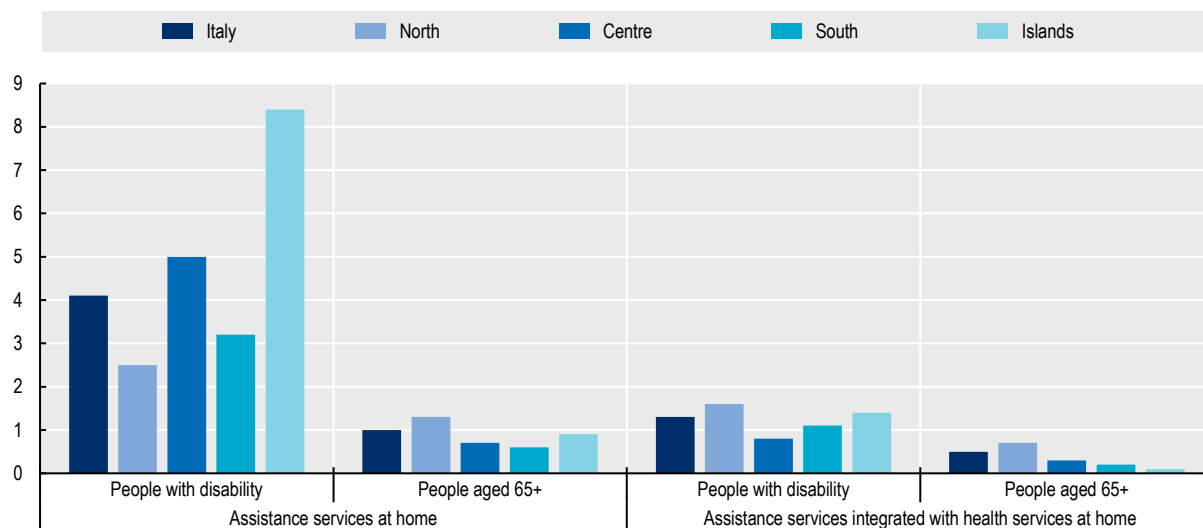
Source: (Ministero della Salute, 2023^[8])

Access to SAD services is even less advanced than ADI. Figure 5 shows the percentage of individuals with disabilities and those over 65 who receive home care and integrated health services from municipalities. This is broken down by geographic area, showing significant variation. In 2020, across the nation, 4.1% of people with disability got social welfare home care, and 1.3% got combined home care with health services. Of those aged 65 and above, 1% received social welfare home care, and 0.5% received combined home care with health services (ISTAT, 2020^[10]). The number of users is down compared to 2011.

To compensate for the lack of public aid for dependent people, over 1.1 million personal helpers (both regular and irregular) were present in Italy in 2021, as estimated by (CERGAS Bocconi, 2023^[11]).

Figure 5. Percentage of individuals with disability and older individuals receiving social care services at home, combined with health services.

Percentage of people with disabilities and those aged 65 and over who received social welfare home care and health-integrated home care services in 2020.

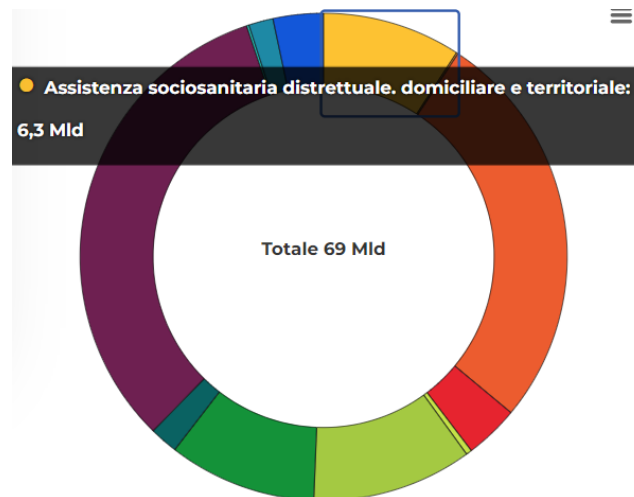


Source: (ISTAT, 2020^[10])

In 2021, the Italian NHS spent 69 billion Euro on care costs, 6.3 billion of which was for local, home and community care. District social and healthcare services include: support for those with addictions, help for children, women, couples, and families, support for children with mental and developmental disorders, assistance for people with disabilities, mental healthcare, and home care (Figure 6).

Figure 6. 9% of all Italian NHS spending on care levels is allocated to district, home and community-based health and social care.

Total Italian NHS expenditure for levels of care, by type of care, 2021



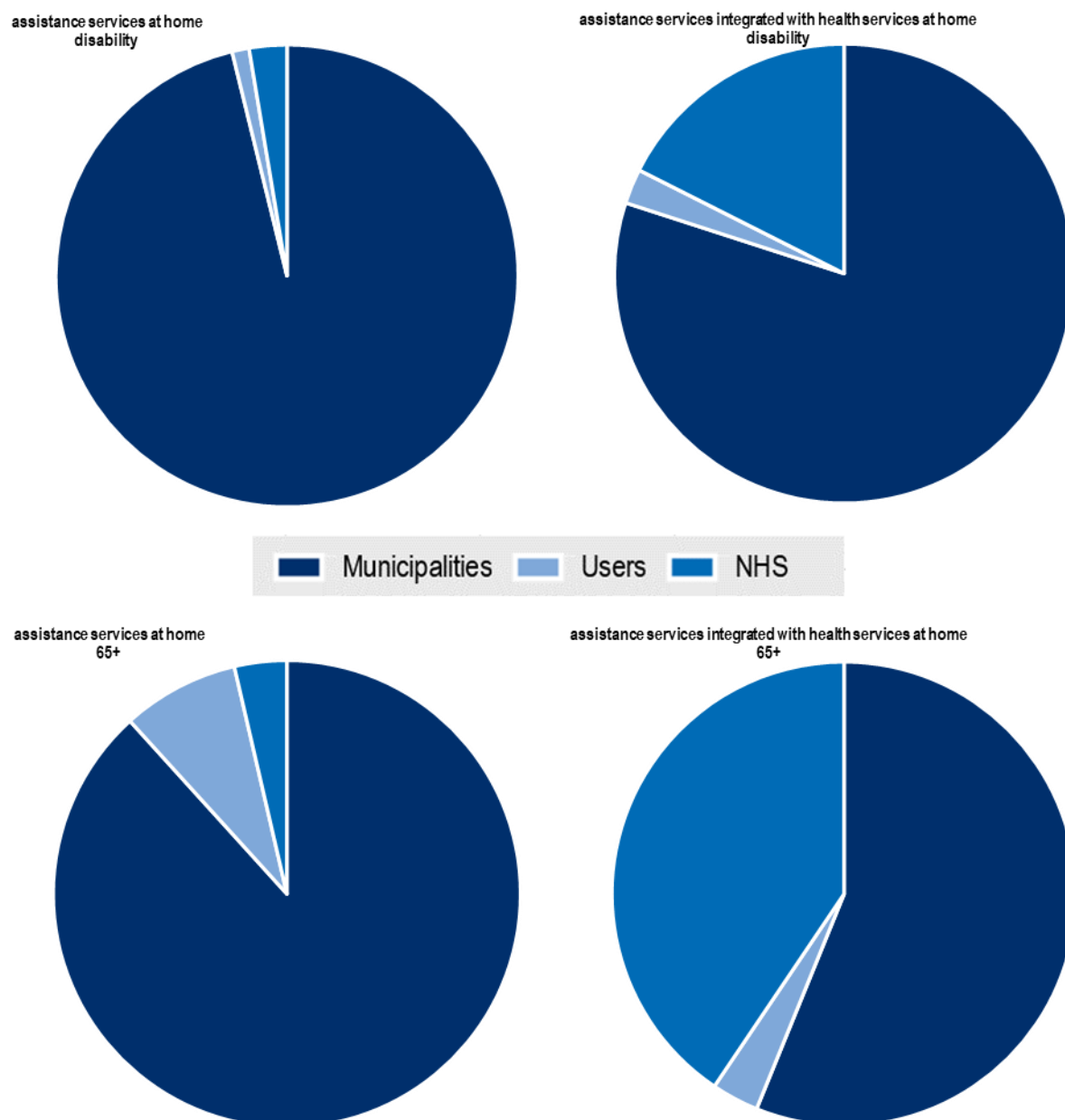
Source: (Open BDAP, 2023^[12])

Of the 6.3 billion Euro spent on local and home healthcare, 1.9 billion Euro is allocated to home care, with significant regional differences. In 2021, Veneto recorded the highest home care expenditure at nearly 246 million Euro, while Molise had the lowest at just over 56 million Euro. This figure does not consider varying regional needs, so it is not meant to be a qualitative judgement of regional comparisons.

SAD services are primarily funded by municipalities, contributing between 56% (for integrated home care for older people) and 96% (for social assistance home care for people with disability) of the total cost for these services. The Italian National Health Service (Italian NHS) primarily funds integrated home care services for older people, covering 41% of the total cost. The fee for home care services, paid directly by users “out of pocket”, ranges from 1% to 8% (Figure 7).

Figure 7. Municipalities are the main source of funds for SAD services

The contribution to overall spending on home care services by municipalities, the Italian NHS and users.



Source: (ISTAT, 2020^[10])

It is important to note that Italy lacks a unified database to match the care needs of dependent people with available services. Box 2 provides an overview of existing information and monitoring systems and discusses the need to grow and enhance the monitoring system. It also highlights the importance of making the most of the data we have now.

Box 2. Information systems and surveys on health and care services provided at home

In Italy there are various information systems and several sample surveys have been carried out aimed at tracking the number of non-self-sufficient individuals, the use of home services and the related costs of provision. The most significant databases and investigations are summarized below.

Sistema Informativo Unitario dei Servizi Sociali (SIUSS) (Ministry of Labour and Social Policies)

The establishment of the Sistema Informativo Unitario dei Servizi Sociali (SIUSS) - managed by the Ministry of Labour and Social Policies - aims to guarantee complete knowledge of social needs and the services provided by the integrated system of interventions and social services. This includes all information necessary for planning, management, monitoring and evaluation of social policies. Furthermore, the system has the task of monitoring compliance with the Essential Performance Levels, intensifying controls on unduly obtained benefits and providing a unified database useful for the planning and integrated design of interventions. This is achieved through integration with other relevant information systems, such as healthcare, employment and other areas of intervention, in addition to the performance management databases already available to municipalities. Finally, the SIUSS is used for data processing for statistical, research and study purposes.

They are part of the SIUSS and are of particular interest:

- The databases of social benefits (PS) and the database of subsidized social benefits (PSA) with regards to the collection of data on the SAD and ADI benefits (for the social component) provided.
- The disability and non-self-sufficiency database (SINA) for multidimensional assessment data of non-self-sufficient people who benefit from home-based services.

Statistics Office of the Ministry of Health (General Directorate of digitalisation, health information system and statistics)

The Statistics Office of the Ministry of Health is responsible for fulfilling the requirements of the European Statistical System and coordinates the Report on the health status of the country. The office applies the principles and provisions of the Official Statistics Code and is dedicated to research and statistical publications in the health sector. It is also responsible for monitoring, verifying, processing, analyzing and disseminating data regarding the structures, resources and activities of the National Health System (NHS), providing support to the general directorates of the Ministry and other competent bodies, both national and international. For example, the office collects data on the number of people receiving ADI each year, and the number of ADI hours provided.

Sistema Informativo per il Monitoraggio dell'Assistenza Domiciliare (SIAD)

The Sistema Informativo per il Monitoraggio dell'Assistenza Domiciliare (SIAD) - managed by the Ministry of Health - aspires to create an integrated national database, centered on the patient, to collect information on health and social-health interventions provided in a programmed manner by the operators of the National Health System in the context of home care. The interventions taken into consideration are exclusively of a health and social-health nature. The information collected covers areas such as the patient's demographic characteristics (without direct identifying elements), the socio-health assessment or re-evaluation and the related care needs, the provision of care, the suspension of care and the patient's discharge.

Open BDAP

OpenBDAP is the website of the State General Accounting Office which makes the data relating to public finances stored in the Public Administration Database (BDAP) accessible in a clear and transparent way. The numerous information and data managed by the State General Accounting Office are organized into thematic sectors, one of which is the Finance of National Health Service Entities, which includes information on NHS spending for levels of assistance.

Surveys by the National Institute of Statistics (ISTAT):

In compliance with the guidelines of the European statistical system, ISTAT uses a single indicator, known as the Global Activity Limitation Indicator (GALI), in its population surveys. This indicator identifies individuals who report limitations in performing daily activities due to health problems.

