



**Italy**

# FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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## Executive summary

Funding of social care for PWDs in Italy mostly relies on families and users' own expenditure, much of which is unaccounted for. As most PWDs in the country are over 65, a vast portion of care for PWDs is handled as care for older people: this depends heavily on families' ability to afford solutions of independent living, often through the help of semi-legally or illegally employed caregivers. As employment in this crucial area of care is mostly un(der) declared, data on families' expenditure is necessarily scarce and incomplete.

Existing data allow to trace only the amounts that authorities spend, be it for the direct provision of social care services, or in the form of integration of families and users' personal budgets through pensions or other indemnities. Local authorities cover 83% of costs of the social services for PWDs they offer, although it should be noted that such services address only a small fraction of care needs. The remaining 17% is paid by National Healthcare Service (13%) and users (4%). For the direct provision of social care for PWDs, Italian municipalities spent €1.311bln in 2019, down from €1.870bln in 2017. National funds exist but their aggregated value is lower than the amount spent by municipalities: in 2020 the key national funds totalled €704.1mln. Italian authorities spend considerably more for integration of families and users' budgets: €20.052bln (2019 data) in tax-funded pensions, and an additional €14bln (2017 data) in pensions funded via social security contributions. Private funds also exist but their development is still in its infancy.

Care for PWDs in Italy is regulated at national and regional level. Social care is in turn managed and delivered at municipal level, either by municipalities themselves or supra-municipal authorities, while care for PWDs that includes elements of healthcare is generally managed and delivered at regional level. Differences in regional laws cause variations in local governance. Massive regional and sub-regional inequalities exist in quality and coverage of care services for PWDs: as social care services are financed with local taxation, municipalities from lower-income areas (especially in the South of the country, and in de-industrialized areas in the North and Centre) are put in a condition of major disadvantage and are unable to ensure more than a negligible amount of social care.

Social care not directly organized by families themselves is accessible (when local budgets allow it) through structures, services or facilities managed by private non-profit organizations or private for-profit ones, and to an ever decreasing extent, by public authorities themselves. Throughout the country, the dominating model for funding of providers is *accreditamento* (accreditation), a process of pre-selection of providers on the basis of strict quality requirements and guarantees of continuity of services which allows to avoid repeating public tenders for every service. Accreditation guarantees high quality, but stifles innovation. All areas of care are considered to be underfunded and providing insufficient coverage, and face major funding problems due to the COVID-19 crisis.

### Main Findings

The Italian system of care suffers from heavy reliance on families and users' budgets: this creates an issue of sustainability as the population ages and family networks of support shift towards narrow, multi-generational structures. It also creates measurement and planning problems, due to the lack of reliable statistics on expenditures for home caregivers, often hired illegally or semi-legally, which leave authorities unable to properly plan and address care needs. Public funding through the accreditation model guarantees very good quality, but does not ensure full coverage. National funds remain secondary to local authorities' ones. Private funds are an underexploited but a promising area of funding for the future.

Besides the lack of resources, the other key problem for the Italian system of care relates to regional inequalities, especially in the area of social care, due to the reliance on local taxation to fund services. The idea of delegating social services to municipalities to ensure a provision and management of services that could correctly reflect the territory's needs eventually resulted in the creation of massive gaps between regions, and between low- and high-income areas within the same regions. North-South inequalities create a situation of "two Italies" with vastly different coverage figures, but inequalities exist also between North-Western and North-Eastern regions. National funds need to be vastly increased and directed with priority at the reduction of regional inequalities.

## Introduction

### Legal framework for governance and delivery of services

Care for PWDs in Italy is regulated by Laws 104/1992 and 328/2000,<sup>1</sup> with a thorough reform expected in 2021.<sup>2</sup> These laws set standards for regional and local authorities, but since social care is often handled with *health-care*, which is the regions' responsibility, Regional Laws (or Provincial ones in Trentino-South Tyrol) help define specific funding mechanisms.<sup>3</sup> This causes a lack of a unified legal framework.<sup>4</sup> Municipalities are tasked with delivering social care, but their influence on governance varies, with groups of smaller ones planning services via "zonal plans";<sup>5</sup> one local decision-maker states, however, that regions exert increasingly centralized control and leave less and less planning space to municipalities.<sup>6</sup>

### Management of care services

**Central authorities define general guidelines and monitor their implementation:** Since 2018, oversight was centralized in a dedicated office, supported by a National Observatory.<sup>7</sup> Both fall under the Council of Ministers, and respond to the Prime Minister, reflecting the multifaceted nature of care.<sup>8</sup>

**19 Regions and 2 Autonomous Provinces** (in Trentino-South Tyrol) **oversee planning and management**, while **7,914 municipalities deliver social services**, including to PWDs.<sup>9</sup> Regions fund healthcare services and the health part of health-and-social services, normally tasking Healthcare Districts (local administrations responsible for the management of healthcare) administering the funds. Regions also distribute central funding, which is regionally allocated, to municipalities. Regions task municipalities or their groupings with delivering purely social services, and the social component of health-and-social care.<sup>10</sup> Funding for these services comes mostly from municipalities' budgets: municipalities use 46% of funds to manage services themselves or transfer funds to families, and 54% to pay private providers,<sup>11</sup> mostly non-profit organizations.<sup>12</sup>