The survey on social interventions and services of individual or associated municipalities offers data on welfare services at local level. Specifically, the survey covers the number of users and expenses incurred for social services (including SAD) offered by municipalities, provinces, regions and other territorial bodies that support or replace municipalities in this function. Furthermore, it provides details on the organization of services in the communities, on costs shared between families and the National Health System, and on sources of financing.

PASSI d'Argento of the Istituto Superiore di Sanità (ISS)

PASSI d'Argento is a survey focused on individuals aged 65 or over and complements the PASSI system, which is aimed at adults. This public health initiative collects data on the health and behavioral risk factors linked to chronic non-communicable diseases from the older population residing in Italy. Initially launched as a pilot project in 2009 and then formalized in 2012 as a cross-sectional survey, it has been an ongoing survey since 2016. Coordinated by the Istituto Superiore di Sanità and managed by the Local Health Authorities and the Regions, it provides territorial data useful for orienting and evaluating preventive strategies over time.

Possible areas for improvement

While there are data on dependency and on people helped via ADI or SAD, there is no specific database linking those dependent people assisted in ADI and/or SAD. This information gap significantly hinders effective planning and evaluation of care policies for dependent people.

Furthermore, the data available mainly concentrates on service coverage, rather than the intensity, quality or suitability of care. Information is often gathered from ad hoc surveys, which might be sample-based and need substantial delay and processing times. This practice curbs their utility for service planning and assessment. In addition, the current data collection and monitoring system offers a performance-focused perspective without providing an integrated view of the care pathway. This emphasises the need to enhance and update the data and monitoring system to better guide policies and strategies in care for older people (Patto, 2023^[13]).

In addition to expanding and enhancing current information sources, it is crucial to optimally utilise the existing databases. For instance, systems like the SIAD (Home Care Monitoring Information System) are a useful information resource that could be better used through broader sharing and use by government bodies.

3 A look at the international landscape of services for dependent people

Integrating social and health services for dependent people is a complex, yet central issue in many OECD countries and in the European Union policies (Box 3). The growing older population and rise in chronic illnesses have made the needs of dependent people more crucial. Over the past decades, many international laws and reforms have been implemented to address this. To fully grasp the challenges and opportunities of social and health integration in Italy, it is helpful to examine international experiences, understand the context, the actions taken, the hurdles encountered and the positive results.

Box 3. The regulatory framework and initiatives of the European Union

The **European Pillar of Social Rights** for social services states in its principle 18 that everyone has the right to affordable LTC services of good quality, in particular homecare and community-based services. Care being the competence of Member States, the EU supports them through legislation such as the Work-Life Balance Directive, and with guidance and funding, monitoring and analysis.

On 7 September 2022, the Commission put forward a **European Care Strategy** that sets out a vision for transforming care to ensure quality, affordable and accessible care services across the European Union and improve the situation for both care receivers and the people caring for them, professionally or informally. In parallel, the Commission proposed two Council recommendations, one of them on access to affordable high-quality LTC. It recommended that Member States establish high-quality criteria and standards for all LTC settings and ensure fair working conditions for carers, including attractive wages in the sector, by promoting national social dialogue and collective bargaining. To address skills needs and worker shortages, Member States should also design and improve initial and continuous education and training, build career pathways through reskilling and upskilling, establish pathways to a regular employment status for undeclared LTC workers, explore legal migration pathways for LTC workers and make the profession attractive to both men and women.

The European Commission **2023 Flagship Technical Support Project** “Towards person-centred integrated care in Italy” aims at helping member states to design and implement structural reforms in the areas of health, social and long-term care. It will help strengthen the coordination between those sectors and the integration of the different levels of care provision.

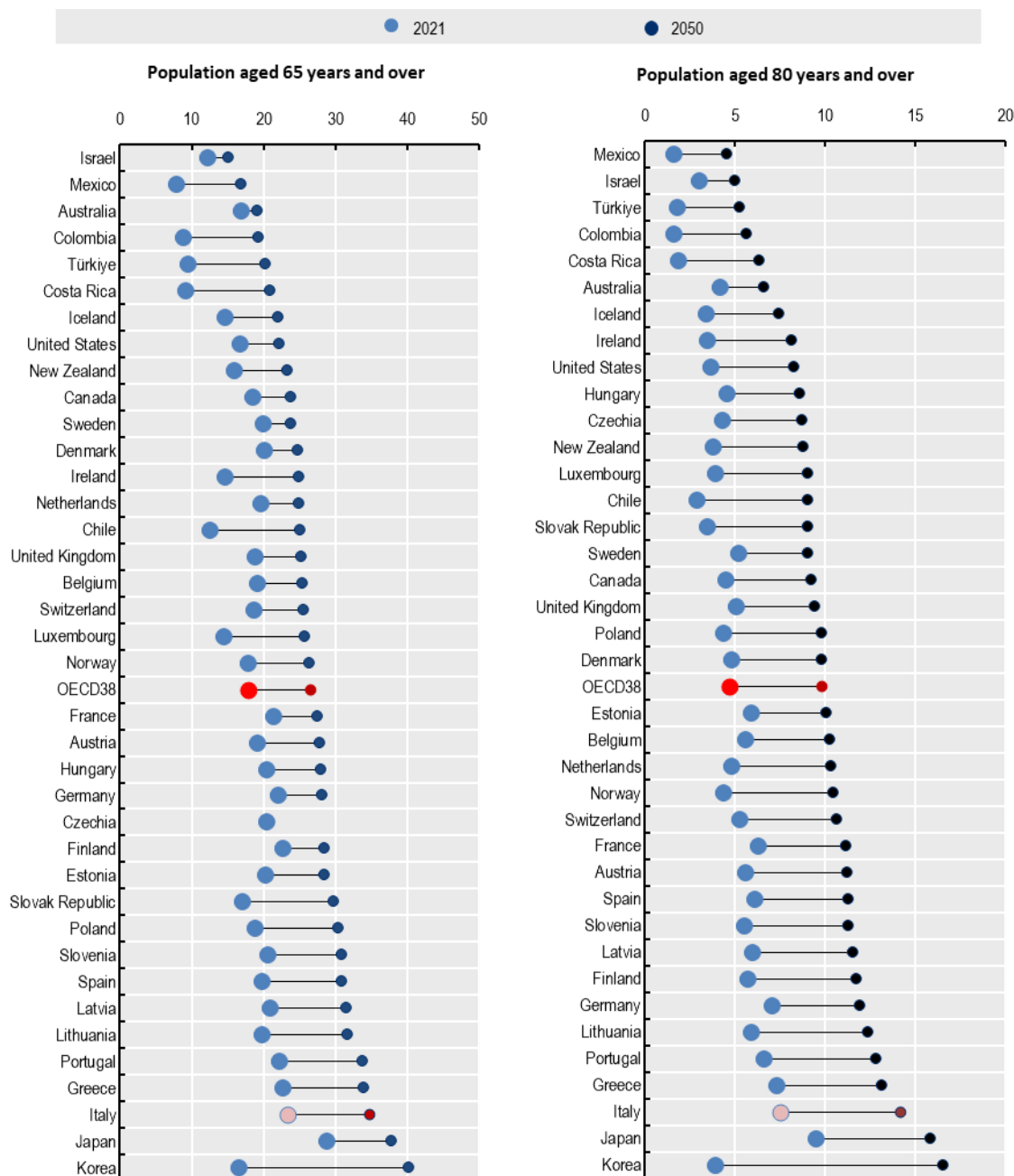
3.1. Dependency: a growing trend among OECD countries

In recent decades, OECD countries have seen a trend of an ageing population and a rise in chronic diseases. The older population has doubled in recent decades and is expected to rise further in the coming years. Indeed, the number of people aged 65 and over has increased from 9% to 18% of the total population in OECD countries, from 1960 to 2021 (OECD, 2023^[4]). OECD estimates also forecast a rise

to 27% by 2050. Italy is currently second only to Japan as the OECD country with the highest proportion of people aged 65 and over. In 2021, those aged 65 or over made up 23.6% of Italy's population (Figure 8).

Figure 8. Italy has the second-highest percentage of older population in the OECD

Proportion of population aged 65 years and over (left) and 85 years and over (right), in 2021 and 2050



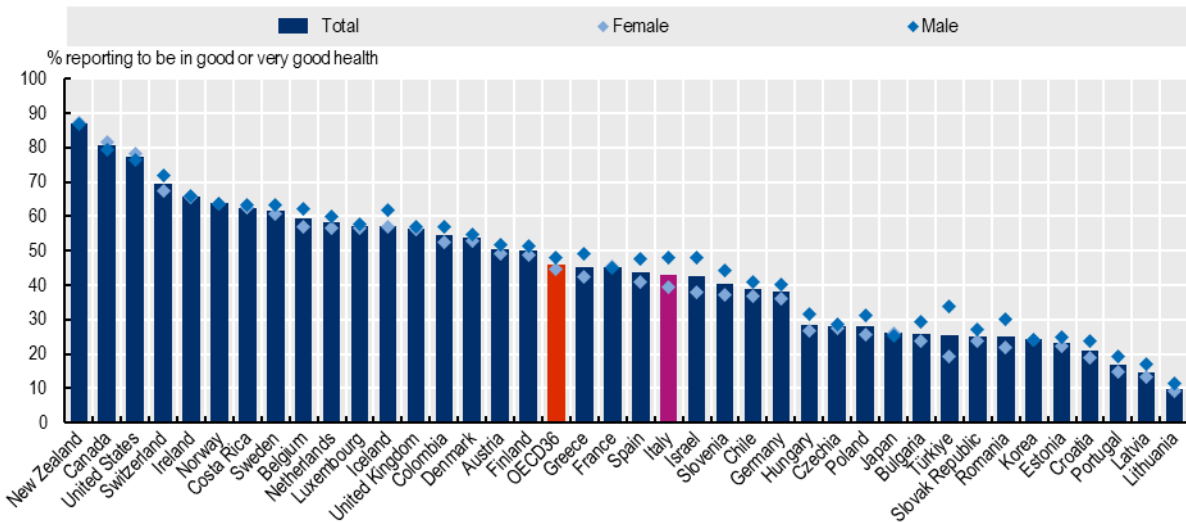
Source: (OECD, 2023^[4])

A larger older population also means a bigger dependent population. Indeed, Italy has a higher demand for care for dependent people than the average for OECD countries. On average, 46% of adults aged 65 and over in OECD countries report having good or excellent health. Italy falls below the OECD average,

with 43% of adults stating they have good or very good health. There is also a higher than average gender gap (Figure 9).

Figure 9. 43% of the older population in Italy declares a good or very good health

Adults aged 65 and over rating their own health as good or very good, 2021 (or nearest year)



Note: Data for New Zealand, Canada and the United States are biased upwards relative to other countries, and so are not directly comparable. Source: OECD Health Statistics 2023.

The European Health Interview Survey (EHIS) confirms that in Italy the rates of dependency are higher than the EU average. Specifically, the proportion of people in Italy aged 65 and over who report struggles with personal care or household tasks surpasses the EU average when considering those with severe difficulties and the older age group (75 and over) (Table 3). In Italy, 28.8% of interviewees say they struggle greatly with personal care or household tasks, compared to an average of 26.6% across the EU. Specifically, 18.4% and 43.9% of Italians aged 75 and over report severe limitations in ADLs and IADLs, respectively. This is higher than the EU average, which is 14% and 38.3% respectively.

Table 3. Dependency rates are higher in Italy than the EU average

Percentage of older people (65 years and over) in selected EU countries in 2019, struggling with personal care or household tasks, categorised by difficulty level and age group.