1 *Legge 5 febbraio 1992, n. 104. Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate.* [www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg](http://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg); *Legge 8 novembre 2000, n. 328. Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali.* [www.gazzettaufficiale.it/eli/id/2000/11/13/000G0369/sg](http://www.gazzettaufficiale.it/eli/id/2000/11/13/000G0369/sg). (Respectively: GU Serie Generale n.39 of 17-02-1992, Suppl. Ord. n. 30, and n.265 of 13-11-2000, Suppl. Ord. n. 186). Accessed 15 Jul 2020.

2 WelForum 2019. *Codice in materia di disabilità, il disegno di legge delega.* [welforum.it/segnalazioni/codice-in-materia-di-disabilita-il-disegno-di-legge-delega/](http://welforum.it/segnalazioni/codice-in-materia-di-disabilita-il-disegno-di-legge-delega/); Castegnaro, C. 2020. "Disabilità e Legge di Bilancio 2020: qualcosa si muove". *WelForum*, 2 Mar 2020. [welforum.it/disabilita-e-legge-di-bilancio-2020-qualcosa-si-muove/](http://welforum.it/disabilita-e-legge-di-bilancio-2020-qualcosa-si-muove/). Both accessed 19 Aug 2020.

3 Interview with user and local policymaker (Brescia and Trento provinces) (15 Jul 2020).

4 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020.

5 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020.

6 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020.

7 Respectively: *Ufficio per le politiche in favore delle persone con disabilità, Presidenza del Consiglio dei Ministri* (Office for policies for people with disability, Presidency of the Council of Ministers) and *Osservatorio nazionale sulla condizione delle persone con disabilità, Presidenza del Consiglio dei Ministri* (National observatory on the condition of people with disability, Presidency of the Council of Ministers).

8 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020.

9 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020; European Commission 2018. *Challenges in long-term care in Europe. A study of national policies*, <https://ec.europa.eu/social/main.jsp?langId=it&catId=89&newsId=9185>, p. 12. Accessed 25 Jul 2020.

10 Interview with national expert and State-Region specialist, 24 Aug 2020; ISTAT 2019. *Conoscere il mondo della disabilità. Persone, relazioni e istituzioni.* [www.istat.it/it/files//2019/12/Disabilit%C3%A0-1.pdf](http://www.istat.it/it/files//2019/12/Disabilit%C3%A0-1.pdf), p. 18-19

11 ISTAT 2019, p. 136

12 Interview with national expert and State-Region relations specialist, 24 Aug 2020; ISTAT 2019, p. 18-19

Smaller municipalities are grouped into 591 *Ambiti Territoriali Sociali* (Social Territories),<sup>13</sup> through which they identify priorities and define coordinated plans to deliver services.<sup>14</sup> Municipalities delegate the delivery of services, planned at the level of each *Ambito*, to **supra-municipal authorities, or “enti capofila” (leading authorities)**.<sup>15</sup> Such authorities are funded proportionately to each municipality’s general population, regardless of whether one municipality’s inhabitants will actually use services.<sup>16</sup>

**Municipalities decide which services to deliver internally or delegate**, and if and how much they want or can cover families’ social care costs, based on families’ needs and income.<sup>17</sup> Thus, it is impossible to generalize as to which services are delivered by municipalities or by supra-municipal authorities, and which are not, and left to families to pay for.<sup>18</sup> By grouping together, smaller towns can provide the same services as cities, but *ambiti* are at times too small to build economies of scale and share best practices, and cause undue bureaucratic fragmentation.<sup>19</sup> The system thus results in insufficient services provision: **“considerable regional/municipal differences in care provision, eligibility criteria and out-of-pocket payments” exist**.<sup>20</sup> One user from a low-income town in the southern province of Pescara remarks not knowing of any services for PWDs from the local supra-municipal authority.<sup>21</sup>

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A visual summary of management and governance is provided in **Annex 1, Figure 1**.

**Annex 1, In-depth sheet 1** provides more details on management and delivery mechanisms.

Regional inequalities are shown in **Table 5 and 6**, and discussed in **In-depth sheet 3, Annex 2**.

## Who delivers services?

Social services cover a small part of demand for care. They do so with 729,666 employees working in 69,903 structures, which can be **private non-profit, private for-profit, and public**.

**Private non-profit structures**, which dominate care service provision, can be independent living facilities, retirement homes, day care centres, home care services or any other service delivered by *private law entities that qualify as non-profit organizations*. 38,000 non-profit organizations (11.4% of the total) are specifically dedicated to PWDs: they receive 23.4% of the non-profit sector’s revenues.<sup>22</sup> 47.8% of the funds of non-profit organizations dedicated to PWDs come from public contracts, 30.9% from sale of services, and 15.8% from other private funding.<sup>23</sup> **For-profit structures** provide the same services but are managed by private companies or other private law entities allowed to pursue and register profits.