	Difficulties in personal care or household activities			Serious ADLs			Serious IADL		
	None	Moderate	Serious	65-74	75 +	Total	65-74	75 +	Total
Italy	52.0	19.1	28.8	2.6	18.4	10.6	12.3	43.9	28.2
European Union (27 countries)	50.3	23.1	26.6	3.3	14.0	8.4	14.7	38.3	25.8
Austria	54.9	18.0	27.1	2.6	19.3	10.8	10.5	43.1	26.5
Belgium	52.6	17.5	29.9	4.1	19.8	11.4	15.6	45.4	29.3
Denmark	62.8	22.3	15.0	0.9	6.9	3.5	7.6	23.5	14.4
Finland	54.7	27.1	18.2	1.9	7.9	4.4	8.7	29.6	17.2
France	57.3	21.2	21.5	3.5	12.1	7.3	11.8	30.7	20.1
Germany	55.7	27.0	17.3	3.7	9.2	6.6	8.0	23.5	16.2

Greece	49.3	21.7	29.0	3.3	15.1	9.3	13.6	44.0	28.9
Ireland	59.8	19.4	20.8	1.9	7.7	4.2	12.2	34.1	20.8
Malta	52.9	24.5	22.6	1.1	6.8	3.3	13.3	37.9	22.6
Netherlands	41.1	32.0	26.9	4.2	14.9	8.5	16.9	39.0	25.9
Poland	36.2	27.9	35.9	3.9	16.4	8.9	20.4	58.1	35.5
Portugal	47.5	19.9	32.7	2.7	16.5	9.4	18.0	46.3	31.6
Slovenia	54.0	16.5	29.5	2.8	16.3	9.0	13.7	46.8	28.9
Spain	56.3	14.8	28.9	3.2	16.3	9.5	14.6	43.0	28.4
Sweden	61.8	26.0	12.3	1.3	7.3	4.0	5.6	19.1	11.8

Notes: The indicator is worked out by leaving out missing values. The respondent decides if their personal care or household tasks are very hard or not, based on their answer to the question “How much do health issues limit your usual activities? Would you say you have severe, non-severe or no limitations?”

Source: (ISTAT, 2023^[14])

The increased care requirement in Italy appears to stem from women’s lower independence. On average, 19.2% of Italian men report serious issues with personal care or household tasks, matching the EU average of 19.3%. However, 28.8% of women report the same, which is above the EU average of 26.6% (ISTAT, 2023^[14]).

Of those with serious difficulties with personal care or household tasks, 42.9% say they get enough help (Table 4). This is more than the EU average of 40.1%, but it also reflects a heavy reliance on informal care, as mentioned earlier (see Table 2) (ISTAT, 2023^[14]).

Table 4. Access to forms of assistance for dependency in Italy is higher than the EU average

Percentage of individuals with serious difficulties in personal care or household tasks, according to the level of assistance received, in a range of EU countries, 2019.

	Help not needed	Sufficient help	Lack of help
Italy	13.0	42.9	44.2
European Union (27 countries)	13.4	40.1	46.5
Austria	7.2	60.4	32.4
Denmark	21.2	35.8	43.0
Finland	13.6	16.0	70.4
France	15.4	45.9	38.7
Germany	6.0	44.3	49.7
Greece	3.9	53.0	43.1
Ireland	13.2	38.3	48.5
Malta	26.9	16.9	56.3
Netherlands	17.2	58.3	24.5
Poland	22.7	30.6	46.7
Portugal	16.7	44.4	38.9
Slovenia	14.9	46.4	38.8
Spain	6.6	45.4	47.9
Sweden	8.1	38.3	53.6

Notes: The indicator is calculated excluding missing values

Source: (ISTAT, 2023^[14])

3.2. The formal and informal workforce for care services for non-self-sufficient people

Although the need for integrated social and health care is growing, the aging population and difficult working conditions make the supply of formal services insufficient to meet demand.

In the long-term care sector, low salaries, part-time and fixed-term contracts and physical and psychological risk factors are problems that have persisted for several years and that the COVID-19 pandemic has highlighted in many OECD countries. Workers in the long-term care sector⁵ earn on average 8% less than their counterparts employed in the hospital sector, faced with high physical and mental risk factors, which are above the labour market average. Approximately 65% of workers in the sector are exposed to mental risk factors and more than 70% to physical risk factors. Furthermore, in the LTC sector the female workforce is strongly predominant and represents 87% of the total workforce (Figure 10). This composition of the workforce, together with unrewarding working conditions, exacerbates the already existing gender gap in the labour market.

Figure 10. Long-term care working conditions make the sector unattractive



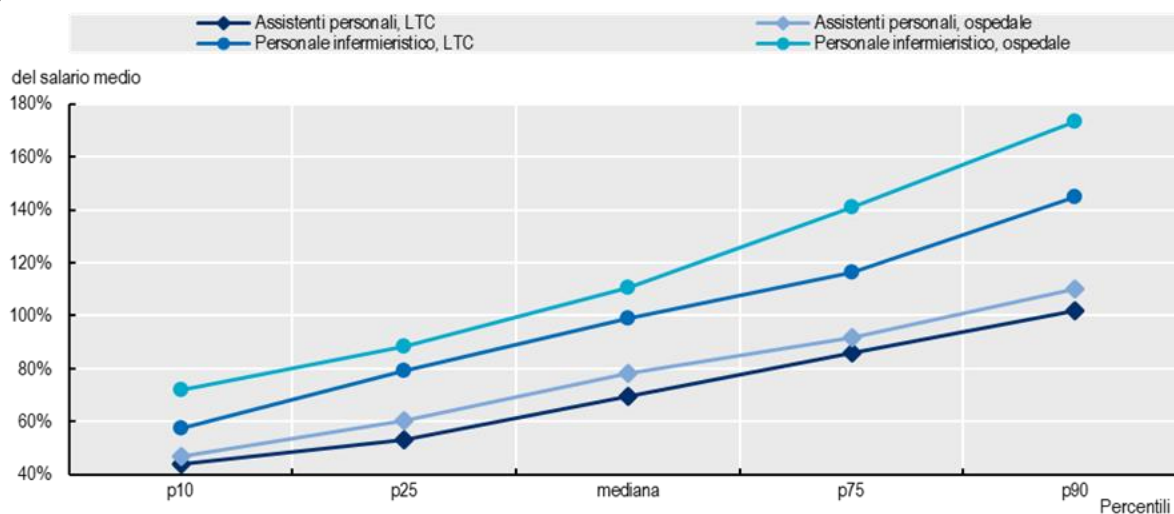
Source: (OECD, 2023^[15]).

Figure 11 shows in more detail that the compensation of workers in the LTC sector is on average lower than in the hospital sector. For both personal assistants and nursing staff, the average salary is lower in the LTC sector than in the hospital sector. The median wages for personal assistants and nursing staff in the LTC sector are 70% and 99% of the average wage in the total economy, respectively.

⁵ In this section, data on long-term care workers refers to nursing staff and personal assistants working in the sector.

Figure 11. LTC workers earn less than their counterparts in the hospital sector

Selected percentiles of the wage distribution of selected occupations in the LTC and hospital sectors, 2017 or latest year available



Note: Based on PIAAC microdata for 31 OECD countries. The LTC sector includes the following NACE sectors: 871, 873 and 881. The hospital sector is NACE sector 861. Personal care workers are identified by ISCO classification code 532.

Source: (OECD, 2023^[15]).

Difficult working conditions in the LTC sector are widely recognized among OECD countries. Some countries have implemented measures to improve the contractual conditions and social recognition of professionals working in the sector (Table 5). In particular, 16 countries have increased the remuneration of professionals in the LTC sector permanently or temporarily (e.g. through one-off bonuses awarded during the pandemic to reward the extraordinary efforts required of the sector during the shock). Furthermore, 8 countries have reformed the education system to allow students of some university courses to convert the experience previously gained in the LTC sector (e.g. as personal assistants) into the form of university training credits. Belgium and Ireland have also introduced mandatory training courses that LTC professionals must undertake annually to ensure the maintenance and improvement of skills. Finally, 5 countries have organized information campaigns to improve the social recognition of LTC professionals, in an attempt to increase the attractiveness of a career in this sector. Italy has not yet put into practice similar measures to improve the working conditions and social recognition of socio-health professions in the long-term care sector and, in general, the attractiveness of professional paths in the field of socio-health assistance services for people not self-sufficient.

Table 5. Measures implemented in OECD countries to improve the working conditions of professionals in the long-term care sector

	Permanent wage increase	Bonus or temporary wage increase	Obligatory education and training	Recognition of experience in education and training	Public information campaign
Australia	•	•			•
Austria					•
Belgium	•		•		
Canada		•			
Chile					
Colombia					
Costa Rica					
Czech Republic	•				
Denmark				•	
Estonia					
Finland					
France	•	•			
Germany	•	•			•
Greece					
Hungary	•	•			
Iceland					
Ireland			•		
Israel					
Italy					
Japan	•	•		•	•
Korea	•	•			
Latvia ¹	•	•			
Lithuania	•	•			
Luxembourg	•	•			•
Mexico					
Netherlands	•	•			
New Zealand					
Norway				•	
Poland					
Portugal				•	
Slovak Republic					
Slovenia	•	•			
Spain					
Sweden				•	
Switzerland				•	
Türkiye					
United Kingdom				•	
United States ²		•		•	

Note: ¹In Latvia, wages for LTC workers are set by municipalities, although within a range determined by law and government regulations. As part of a broader wage reform for public sector workers, which will gradually come into force over the period 2022-27, the maximum wage for LTC workers will be substantially increased and a minimum wage will be introduced. However, it is unclear to what extent LTC workers' wages will be impacted.

²In the United States, the federal government has not provided bonus payments to LTC providers in response to COVID-19, but bonuses have been provided by several states.

Source: (OECD, 2023^[15]).

The OECD has selected the following 7 areas in which countries can intervene to improve working conditions in the LTC sector and respect its professionals:

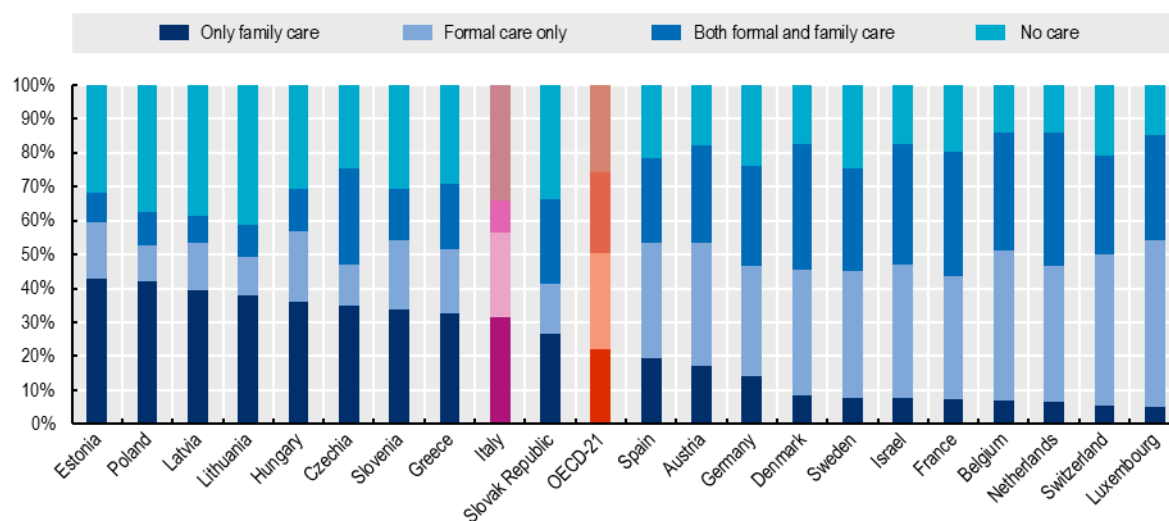
- Recognize, from an economic and social point of view, workers in the LTC sector
- Implement effective regulations to improve governance of the sector
- Establish sustainable and adequate financing
- Pay higher wages
- Equip the workforce with new technologies
- Collective bargaining tables to improve working conditions
- Training and continuous education for professionals in the sector

Faced with a formal sector currently unprepared to address the needs of social and health care, the informal sector plays a fundamental role in assisting non-self-sufficient people in OECD countries. Around 60% of older people (65 years or older) receiving care report receiving support only through the informal sector, while more than a third receive a mix of formal and informal services. In Italy, the percentage of older people who report receiving only informal services is higher than the OECD average, reaching almost 70% (Figure 12). Most people involved in caring for a family member or acquaintance are women who provide care for partners or their partners' parents. On average across 25 OECD countries, 61% of family caregivers providing care on a daily basis are women, often aged between 50 and 65. In Italy this percentage is above average and stands at 65%, based on 2020 data (Rocard and Llana-Nozal, 2022^[16]).

The predominant role of the informal sector is evident and cannot be underestimated. In parallel with measures to improve the working conditions of professionals in the formal sector of providing social and health services for non-self-sufficient people, it is essential to provide forms of regulation and support for family caregivers and informal personal assistants. The European Union directives on work-life balance, published in 2019, require that people who provide informal care services for a family member must take at least 5 days of annual leave from work to be able to dedicate themselves to care activities (European Commission, 2022^[17]). In Italy, leave for family caregivers is already quite well developed, with 3 days of paid leave every month. However, the integration between the formal and informal care sectors in Italy is rather lacking and requires further improvement actions, as discussed on page 49.

Figure 12. Around 60% of older people receiving care receive only informal care

Percentage of people aged 65 and older receiving care, by type of care they report receiving, 2020



Note: Family care is received from family and friends; formal care is delivered by paid carers. Countries are sorted by the number of people receiving formal care.

Source: (OECD, 2023^[15])

3.3. Legislation on the integration of social and health services in OECD countries

As stated, there is still no internationally accepted definition of dependent people. In many OECD nations, including Italy, people with limited independence often receive a blend of mainly health and social services. However, these services are frequently poorly coordinated. The governance of these services is therefore often divided between the Ministry of Health and the Ministry of Social Policy, and responsibility is often shared between central government and local authorities. Local authorities often lead in delivering services (OECD, 2022^[18]). The key role of the informal sector, such as family carers and personal helpers, along with the weak merging of information systems, are further common challenges faced by many OECD countries.

The fragmentation of care services for dependency is a challenge many countries face. More and more are taking steps to better integrate social and health services. Finland, Slovenia, Spain and the UK are currently going through a long process of reforming their health and social services. Achieving greater integration of social and health services involves improving integration at the political-institutional, organisational, functional and operational levels. The leading global examples of social-health coordination and integration mechanisms indeed incorporate elements to enhance integration at all levels - political, institutional, organisational, and care. Among the most frequently implemented measures in other European countries are the following:

- **Eleven OECD countries have a single ministry or department handling health and social policies** (Table 6). Italy also set up a unified Ministry for health and social policies in 2008, known as the Ministry of Labour, Health and Social Policies. In 2009, this Ministry was again divided into two separate entities.

Table 6. List of OECD countries with a single Ministry responsible for health and social policies

Country	Ministry
Austria	Ministry of Social Affairs, Health, Welfare and Consumer Protection
Colombia	Ministry of Health and Social Protection
Estonia	Ministry of Social Affairs
Finland	Ministry of Social Affairs and Health
Japan	Ministry of Health, Labour and Welfare
Korea	Ministry of Health and Welfare
Netherlands	Ministry of Health, Welfare and Sport
Norway	Ministry of Health and Care Services
Sweden	Ministry of Social Affairs
United Kingdom	Department of Health and Social Welfare
United States	Department of Health and Social Services

Source: OECD Secretariat, 2023

- **Setting up a single public body to manage services for dependent individuals.** In some countries, a single public body, sometimes specifically formed, manages social and health services for the older people, people with disability or dependent individuals. This approach aims to enhance the integration of governance and service delivery. In 2020, France gave the National Solidarity Fund for Autonomy (CNSA) a more prominent role. The institution, traditionally funding disability services, will fully fund and provide services for the older people and people with disability by 2030. Slovenia, currently reforming its long-term care system, also aims to give the health insurance fund more responsibility for managing long-term care resources.
- **Forming intergovernmental groups to boost communication between those involved in planning and managing services.** In other countries, including France and Spain, there are bodies in place to foster coordination between national and local actors in the field of *long-term care* services. For instance, the Territorial Council for Autonomy and Dependency Care is a Spanish entity where the regions and central government discuss the characteristics of dependency services. In France, a “funders” conference⁶ is required to discuss measures and funding for services for the dependent population over 60. In Finland, the reform process envisages the establishment of 21 “welfare service districts”, financed by the central government and in which responsibility for social and health services, currently managed by municipalities, will be centralised.
- **Activating coordination and communication systems among those involved in planning and managing services.** Other OECD nations have established coordination systems, such as intergovernmental committees and regular meetings, between the bodies in charge of services. This is to enhance integration and cooperation among various players. In Denmark, Finland, Norway and Sweden, the central government and local authorities meet regularly to discuss measures concerning services and possible difficulties. In Finland, for instance, the Health and Social Policy Ministry, the Interior Ministry and the Finance Ministry should hold yearly talks with each of the 21 aforementioned “welfare service districts”. In some countries, incentives also exist for local cooperation. In France, municipalities are incentivised to join so-called “public exercises for intermunicipal cooperation” (EPCIs) through specific subsidies intended only for municipalities participating in an EPCI.
- **The formal sector should recognise and integrate with family caregivers, personal helpers (carers) and foreign workers.** Family caregivers and informal carers often form the core of the care system for dependent individuals. The rising demand for care and staff shortages in many OECD countries highlight the need to acknowledge the informal sector’s role. It is crucial to support and formalise their role, and enhance their integration with the formal sector. Furthermore, foreign workers are becoming increasingly vital to the social and healthcare systems in many OECD countries. Currently, most OECD countries have support systems for family and informal carers. Around two-thirds of OECD nations offer care leave, though it is not always paid. Training opportunities are often scarce and typically provided online by the third sector. Several countries, such as Israel, Canada, Germany and Spain, have introduced measures to help regularise informal migrant carers. In 2022, Spain acknowledged the importance of foreign workers by streamlining immigration processes. This was done to promote and ease the legal immigration of social care assistants who are actively participating in training courses (European Commission, 2022^[17]).
- **Enhancing the integration of information systems in both the health and social sectors.** For instance, in Finland, the National Statistical Office (THL) is revamping the statistical system. Their goal is to establish a unified data register for all services, following the [Kanta model](#)⁶. It is worth

⁶The Kanta model is a unified, nationwide data system. It is shared among health and social sectors, pharmacies and people. Patient information is available through MyKanta in an electronic medical record. By 2020, 63% of Finnish adults were using MyKanta, showing its strong popularity. By 2024, Finland aims to boost the use of MyKanta. The new Electronic Health and Social Services Data Processing Act will require all providers to use it.

noting that Finland has a single Health and Social Policy Ministry. This likely makes coordinating and integrating data and services for dependent individuals easier.

- **Strengthening the workforce in the health and care sector:** The UK is firmly dedicated to backing the NHS, public health and social care staff, focusing on skills and abilities. The UK NHS plans to hire an additional 50,000 nurses and invest a minimum of £500 million in reforming adult care, as part of the “People at the Heart of Care” initiative. In workforce planning, the absence of common forums and clear understanding of required skills and multi-level duties causes competition for staff attraction and retention among social care providers, local authorities and the NHS. To address this challenge, Health Education England was tasked with studying long-term workforce trends in both social and health sectors. They provided a framework to steer planning for the next 15 years. In terms of training, the goal is to enhance both initial and continuous learning, particularly for staff bridging health and social care. This ensures they possess the necessary skills and knowledge for effective cross-sector collaboration. The UK NHS also plans to foster joint learning and professional growth on common topics like mental capacity and frailty. It aims to boost careers in both health and social care sectors to reinforce the view of health and social care as an equally valuable, integrated system. On the subject of career progression and mobility, barriers exist that hinder movement between different health and care sectors. To overcome these barriers, the UK NHS plans to introduce shared job roles across the health and social sectors, along with an “Integrated Skills Passport”. This will ease the transfer of skills and knowledge between the UK NHS, public health and social care. Ultimately, the UK NHS aims to broaden training in social care, aspiring for every medical student to gain hands-on experience in this field. This will encourage interdisciplinary teamwork and career flexibility (Department of Health and Social Care, 2022^[19]).

Table 7 summarises key legislation from 13 OECD countries, enacted in recent decades to enhance social and health integration for people with limitations on their independence. This provides insight into how different nations have legislated to improve care services.

Table 7. The regulatory framework of services for the dependent population, selected OECD countries

	Main legal acts structuring the LTC framework	Description
Austria	<ul style="list-style-type: none"> - Federal <i>Long-term care Allowance Act</i> (Bundespflegegeldgesetz), 1993 - Agreement according to article 15a of the Austrian Constitutional Act' between the Federal Republic and the federal provinces, 1993 - '24-hour home-based care', 2007 	<ul style="list-style-type: none"> - The Act codifies cash benefits for people in need of <i>long-term care</i> - This agreement defines the responsibilities of federal provinces. They are responsible for developing and upgrading the decentralised and nationwide delivery of institutional inpatient, short-term inpatient, semi-inpatient (day care) and outpatient/mobile care services. - The 2007 reform legalises privately organised 24-hour home-based care LTC, which is primarily dependent on temporary migrant carers from countries like the Slovak Republic and Romania.
Belgium	6th State Reform, 2014	<ul style="list-style-type: none"> - The federal level is responsible for home nursing and physiotherapy (Federal health insurance), service vouchers (Unemployment insurance and tax rebate), and integration allowance for persons with disability (Federal ministry of social affairs). Regions are responsible for residential care for older people, including price control, day care facilities, home care, care allowance for older people, other service vouchers and care for persons with disability. Only Flanders has a regional LTC insurance (VSB).
Denmark	Consolidation Act on Social Services, 2018 ¹ (first version in 1998)	<ul style="list-style-type: none"> -The Act on Social Services municipalities are responsible for residential care in a nursing home or in a non-profit care home, and that waiting time cannot exceed two months. The Act on Social Services also prescribes that the municipal council shall offer (i) personal care and assistance, (ii) assistance or support for necessary practical activities in the home and (iii) meals services. The assistance mentioned is offered to persons who are unable to carry out the activities due to temporary or permanent impairment of physical or mental function or special social problems
Estonia	Health Services Organisation Act The Social Welfare Act	<ul style="list-style-type: none"> - Nursing care service providers need to have a permit from the Health Care Board. The Ministry of Social Affairs regulates nursing services and requirements. - Municipalities to provide 11 social services (among them some LTC services), but not all municipalities abide by the law and the law allows broad interpretation.
Finland	- Health and social services reform in process	<ul style="list-style-type: none"> - 21 wellbeing services counties would be established in Finland and entrusted with the health, social and rescue services duties that are currently the responsibility of municipalities and joint municipal authorities. The counties would be public law entities that have autonomy in their areas. A county council, elected by direct popular vote, would be the highest decision-making body of wellbeing services counties. There would be five collaborative catchment areas for regional coordination, development and cooperation in healthcare and social welfare. The Government would confirm the strategic objectives of healthcare, social welfare and rescue services every four years. The Ministry of Social Affairs and Health, the Ministry of the Interior and the Ministry of Finance would hold annual negotiations with each wellbeing services county. The operation of wellbeing services counties would be financed mainly from central government funds and partly from client fees to be collected from the users of services.
France ²	<ul style="list-style-type: none"> - Specific allowance for dependency, 1997, reformed in 2002 - Law on solidarity and loss of autonomy, 2004 - the Hospital, Patients, Health and Territories Act, 2009 - Act on adapting society to an ageing population, 2015 	<ul style="list-style-type: none"> -The cash-for-care scheme is paid to any person aged 60 or over who needs assistance to accomplish everyday activities or who needs to be continuously watched over. Each level of dependency gives access to a maximum amount), which is then adjusted according to the recipient's needs and level of income. At home, the allowance is paid either to finance a specific 'care plan' in the home elaborated by a multidisciplinary team (health and social professionals from the <i>départements</i>) after an assessment of needs, or in a residential home. The APA represents over EUR 5 billion of expenditure, of which 70% comes from the <i>départements</i> and 30% from the CNSA. - The 2004 law introduced the CNSA (the national solidarity fund for autonomy), a new institution responsible for implementing policy measures aimed at older and people with disability -The 2009 law created a new regional institution representing central government that encompass regional and local health administrations and included interventions to the social sector -The 2015 law aims to support older people facing loss of autonomy, with a

		priority given to home-based care, but also included healthy ageing policies and housing adaptations.
Germany	- Long term care insurance, 1995, major reform in 2017	-Statutory health insurance (SHI) members are insured under the social LTCI scheme and all members with private health insurance (PHI) are insured under the private scheme. The structure and level of benefits does not differ between social and private LTCI. Since 2009, insurance has been mandatory for every citizen. In 2017, the social LTCI covered 72.7 million citizens and private LTC covered 9.4 million citizens (2015). Under the social LTCI, 71.9% of benefit recipients were being cared for at home, most of them by female family members or unpaid carers. In 2017, total expenditure on benefits paid under the social LTCI scheme was EUR 35.54 billion. The 2017 reform included an expansion of eligibility criteria to include mental and psychological disabilities (e.g. dementia). In 2017, the LTCI expenditure rose of 26% compared with 2016.
Latvia	- Law on Social Services and Social Assistance - Health care laws for health care - Programme of mobile teams, 2010	The official institutional norms are formulated in the Law on Social Services and Social Assistance, as well as in the internal regulations of the social service agencies. The official institutional norms are: assessment of the individual's needs; provision of services at the place of residence of the client; inter-professional and inter-institutional cooperation; user participation; cost control. - Health care for older people are regulated based on the health care laws - Mobile teams of specialists (i.e. social worker, social care worker, psychologist), provide social services to older people in their homes. These mobile teams are becoming the standard suppliers of care services in rural areas, especially those with low population density.
Netherlands	- Social Support Act (Wmo), 2015 - Long-term care Act (Wlz), 2015	-Wmo: municipalities provide social services funded by block grants from the state. They are responsibilities for providing help with IADLs (cleaning, cooking, etc.) for older people. Municipalities have very limited tax-raising abilities. - Wlz: it is a statutory social insurance scheme.
Portugal	Decree Law 265/99, 14 of July - National Network for Integrated Continuous Care (RNCCI), 2007	Regulates the supplement for dependency, the cash benefit for people having LTC needs The RNCCI provides convalescent care, post-acute rehabilitation services, medium- and long-term care, home care and palliative care. The Ministries of Health and Social Solidarity jointly set up the network. It comprises both public and private not-for-profit units (funded by the state jointly by both Ministries). The financing model is based on the types of services provided, with joint protocols across the health and social sectors.
Scotland	- Regulation of Care Act, 2001 - Community Care and Health Act, 2002 - Public Bodies (Joint working) Act, 2014 - The Social Care (Self-directed Support) Act, 2013 - Carers Act, 2016	- The 2001 Act aimed to is to improve standards of social care services. - The 2002 Act introduced 2 new changes: free personal care for older people, regardless of income or whether they live at home or in residential care and the creation of rights for informal or unpaid carers. - The 2013 Act enshrines in the law that people who are eligible for social care support must be involved in decisions about what their support looks like and how it is delivered. - The 2014 Act sets the framework for integrating adult health and social care, particularly for people with multiple, complex, long-term conditions. - The 2016 Act includes a duty for local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria, a carer support plan, a requirement for local authorities to have an information and advice service for carers, and a requirement for the responsible local authority to consider whether respite care should be provided, including on a planned basis.
Spain	- Dependency Act, 2007 - Regulation on foreigners, 2022	-The law guarantees a right to long-term care services to all those assessed to require care subject to an income and asset test. Entitlements to cash and in-kind services are slightly different, with cash allowances being universal, while not all individuals might receive in-kind services. Recipients are expected to pay one-third of total costs of services. The central government and the regions are jointly responsible for the funding and provision of LTC. - As part of the care reform, Spain has foreseen the modernization of the migration law in order to facilitate the regularization of the situation of migrant workers working in the care sector (as well as other sectors where labor

		supply is low). The workers are required to enroll in a training course in order to obtain a work permit.
Sweden	<ul style="list-style-type: none"> - Social Services Act, 2001 - National Centre for support of Informal Care Providers and law in support to informal caregivers, 2008 	<ul style="list-style-type: none"> - The management and planning of care for older people is split between three authorities – the central government, the county councils, and the local authorities. Each unit have different but important roles in the welfare system of Sweden. They are represented by directly elected political bodies and have the right to finance the activities by levying taxes and fees within the frameworks set by the Social Services Act. - The Centre is co-run by several research institutes in Sweden with mandate from the National Board of Health and Welfare. Its aim is to coordinate research and development, supply information and documentations to caregivers and increase the awareness among the public and the authorities. In addition, since 2009, the municipalities are by law required to support informal caregivers.
United Kingdom	- Health and care act, 2022	The health and care act 2022 sets the scene for reforming health and social care in England. It aims at reducing bureaucracy and at facilitating communication and integration between the social and health sectors.
United Kingdom (England)	- Health and Social Care Act, 2012	The Health and Social Care act defines the role of the Health and Social Care Information Centre Special Health Authority. It is a non-departmental public body which collects, analyses and published information on health and social services for adults at the national level. The act also establishes funding mechanisms for health and social services for adults, as well as defining monitoring and regulating powers on such services
United Kingdom (Scotland)	<ul style="list-style-type: none"> - Regulation of Care Act, 2001 - Community Care and Health Act, 2002 - Public Bodies (Joint working) Act, 2014 - The Social Care (Self-directed Support) Act, 2013 - Carers Act, 2016 	<ul style="list-style-type: none"> - The 2001 Act aimed to improve standards of social care services. - The 2002 Act introduced 2 new changes: free personal care for older people, regardless of income or whether they live at home or in residential care and the creation of rights for informal or unpaid carers. - The 2013 Act enshrines in the law that people who are eligible for social care support must be involved in decisions about what their support looks like and how it is delivered. - The 2014 Act sets the framework for integrating adult health and social care, particularly for people with multiple, complex, long-term conditions. - The 2016 Act includes a duty for local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria, a carer support plan, a requirement for local authorities to have an information and advice service for carers, and a requirement for the responsible local authority to consider whether respite care should be provided, including on a planned basis.

Note: ¹ The latest translated consolidation act is from 2015, and the latest consolidation act in Danish is from 2018. ²In France, there are 101 *départments* (implemented in 1789) and 18 *régions* (implemented in 1956).

Source: country-specific ESPN reports on challenges in *long-term care*. For [Finland](#), [Sweden](#), [Scotland](#), click on hyperlinks. For Denmark, see the Questionnaire on the rights of older persons with disabilities, the Danish Institute for Human Rights (2019), for Spain (European Commission, 2022^[17]).

4

Current legislation on the integration of services for dependent people in Italy

The topic of merging social and health services in Italy has often been discussed in literature and law since the late 1970s, and has gained more focus in recent years. The growing attention to this topic partly stems from the trends of an ageing population and rising chronic disease rates.

4.1. Italian legislation on social and health integration from the 1970s to the present day

As far back as Law no. 833/1978, Italian law stressed the importance of merging health and social sectors. The law set up the Italian National Health Service (SNN) and arranged for local coordination between health and social services. Legislative Decree no. 299/1999 is a key piece of Italian law on health and social care integration. It defines social services with health impact, health services with social impact, and services with strong health and social integration.

Law no 328/2000 then required the establishment of basic social assistance levels, in addition to the existing basic healthcare levels. The definition of basic social assistance levels has faced many hurdles and is still under development. In 2001, Constitutional Law no. 3, also known as the Title V reform, granted regions shared control over health and sole control over social welfare. This meant regions were now in charge of integrating social and health services.

A few years later, the 2003-2005 national health plan identified social and health integration as a key principle of the Italian health system. It also made building an integrated network of social and health services one of its main goals. The national health plans of 2006-2008 and 2011-2013, along with the health pacts of 2007-2009 and 2010-2012, all highlight the significance of social and health integration in Italy. However, in 2011, the financial strategy wiped out the National Fund for Dependency, hindering the progress of social and medical integration in the country.

In 2015, Ministerial Decree 70/2015 set guidelines for promoting and coordinating integrated home care. It also championed this as an alternative to hospital stays. Law 328/2016, Legislative Decree 107/2018 and Law 114/2018 often discuss the blending of social and healthcare. They stress its value and set aside money to boost social-health services, including at home (for example, Law 114/2018).

In recent years, the integration of health and social services for dependent individuals has gained more attention. Renewed focus on this subject has led to more laws and regulations, national plans and funds aimed at enhancing social and health integration. Italy is currently reforming its integrated social and healthcare services for dependent individuals. To better grasp recent Italian regulatory changes and the challenges of implementing ongoing reforms, the following sections will closely examine the key aspects of the current reforms in the country.

4.2. Towards policies for dependency, beyond the silos of disability and the older population

A structural challenge in dealing with non-self-sufficiency is the separate treatment of disability and old age, even though both are often labelled as “dependent”. This distinction shows both at the ministerial level and practically through specific services and groups.

However, there are instances that showcase the endeavours of both national and regional institutions to transcend the divide between disability and old age by adopting a unified approach to “dependency”.

Nationally, interest in the issue of dependency is growing. This is evident in the formation of various ministerial and inter-ministerial committees. Recently, these groups have focused on studying the issue in detail and formulating intervention or reform proposals. For instance, in March 2021, a task force named “Social Interventions and Policies for Dependency” was established at the Ministry of Labour and Social Policy (Ministero del Lavoro e delle Politiche Sociali, 2022^[1]). The National Plan for Non-self-sufficiency (PNNA) also constitutes a significant initiative aimed at encouraging a constructive debate on the topic of non-self-sufficiency, while providing a homogeneous definition on a national scale.

Examples of collaboration on the issue of dependency can also be seen at a regional level. For example, to access the National Fund for Dependency, regions must create a regional dependency plan.⁷ Some regions have coordinating bodies to ensure the creation of the regional dependency plan is participatory and coordinated, using input from various stakeholders. For instance, in the Marche region, a team was formed to create the Regional Dependency Plan. In Umbria, Decree no. 1400 of 28/12/2022 set up a steering committee⁸. Their job is to create the Integrated Regional Plan for Dependency (PRINA) for 2022-2024.

4.3. Ongoing reforms and reflections on implementation

4.3.1. The National Recovery and Resilience Plan (NRRP)

The European Commission approved the NRRP on 22 April 2021. It plans for investments of €191.5 billion, funded by the Recovery and Resilience Facility (RRF), and an extra €30.6 billion from the Supplementary Fund. The NRRP foresees six missions, two of which are relevant for improving the integration of social and health services: mission 5 (cohesion and inclusion) and mission 6 (health).

Mission 5 of the Plan involves building and refurbishing facilities for people with severe disability and dependent older individuals, and creating independence pathways for people with disability, with a total budget of €1 billion. Mission 6 plans to improve local care services, home care, and the growth of remote medical services. It also aims to combine all social and medical services, digitise the national health service (for example, spreading the use of Electronic Health Records), and monitor and provide Essential Levels of Care (LEA). This will involve a total investment of 15.63 billion Euro (PNRR, 2021^[20]).

The NRRP thus offers a unique chance, providing specific funds to enhance and expand home care services. However, in accordance with the testimonies collected from several stakeholders interviewed within the framework of this project, the NRRP presents several challenges related to its implementation.

Primarily, the funds provided by the NRRP must be used within three years. Some stakeholders believe this time window is unreasonably short for the regions to achieve this. Some stakeholders, particularly from

⁷ A tool for planning how to combine health and social care, how to identify those who will benefit, what interventions and services are planned, and how to monitor the system.

⁸ Consisting of: Regional Health and Welfare Director, or Health and Welfare Directorate Executives or Regional Health Authority General Managers, or Anci President, or Disability Observatory President, or Disability Rights Watchdog.

the south, doubt the feasibility of increasing ADI coverage to 10% of the over-65 population, as they lag significantly behind other regions nearing this target.

Secondly, several metrics used to measure the achievement of the NRRP objectives raise questions both among the stakeholders interviewed and in the academic literature. Gugiatti, Lecci and Rotolo (2022^[21]) suggest that the output indicators proposed in the NRRP, like the number of home-assisted patients and home care services provided, lack detail about the reference needs and their even distribution across the country. Furthermore, many interviewed stakeholders believe that the NRRP's aim to boost the number of ADI users (to cover 10 per cent of those over 65) seems restrictive if not paired with a pledge to enhance the intensity of care, which is currently quite low in Italy.

Furthermore, the plan does not set a basic care standard for home services, making it hard to ensure consistent, high-quality care nationwide. It also lacks a clear strategy for developing and implementing home services, which are currently absent in some parts of the country.

Finally, the limited involvement of municipalities in creating Mission 6 of the NRRP offers a chance for further improvement of the process. Greater involvement at the municipal level could have improved the relevance and effectiveness of the proposed measures, strengthening the reform from a local implementation viewpoint.

4.3.2. Law no. 227 of 22 December 2021. Delegation of powers to the government on disability issues

Law no. 227/2021 aims to review and restructure the current disability laws in Italy. The law delegates the government to adopt legislative decrees on the following topics:

- Reorganisation of legislation concerning the definition of the condition of disability;
- Enhancing systems to determine disability status, assess diverse needs and personal life goals;
- The computerisation of needs assessment and data storage processes;
- Redevelopment of public services to improve their inclusion and accessibility;
- Establishment of a National Guarantor of Disabilities;
- Boosting the Disability Policies Office.

The law's decrees are being implemented, but there is a noticeable caution in the process, according to some stakeholders interviewed. It is worth noting that the law has not yet directly tackled aspects like home care and the merging of health and social services.

Interviews with stakeholders also show that Delegation Law no. 227/2021 (Government Delegation of Powers on Disability) and Law no. 33 from 23 March 2023 (Government delegations for policies for older people) work separately without overlap, maintaining a division that does not support a comprehensive approach to the needs of the dependent population. This divide is even clearer in the dedicated work tables, which do not share either objectives or strategies.

4.3.3. Law no. 234 of 30 December 2021. Budget Law 2022

Law no. 234 of 2021 set out the single access points (PUA), the multidimensional assessment units (UVM), the Integrated Individual Care Plan (PAI), and the new Essential Levels of Social Benefits (LEPS), as shown in Table 8. Article 1, paragraph 4-bis, provides for the implementation of regional projects on the experimentation of proximity structures, to which 25 million euros have been allocated for the year 2020 and 25 million euros for the year 2021, to be shared between the Regions and the Autonomous Provinces of Trento and Bolzano based on their respective quotas of access to NHS financing for the reference years 2020 and 2021. Moreover, paragraph 168 also states that the fund for dependent people will gradually increase from 2022 to 2025. This fund will receive an extra €100 million in 2022, €200 million in 2023, €250 million in 2024 and €300 million in 2025, as per Law no. 324/2021.

Table 8. Provisions of Law no. 234/2021 relevant to the integration of social and health services for dependent persons

Legislative reference	Defined measure	Definition
Law no. 234/2021, Article 1, Paragraph 159	Essential Levels of Social Benefits (LEPS)	The LEPS are the actions, services, activities and combined benefits that the Republic provides. These are based on the rules of Article 117, second paragraph, letter m) of the Constitution. They also follow the principles and guidelines set out in Articles 1 and 2 of Law no. 328 of 8 November 2000. These are available to everyone across the country. Their aim is to ensure a good quality of life, equal chances, no discrimination, prevention, and to lessen or remove conditions of disadvantage and vulnerability.
Law no. 234/2021, Article 1, Paragraph 163	Single Access Point (PUA)	The Italian National Health Service and the Local Social Welfare Division (ATS) ensure, using their resources, that dependent people can access social and medical services. This is done through single access points (PUAs), located at the health service's branches known as "Community Homes". Integrated teams composed of adequately trained and numerically sufficient personnel from the Italian National Health Service and the ATSS operate in the PUAs. These integrated teams, following the rules of the Prime Minister's Decree of 12 January 2017, assess people's complex clinical, functional and social needs. They ensure the working of the multidimensional assessment units (UVM) for each person's bio-psycho-social capacity. This is done to outline the care needed to help dependent people, allowing them to stay in their own homes with dignity, safety and comfort. It also aims to reduce the risk of social isolation and unnecessary hospital stays.
Law no. 234/2021, Article 1, Paragraph 163	Integrated Individual Care Plan (PAI)	Based on the UVM assessment, the integrated team, involving the person who is not self-sufficient, their family or support administrator, sets out the individual care plan (PAI). This outlines the necessary actions, tailored to the level of need. The IAP also outlines the duties, tasks and methods for health, social and care workers involved in the person's care. It also details the family's role and other parties who contribute to its execution. The planning of actions and assigning of responsibilities leverages the information link with INPS, including digitally.

Source: Law no. 234/2021

4.3.4. The National Dependency Plan

The 2019-2021 National Dependency Plan aimed to boost services for the dependent across the country, striving to even out regional differences as much as possible. The Plan sets out a national definition of severe disability and highlights the need for a clear national definition of dependent individuals. It also proposes a system to identify those eligible for benefits and services for dependent people.

The PNNA 2022-2024 refers to current laws, especially Budget Law no. 234/2021, and the NRRP to set out a plan of actions to better the social and healthcare for dependent people.⁹ The programming matrix includes seven axes:

- Social home care and social assistance integrated with health services;
- Respite social services (e.g. temporary replacement of caregivers, support to family caregivers);
- Support services such as help in finding personal helpers, and legal and administrative aid for families of dependent individuals;
- Contributions to support home and personal autonomy;
- An Individual Care Plan (PAI) for people who are dependent or seriously disabled, which includes the following stages: Entry, first check, comprehensive evaluation, creation of a personalised care plan, health result tracking;
- Strengthening the staffing of Local Social Welfare Divisions (ATS);
- Training activities.

The plan also sets out the Dependency Fund (FNA) amounts for 2022-2024: 822 million Euro in 2022, 865.3 million Euro in 2023, and 913.6 million Euro in 2024. It also details the fund's regional distribution (Ministero del Lavoro e delle Politiche Sociali, 2022^[1]).

While the PNNA is on the right track, it faces some implementation challenges, according to stakeholders interviewed for this project. The regions are tasked with executing the PNNA during a period of redefining the care system for dependent people, adding to the complexity of its implementation. For example, it is important to mention that the adoption of the PNNA happened at the same time as the end of the talks about Law no 33 of 23 March 2023. (Government delegations on policies supporting the older population). This time clash could hinder the plan's successful execution.

Moreover, some regions are likely to be better at implementing the PNNA than others. Some regional public bodies may struggle to implement the PNNA effectively due to limited management skills and tight deadlines. In such situations, there is a risk that allocated funds may be directed towards monetary benefits like care allowances, rather than promoting service optimisation.

4.3.5. Law no. 33 of 23 March 2023. Delegations to the Government on policies supporting the older population

Delegation law no. 33/2023 allows the government to pass legislative decrees by 31 January 2024 that aim to promote dignity, independence, social inclusion, active ageing, and prevention of frailty and disability in the older population. The law specifies the following guiding criteria for the definition of legislative decrees:

- Promotion of lifelong health and prevention, including through awareness campaigns and initiatives in schools and workplaces;
- Combating isolation and social exclusion of older people;

⁹ As outlined, the focus of the PNNA 2022-2024 is on older people (65 years and above) who cannot care for themselves and have either low or high care needs. It also includes people with severe or very severe disabilities. This includes those recognised as having disabilities or impairments under Italian law.

- Provision of preventive health services in the homes of older people;
- Involvement of older people in voluntary activities;
- Facilitation of autonomy and mobility in cities;
- Promotion of forms of solidarity-based home living and co-housing for the older people;
- Computer literacy of the older population;
- Promotion of ways to maintain physical and mental health through sports and pet interaction;
- Promotion of slow tourism and wellness tourism;
- Support for intergenerationality through experiences of solidarity and cultural promotion between generations;
- Carrying out multidimensional needs assessments.

On home care, some of the main innovations include a more flexible duration and intensity of home care, a combination of various professionals to provide care, and better collaboration between municipalities and health districts. It also proposes introducing a universal allowance for dependent older people (see Box 4).

Still, the law faces big challenges in being put into action. Firstly, the issue of the funds allocated for the reform remains unclear and will be a key topic in upcoming debates, especially during the preparation of the next Budget Law. Another challenge is the country's severe lack of health staff, in particular nurses.

Some stakeholders highlighted a conflict between the enabling act's directions and the NRRP's objectives on ADI. The NRRP aims to boost the number of over-65s using ADI services to 10%, maintaining the same service duration and intensity, using a one-professional approach. This contradicts the delegating law, which aims for a lasting, multi-professional care system. If not rectified, this could cause a mismatch between the new law and future financial initiatives.

Among the challenges highlighted in stakeholder interviews, the lack of expert knowledge in government and academia about long-term care and dependency stands out. limited dialogue with the regional and municipal authorities during the approval phase of the law; The legislative text is complex and there are no official documents to aid comprehension.

In short, while the Delegation Law for the Older is a key step towards more adaptable, long-lasting and multifaceted home care, its success largely depends on the execution of the related decrees and policies in practice.

Box 4. The universal allowance for the dependent older population

Among the highlights of the Delegation Law for the Older population of 30 March 2023 is the introduction of a universal allowance for the dependent older people. This welfare benefit will take over and replace earlier allowances given, such as the care allowance.

The current initiative aims to tie the money given out – now without income or job restrictions – to the use of official social and health services, including home care. In particular, beneficiaries will be able to choose between two options: (a) an unrestricted financial contribution; (b) the use of personal services (provided by private firms, public organisations or regular carers). To promote the use of formal services, option (b) involves a rise in the amount.

This reform has many benefits worth considering. First, it aims to encourage service creation through demand-led incentives, offering a supportive environment for the development of high-quality services. It also promotes the formalisation of work contracts, including those for carers, aiding a more clear and regulated job market. Ultimately, the reform seeks to promote free choice of services for users, providing flexibility and tailored options to suit various needs.

The reform's roll-out, while promising, brings several complexities and challenges. Various stakeholders have highlighted these, as outlined below:

- One is the regional disparity in the current standard of service provision. In certain areas, particularly the south, there is a near absence of suitable services, making reform harder to implement there.
- It is still unclear which bodies (public, private or accredited) the cash transfers will fund.
- It is unclear if the cheque will go straight to the recipients, who will then decide where to use the funds (in this case, it is crucial to establish who will oversee the proper use of the money), or if the cheque will go directly to the service providers.
- It is still not clear if Local Health Authorities (ASLs) and municipalities will merely guide beneficiaries, or if they will be directly providing services.
- Another factor to consider is the method of adjusting money transfers to reflect changes in buying power over time. This calls for creating a clear, transparent formula, which is yet to be established.
- There is also an open question related to the potential erosion of the public health system due to the shift of public resources to accredited private facilities.

In summary, the reform has the potential to bring about significant improvements, but its effectiveness will be closely linked to the implementing decrees and the quality of its implementation.

5

Current reflections in Italy on the subject of health and care integrated services at home for the dependent population

After a thorough literature review and stakeholder interviews, this report section delves into Italy's current views on home-based health and care integrated services for dependent individuals.

5.1. Home services in Italy: the main discussion points

Italy struggles to provide comprehensive home services, especially affecting dependent individuals. One of the obstacles to full integration between healthcare and social services in Italy is the presence of two distinct home care systems, managed by different institutional entities. On the one hand, there is Integrated Home Care (ADI), under the aegis of the Local Health Authorities (ASL); On the other hand, there is a Home Care Service, often referred to as SAD, AD, or other names depending on the region, which the municipalities manage.

The key difference between ADI and SAD is in the type and range of services, as well as the intended beneficiaries (Longo and Maino, 2021^[22]). While ADI focuses mainly on medical and nursing services, responding to specific clinical needs, the municipalities' SAD has a more social support-oriented approach. ADI is typically short-term and guided by clinical hospital reasoning. On the other hand, SAD tends to view the absence of family support networks and financial resources as key factors for providing services.

The professionals involved also vary: Nurses and health workers manage ADI, while social workers or those trained in social work handle SAD. These divergences reflect the prevalence of two different cultures: ADI is more aligned with a hospital-based approach, while SAD is more in line with a care culture rooted in local social services.

We need to merge these two approaches to better address care needs. Indeed, data reveals that currently, only 7% of older people ADI users also utilise integrated services with SAD (Patto, 2023^[13]).

Besides the poor link between services, home care access remains limited. Current ADI coverage only extends to 6% of those over 65 (Longo and Ricci, 2022^[23]), with significant regional differences.

There are significant regional gaps: Molise encompasses roughly two-thirds of the target group, whereas Valle D'Aosta and the Autonomous Province of Bolzano only account for 2% of the relevant population. Leaving out Molise as an exception, the other regions fall into three groups: the North-Central regions¹⁰, covering more than a quarter of the requirements; a second group with a coverage of between 10 and

¹⁰ Lombardy, Veneto, Tuscany, Emilia-Romagna, Friuli-Venezia Giulia, Autonomous Province of Trento

20%;¹¹ Lastly, several regions¹² do not even achieve 10% of the target (Fosti, Notarnicola and Perobelli, 2023^[24]).

Besides access, ADI is restricted in intensity and does not fully address actual care needs. This situation appears evenly distributed over all Italian regions. Indeed, ADI is typically given for brief periods, usually 2 to 3 months, with a moderate level of intensity. On average, a service user gets 9 hours of nursing care and 6 hours from other caregivers each year. 80% of users use the service 1 to 3 times a month (Patto, 2023^[13]). This approach does not align with the long-term care needs, often spanning several years, shown by the dependent population.

The COVID-19 pandemic further worsened the quality of home care services. From 2019 to 2020, the hours of ADI provided dropped by 16%. Specifically, in the crucial initial months from March to June 2020, restrictions and the halt of non-essential services made home care nearly impossible. This had negative impacts that continued in the subsequent months (Fosti, Notarnicola and Perobelli, 2023^[24]).

Municipalities provide SAD sporadically and inconsistently, and it is even less uniformly developed than ADI. The 2020 survey data also shows notable regional differences in social interventions and services provided by individual or associated municipalities. In South Italy, nearly 30% of municipalities do not offer home care for the older people (65 and over), and 38% do not for the people with disability. This contrasts with just 6% in the North, where 30% do not provide for the people with disability. In addition, there has been a persistent decline in user numbers since 2011, a trend that raises further concerns about the sustainability and effectiveness of the services (ISTAT, 2023^[14]).

In certain areas, a lack of home care services (ADI or SAD) prompts the care system to shift towards solutions involving cash transfers (Tagliabue and Tesauro, 2011^[25]). Even though regions do use the available funds (e.g. from the Non-Self-Sufficiency Fund), they often use them not to improve existing services, but to offer cash benefits (e.g. care allowances).

For instance, the Campania Regional Social Plan 2022-2024 reveals that some Local Social Welfare Divisions have indeed swapped services for care allowances. This choice skews the nature of both the service and the allowance, which should ideally work together. This essential complementarity not only ensures ongoing care, but also provides for those unable to access the Care Allowance, perhaps due to not meeting eligibility criteria (Consiglio Regionale della Campania, 2022^[26]).

Another challenge in Italy's home care sector is the lack of trained staff, especially nurses, but also care assistants (OSS) and social workers. For instance, in 2020, Italy had 6.3 nurses for every 1,000 people, one of the lowest rates in Europe. Compared to this, the average in European Union countries was 8.3 nurses for every 1,000 people (OECD/European Union, 2022^[27]). Despite demand, Italy has struggled for years to fill jobs in nursing faculties, indicating the profession's lack of appeal.

Furthermore, ADI is particularly affected by this shortage of nursing staff compared to other areas. Home care workers often lack the specific training needed to handle the unique demands of their job. Some stakeholders suggest that ADI does not appeal to nurses, who often favour working in places like hospitals. Indeed, ADI is seen as not very useful, unrewarding, and offering limited career prospects. The absence of financial incentives and reward mechanisms for staff working in home care further limits the attractiveness of the sector. Indeed, ADI tends to draw less skilled and often unmotivated staff, becoming a career choice for professionals who cannot find opportunities elsewhere.

A key tool for improving the integration of social and health services is the Individual Care Plan (PAI). The PAI is a plan, written by a multidisciplinary team and overseen by a project manager. This plan outlines

¹¹ Marche, Apulia, Campania, Umbria, Sicily, Liguria, Abruzzo, Lazio

¹² Sardinia, Calabria, Autonomous Province of Bolzano and Valle d'Aosta

the care actions and health goals the patient should reach within a set timeframe, including via home care services.

However, its execution is often inconsistent and irregular. Some key issues include:

- Patient assessments are typically carried out solely by medical staff, focusing only on medical needs and overlooking a more comprehensive approach that includes other forms of support and protection.
- When considering the social aspect, the trend is to form two distinct PAIs, one social and one health, rather than a single plan that tackles both dimensions.
- The PAI should be a shared plan between the patient, their family, and the personal helper. In reality, it is often one-sided, determined solely by healthcare staff.
- Though the PAI should adjust to the patient's shifting needs and context, this is seldom so.
- Another issue involves the difficulties in constantly monitoring the PAI, particularly regarding the anticipated results and effects of interventions.

Some regions' experience confirms that the use and effective execution of PAIs could be enhanced. For instance, in Campania, PAIs mainly concentrate on health services. A holistic approach, encompassing nursing support and guardianship, is often missing. This is because neither the ASLs nor the Local Social Welfare Divisions have the necessary professionals like care assistants (OSS) to ensure genuinely integrated home care (Consiglio Regionale della Campania, 2022^[26])

5.2. The governance of social and health integration

The issue of integrating health and social care has been discussed in Italy for years. Despite many laws, its practical application is still not achieved in many areas.

Consequently, today's Italian citizens grapple with the complex task of independently navigating numerous social and health services. Each service has its own access requirements and channels, leading to confusion about rights and opportunities.

The institutional setup, with the Ministry of Health overseeing health policies and the Ministry of Labour and Social Policies handling the social aspect, reveals a clear division at a national level between these two vital sectors. In 2008, the fourth Berlusconi government established a new Ministry of Labour, Health and Social Policies, but it was dissolved again by the end of 2009.

In line with some stakeholders, there is a need to progress the current model from a basic national health service to a more complete, integrated national health service. This would allow us to meet the population's needs more fully, merging medical care and social support into one system.

Another hurdle to merging health and social sectors, tied to the earlier issue, is the existence of separate funders for health and social costs. This split makes both aligning efforts and evaluating care needs overall more complex.¹³

¹³ For instance, some costs, like those for carers, are not included in traditional "out-of-pocket" expense measures.

The literature highlights more key issues, besides those already noted, in the present model of health and social services integration. For instance, Accorinti et al., (2022^[28]) suggest that the system's intrinsic complexity, with many players having different roles and interests, creates hurdles for effective teamwork. Moreover, the division of laws at both national and local levels often causes confusion and misunderstanding.

National coordination issues similarly lead to problems at regional and local levels. Stakeholder interviews confirmed significant regional inequality in social and health integration. Some regions in the centre-north have achieved a more advanced level of integration, in contrast to regions in the centre-south that have some of the lowest levels of integration in Europe.

This disparity was primarily due to a lack of central coordination. Regional authorities are responsible for delivering social and health services. This has led to significant differences between regions, with some achieving better results than others (Tagliabue and Tesauro, 2011^[25]).

But other factors also contribute to this fragmentation. Locally, the boundary mismatch between *Ambiti* and *Distretti Sanitari* (Local and District Health authorities), which often do not align, is a major barrier to social and health integration. This territorial inconsistency greatly hinders the smooth operation and coordinated provision of services, negatively impacting the quality of care given (Patto, 2023^[13]).

In some regions (such as Liguria and Lazio), *Ambiti* and *Distretti Sanitari* are merged within the *Distretto Sociosanitario*, a territorial structure that aims to integrate health and social interventions. However, Italian national law does not formally recognise this entity. It is solely the regions' responsibility (Accorinti et al., 2022^[28]).¹⁴ In other areas, different ways to combine services exist (like the joint social-health office in Piedmont, which helps the *Ambiti* and *Distretti* work together)¹⁵, but these efforts often stay limited and unplanned.

Finally, the consulted stakeholders also highlighted paradoxical situations that warrant attention. For instance, in areas with low living costs, even small public subsidies like carer's allowance can help families employ a home carer, ensuring decent care. This differs from high-cost areas, where despite more developed social and health services, public funds are not enough to employ a personal helper and provide proper care.

However, it is worth noting some good examples of social and health coordination at the regional level:

- Some regions, such as Basilicata, Emilia Romagna, Friuli, Lombardy, Marche, Tuscany, and Veneto, already implement integrated territorial planning through combined regional social and health plans. The integrated health and social plan is a cross-sector tool used by some regions to set health and social policy goals. It also outlines the criteria for organising health and social services, considering the population's care needs, multi-level planning and integration tools.
- Even without integrated social and health plans, there are instances of cooperation between the social and health sectors. For instance, in Apulia, the Welfare Department, aided by A.Re.S.S., has requested the health sector's input for the 2022-2024 Regional Social Policies Plan. They have asked them to share their priorities, particularly where social and health matters are concerned.

The launch of the Social and Healthcare Integration Observatory (OISS) by AGENAS and Federsanità ANCI, working with the PONGOV ICT and Cronicità group, is a key step in promoting best practice in the social and healthcare sector. In its first year, the OISS documented over 80 experiences from various

¹⁴ While Law 328/2000 clearly defines the *Ambito*, and rules like Legislative Decree 502/92 govern the *Distretto*, only the Regions have the right to determine the structure and function of the *Distretto Sociosanitario*.

¹⁵ In Piedmont, the office for integrated health and social care is the tool for managerial and professional co-operation between the ATS and the Health District. This office ensures the execution of plans and oversees the activities managed by this agreement.

bodies like local health authorities, hospitals and councils. The aim is to offer valuable data and insights to decision-makers and organisations, both public and private. Top of Form

5.3. The informal sector (family caregivers and personal helpers)

In Italy, home care mainly relies on informal aid from family or caregivers, often called “*badanti*”. This shows a system where families bear most of the care burden (Longo and Maino, 2021^[22]); (Tagliabue and Tesauro, 2011^[25]). For families with a dependent member, home care is often the chosen solution, while the use of care homes is less common. Of the 3.9 million dependent people, only around 300,000 currently live in assisted-living facilities (RSA) (Longo, 2023^[29]). Of the 3.6 million dependents not using care homes, 1.1 million receive help from personal helpers, while family members look after the remaining 2.5 million (Longo, 2023^[29]).

5.3.1. Family caregivers

The family caregiver is someone who looks after another person, often dependent or with disability, in their own home. Typically, a family member arranges and decides the care required for the individual in need (Camera dei Deputati, 2023^[30]). The 2018 Budget Law (Article 1, paragraph 255 of Law 205/2017) formally identifies and acknowledges the family caregiver as the “individual who helps and looks after certain people”.

According to the 2019 EHIS, 13.5% of Italians aged 15 and over – more than 7 million people – give care and help to those in need at least weekly, mostly to family members. Women provide 15.1% of care, a higher share than men’s 11.7%.

The primary caregivers in Italy are aged 45-64, with over 20% of this age group providing family care. Important gender gaps also exist here: In Italy, nearly 26% of women aged 55-64 provide care and assistance, highlighting the key role women play in this field (ISTAT, 2019^[31]).

Under existing laws, caregivers receive various permits and benefits to aid their dedication to looking after the dependent individual (Vegliante, 2021^[32]). For example:

- Family carers can indirectly benefit from the support allowance, a provision governed by the 1980 Law 18;
- They can activate the Ape Sociale, an early retirement option, in some cases;¹⁶
- They can take three paid days off each month to look after a sick relative or a relative with disability (Law 104/92);
- They can take special leave (Law 104/92);
- They can choose their workplace to be closer to the person they are assisting, as per Law 104/92;
- They can claim various tax deductions for buying transport, healthcare costs or aids.¹⁷

Moreover, the 2018 Budget Law established the Family Caregiver Fund¹⁸. This fund offers financial aid to regions for laws that aim to acknowledge the social and economic worth of care given by family caregivers. Moreover, the 2021 Budget Law¹⁹ established a “Fund to Boost Non-Professional Caregiver Activity”. The

¹⁶ If you have been assisting a spouse or first- or second-degree relative for at least six months; Or if the person with the illness or disability has parents or a spouse who are at least 70 years old and have a disabling disease.

¹⁷ Application of VAT at 4% for the purchase of a car; 19% income-tax deduction on the purchase cost of means of locomotion; 19% income-tax deduction for health costs or aid purchases.

¹⁸ 2018 Budget Law, Law 205/2017, Article 1, clauses. 254-256

¹⁹ paragraph 334, Art. 1 of Law No. 178/2020

Ministry of Labour and Social Policies manages this, with an annual budget of €30 million for 2021-2023 (Camera dei Deputati, 2021^[33]).

In Italy, we can also see positive actions for family caregivers at a regional level. Emilia-Romagna, leading all regions, acknowledged the role of caregivers with a 2014 law. It offers training and diverse support, from home health services to flexible work hours. Lombardy also stood out with trial projects like financial aid for families of the terminally ill and a dedicated scheme for caregivers of people with severe disability, backed by a budget of €3.9 million. Both regions aim to integrate caregivers into the care network by offering services and financial support to improve the quality of care provided (Camera dei Deputati, 2023^[30]).

Despite positive law changes at both national and regional levels, the family carer sector still faces many challenges. A key challenge is the drop in potential carers, especially daughters and daughters-in-law, which coincides with a rise in the older population. According to ISTAT data from 2020, the ratio of women aged 46-69 to individuals aged over 70 has decreased from 2.3 to 1.6 over the last 30 years (Longo and Maino, 2021^[22]).

The dwindling number of potential carers is worsened by more women working. This trend is set to grow as the retirement age increases. Consequently, women have less time for unpaid care, heightening the need to balance work and family duties.

Family carers also struggle to access services and are not fully part of the formal care system yet. A survey of 1,032 caregivers in Lombardy showed a strong dissatisfaction with institutions (Pasquinelli and Assirelli, 2021^[34]). Indeed, over half the participants feel little to no institutional support, and in half the cases, there is a wish to lessen the care burden somewhat.²⁰

Distance from formal care services can be a big hurdle for family carers trying to join the job market. This situation is especially challenging for highly vulnerable households, and within these, for women. Indeed, studies show a clear link: the lower the household income, the more family members are involved in caring for the older or dependent persons (Longo and Maino, 2021^[22]).

Boosting aid for family carers and reforming policies in this area has become essential due to demographic shifts and socio-economic trends.

Some stakeholders particularly stress the vital need for Italy to introduce pension benefits for caregivers. This could be achieved by recognising assumed contributions for periods of care work, helping to avoid financial instability and poverty in later life. This proposal - already suggested in some pending bills (Camera dei Deputati, 2023^[30]) - would not only acknowledge the priceless work of carers, but also align Italy with top social protection practices.

Another key focus involves providing information services to family carers to aid their caregiving tasks. A 2020 online survey of 1,000 people across Italy (Pasquinelli and Assirelli, 2021^[34]) reveals surprising insights into the kind of help caregivers find most useful. Contrary to the usual expectation of favouring financial aid, here 43% of caregivers clearly prefer home-based services, with just 33% needing direct financial help. Among those seeking services, 88% primarily want information on local resources.²¹

²⁰When asked why few use public services, many carers either cannot answer or say they do not know about them (over half have no experience with the services, so cannot form an opinion). The reasons for non-use appear to be more due to the services themselves, rather than a pre-existing refusal to use them. Among them, there are often bureaucratic access difficulties (28%), high costs (24%) and stringent eligibility requirements that make access impossible for 9% of caregivers. A small percentage, 2.3%, criticised the quality of the services offered, while another 2.1% reported a refusal by the older care recipient (Pasquinelli and Assirelli, 2021^[34]).

²¹ Other types of assistance of interest include, in order of importance: Help with direct personal care, emotional support for both the carer and the individual being cared for, home assistance, and finally, access to improved tech like computers and better internet connections.

Several proposed laws, such as Draft Law no. 1461 “Rules for recognising and supporting family caregivers”, tackle these issues. However, they are still under review (Camera dei Deputati, 2023^[30]) (Senato della Repubblica, 2019^[35]).

5.3.2. Personal helpers (“badanti”)

A personal helper, or “*badante*”, is a family caregiver responsible for looking after a dependent person, always under the direct or indirect oversight of a family member (Camera dei Deputati, 2023^[30]).

In Italy, more than one-third of older people with dependency-related problems rely on the support of a family assistant (Pasquinelli and Pozzoli, 2021^[36]); (Pozzoli and Pasquinelli, 2021^[37])²². Some estimates suggest about 1.4 million Italian homes depend on family carers, with an average yearly cost of €11,325 (Longo and Maino, 2021^[22]).

The private home care sector is largely defined by a particular gender and nationality, with non-Italian women prevailing. Women make up 90 per cent of the workforce, and 88 per cent are foreigners (Pasquinelli and Pozzoli, 2021^[36]).

The personal helper sector in Italy features an older workforce and limited renewal. The typical age of personal helpers is 49. Currently, around 54% are over 50, and a third of these are over 60 (Pasquinelli and Pozzoli, 2021^[36]). The personal helper market has a low turnover rate, partly due to inconsistent migration patterns that restrict staff changes.

Some stakeholders suggest there is a shortage of carers willing to live-in, as many have become independent and integrated. This means there is a need for full-time care that is not being met. It is for those who had rather not use care homes and want to stay in their own homes, but cannot find the right carer.

Furthermore, the problem of black-market work among family carers is significant in Italy. A recent study by Pasquinelli and Pozzoli (2021^[36]) showed that 76% of the personal helpers surveyed said they had worked, or were working, without a formal job contract. Furthermore, an estimate by Fosti et al. (2022^[38]) shows that in 2020, Italy had over a million carers, with 60% working unlawfully.²³

The link between family carers and formal services is notably weak, with under a third stating a substantial presence of these services, based on self-reported data (Pasquinelli and Pozzoli, 2021^[36]).

There is a lack of rules for personal helpers, who often provide health and social services without proper guidelines or structures. Currently, there are no national standards or guidelines that specifically define the skills needed for these professions, nor are there criteria for assessing prior skills (Patto, 2023^[13]). Indeed, Pasquinelli and Pozzoli’s study (2021^[36]) shows that over a third of carers in the country have never been on a training course. Of those who have, most chose to learn Italian.²⁴

²² By cross-referencing data from INPS on domestic work and ISTAT demographic stats, we can yearly update the count of family carers, or “badanti”, in Italy. In 2021, the estimated total of carers, both regular and casual, is 1,128,428. This means that for every 15.77 citizens over 75, there is one family caregiver. Or, for every 37.32 dependent citizens over 75, there is one caregiver (Fosti, Notarnicola and Perobelli, 2023^[24]).

²³ Some stakeholders suggest that tax relief for families hiring carers could boost the employment of skilled staff. This could enhance family care quality and integrate the sector into the official economy.

²⁴ Training access is closely tied to free courses and scholarship availability. This is crucial as many family carers cannot afford to take time off.

According to some stakeholders interviewed, it is imperative to transform and raise the level of professionalism of the 1.1 million carers currently employed in the family environment. The Older people Proxy Law seeks to go in this direction, as:

- Sets out to introduce training standards for family carers to enhance their professional skills. However, it is key to note that these standards will be detailed in specific national guidelines, not set as entry requirements for the profession.
- It strongly suggests the need to include these workers in the current service network, asking what links could be built with the formal service network.²⁵

5.4. Integration between the formal and informal sector

Integrating the formal and informal home care is a key area for enhancement. As shown earlier, family caregivers and personal helpers are vital in Italy's home care scene. However, these key actors often remain detached from existing formal services. This gap not only hinders holistic care management, but also reduces the effectiveness and longevity of the services offered.

For instance, interviews with various stakeholders suggest that the Individual Care Plan (PAI) should be created together with family members and personal helpers to guarantee it can be effectively put into action. The PAI should also have adaptable mechanisms for regular revisions to meet the patient's changing needs and care context, which may involve family, social or health factors. However, such adaptability and inclusiveness are not yet widely practised in PAI implementation.

5.5. Summary of ongoing reflections

One of the main complexities in home care in Italy lies in the coexistence of two different service models, each under the jurisdiction of different institutions. On the one hand, Integrated Home Care (ADI), managed by Local Health Authorities (ASL); on the other, home care services known as SAD, which fall under the jurisdiction of the municipalities.

These two models follow different philosophies: while the ADI is based on a performance approach linked to the medical and healthcare context, the SAD is closer to a welfare approach, which has its roots in local social services. The lack of coordination between the two systems is evident.

Furthermore, in the general framework of social and health care, home services currently constitute only a fraction of the offer intended for non-self-sufficient people. Access to ADI services is limited and, furthermore, the intensity of care provided is not adequate to cover the needs of non-self-sufficient people. In this context, the ADI ends up mainly representing support in the transition process from the residential or hospital facility to home. As regards the SAD, the situation is even more fragmented, with a significantly uneven distribution of services across the national territory.

In some regions, the scarcity of home services, both ADI and SAD, pushes the healthcare system to favor solutions based on monetary transfers. Often the financial resources available in the regions (such as the funds from the Non-Self-Sufficiency Fund) are used not to strengthen existing services, but rather to provide economic benefits, such as care allowances.

There are also governance barriers that limit the effective integration of services. Consequently, in Italy, citizens are faced with the complex task of orienting themselves independently between various services,

²⁵ One possible solution, suggested by some, could be to set up dedicated help desks for families seeking carers. These centres, already present in some areas, could offer guidance and help in choosing the right staff for specific needs.

both social and health. Each of these has its own channels and access criteria, making it difficult to understand your rights and opportunities.

This complexity is partly due to the institutional structure at national level: the Ministry of Health deals with health policies, while the Ministry of Labour and Social Policies manages the social sphere. This division highlights an intrinsic fragmentation between these sectors.

Related to this, another impediment to the integration of the health and social sectors is the separation of financial flows intended for spending in each area. This dualism further complicates both the integration of initiatives and the overall assessment of care needs.

The lack of coordination is not only a problem at the national level but is also reflected at regional and local scales. For example, at a local level there are territorial discrepancies between areas and health districts, whose borders often do not coincide, hindering social and health integration. In some regions, such as Liguria and Lazio, these entities are integrated into a single Social and Health District. However, this solution does not enjoy recognition in national legislation and is not applied in all regions, with other alternative coordination mechanisms adopted ad hoc.

Another crucial challenge for Italy consists in perfecting monitoring systems to optimize home services for non-self-sufficient people. Information flows on non-self-sufficient people and those assisted through ADI or SAD are available, but an integrated database is missing. This lack represents a serious obstacle to the planning and evaluation of welfare policies. Not only that, but existing data also focus mainly on service coverage, neglecting aspects such as intensity, quality and appropriateness of care.

Beyond expanding and improving data collection procedures, it is imperative to also maximize the effectiveness of using existing databases.

Another challenge in the panorama of home care in Italy is represented by the shortage of qualified personnel, both nurses and social health workers and social workers. Many professionals in the sector are not adequately trained to manage the needs of integrated home care, which requires transversal skills in particular for communication and collaboration and for the management of complex tasks. Furthermore, the home care sector encounters difficulties in recruiting qualified staff, as they are often perceived as uninspiring and with poor career prospects.

Finally, the informal sector made up of family caregivers and personal assistants constitutes the backbone of home care in Italy. However, these figures encounter various difficulties in providing assistance to non-self-sufficient people. On the one hand, the decrease in the number of potential family caregivers - attributable to various variables such as the reduction in family size, increased geographical mobility and the growing female presence in the market of work - generates an increase in demand for formal home care services.

In addition, there is a shortage of personal assistants available for cohabitation, resulting in unmet demand for full-time home care. This concerns individuals who, although preferring to avoid residential facilities, have difficulty identifying the right assistant to remain in their homes.

In the current context of demographic changes and socio-economic dynamics, strengthening support for family caregivers and personal assistants, and implementing policy reforms in this area has become an imperative necessity.

In particular, the integration between the formal and informal care sectors becomes a field in which significant improvements are possible. For example, the Individualized Care Plan (IAP) could be co-designed with family members and personal assistants to ensure its practical applicability, and continuously updated according to the care recipient's changing needs.

Italy is standing out for its commitment to defining policies aimed at improving the level of integration of health and social care systems. For example:

- The National Plan for Non-Self-Sufficiency, pioneering in defining the Essential Levels of Social Services, lays the foundations for equitable and humanized assistance.
- The National Recovery and Resilience Plan puts the spotlight on the integration of social and health services, making specific budgets available to implement reform policies.
- Various legislative decrees aim to modernize and strengthen the legislation relating to home services for non-self-sufficient people—such as the Decree of 23 May 2022, n. 77; the Legge Delega on Disability and the Legge Delega on Non-Self-sufficiency.

The reforms currently underway offer a unique opportunity in Italy to increase the supply, improve the quality and increase the effectiveness of home care services for non-self-sufficient people. However, the success of the reforms in question will be conditioned by the implementation capacity at the local level and the resources allocated for their implementation.

For example, some stakeholders have highlighted contradictions between the Delegation Law and the objectives of the PNRR relating to the ADI. While the PNRR aims at greater inclusion of the over 65s in ADI services, maintaining unchanged levels of duration and intensity with a single-professional and performance approach, the Delegating Law aims at multidisciplinary and continuous assistance. This discrepancy, if not resolved, could lead to a misalignment between the new legislation and future financial initiatives.

The Legge Delega on Non Self-sufficiency also represents a step forward towards a more flexible and multidimensional assistance system, but its actual implementation will remain strictly conditioned by the implementing decrees and the practical implementation of policies in the field.

Annex A. Annex A List of stakeholders interviewed.

- Agenzia Nazionale per i Servizi Sanitari Regionali (AgeNaS)
- Agenzia Regionale per la Salute ed il Sociale, Puglia
- Associazione Nazionale Comuni Italiani (ANCI)
- Associazione Salute Diritto Fondamentale
- CERGAS Bocconi
- Istituto per la Ricerca Sociale, Milano
- Istituto Nazionale di Statistica (ISTAT)
- Fondazione GIMBE
- Ministero della Salute
- Patto per un nuovo welfare sulla non autosufficienza
- Ricerche Economico-Sociali per l'Invecchiamento, IRCCS-INRCA (Istituto di Ricerca e Cura a Carattere Scientifico – Istituto Nazionale Riposo e Cura Anziani)

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