13 Ministero del lavoro e delle politiche sociali 2020a. *Ambiti Territoriali del SIUSS*. <https://www.lavoro.gov.it/strumenti-e-servizi/Sistema-informativo-servizi-sociali/Pagine/Ambiti-Territoriali-del-SIUSS.aspx> Accessed 9 Sept 2020.

14 ATS n. 15 2015. *L’ATS 15*. [www.ats15.marche.atsit.it/ambito.asp?idn=1](http://www.ats15.marche.atsit.it/ambito.asp?idn=1) Accessed 9 Sept 2020.

15 The region of Veneto is an exception as it implemented only some of the indications in Law 328, and very chaotically; as a result, planning is still based on assemblies of mayors of municipalities of long-disbanded healthcare administrative units called “USL”, and disability services are mostly managed and funded by Healthcare Districts (Exchange with social services office employee, Belluno Province, 10 Sept 2020).

16 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020

17 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020; with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020; and with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020; European Commission 2018, p. 15. Consortia, Territorial Authorities for the Delivery of Services to the Person and Social Authorities sometimes coincide with Mountain Communities or part of them (Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.)

18 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020; interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020.

19 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020.

20 European Commission 2018, p. 13

21 Interview with user caring for a mentally and physically disabled relative (Pescara province), 20 Aug 2020.

22 ISTAT 2019, p. 145-147

23 ISTAT 2019, p. 147-148

**Public structures** can be managed by the supra-municipal authorities or by municipalities themselves. After legal changes in 2000-2001, they began morphing into Consortia, Territorial Authorities for the Delivery of Services to the Person and Social Authorities. Most of these are private-law entities and must balance budgets as private companies would.<sup>24</sup> They provide some input into planning, which remains a duty of local political assemblies.<sup>25</sup>

A detailed regional distribution of structures by type can be seen in **Table 1 in Annex 1**.

## Amounts and main funding models in day care, supported living, long-term care

Social care for PWDs in Italy is funded primarily through:

★ **Families and users' personal budgets**, spent to hire private home caregivers or purchase services sold by providers on the market. **Most of this outlay cannot be estimated** due to lack of statistics on families' expenditure for care. **Part of these budgets come from various state pensions for PWDs**, disbursed in two separate strands:

- **Tax-funded pensions**, amounting to €20.052bln (2019 data).<sup>26</sup>
- **Pensions funded via social security contributions**, for €14bln (2017 data).<sup>27</sup>

★ **Local authorities payment for direct provision of services**, i.e., funds spent by municipalities or supra-municipal authorities to pay for social services. In 2019, these amounted to €1.311bln in social services

for PWDs<sup>28</sup> (down from €1.870bln in 2017).<sup>29</sup> This funding is generally allocated with **two separate strands**:

- **Direct purchase of services from private providers** through a procedure called *accreditamento* (accreditation), described in following sections.
- **Payments for services from accredited providers via vouchers**: these are given to families to buy services, but in practice they are direct payments from authorities.

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A detailed split of such funds is shown in **Table 3, Annex 1**.

★ **Central funds for disability**. These funds are distributed regionally for specific types of projects or services and administered by regions or municipalities depending on whether healthcare is involved or not (figures for the main funds are detailed in later sections).

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Trends for central funds are shown in **Table 4, Figure 4 and Figure 5, Annex 1**.

★ **Private donations** (grants, project-based funding from foundations or other donors, bequests) exist, but play a minor role, and are mostly relevant as a future funding model.

## Personal budgets and families' resources

Interviewed national experts agree that **care mostly relies on personal budgets and families' own resources**<sup>30</sup> especially for supported/independent living. Families' budgets are **only partly integrated by**

24 Capiello, G., Monteduro, G. 2009. "L'aziendalizzazione dei servizi pubblici alla persona: dalle Ipab alle ASP". *Non profit*, vol.1, pp. 75-88

25 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020

26 2019 data (internal ISTAT document provided by authorities). Definitions as per ISTAT 2012. *Glossario. Spesa delle amministrazioni pubbliche per funzione. Anni 1990 – 2010*. [www.istat.it/it/files//2012/01/glossario.pdf](http://www.istat.it/it/files//2012/01/glossario.pdf)

27 ISTAT 2019, p. 126

28 Internal ISTAT document provided by expert from *Osservatorio disabilità* during interviews.

29 ISTAT 2019, p. 132; ISTAT 2020. *La spesa dei comuni per i servizi sociali (Tavole spesa sociale dei comuni)*. <https://www.istat.it/it/files//2020/02/Tavole-Spesa-sociale-dei-comuni.xlsx>. Accessed 9 Sept 2020.

30 Interview with national expert Alessandro Solipaca, 6 Aug 2020; interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020.

**state help:** In 2019, authorities allocated €20.052bln in tax-funded, no-strings-attached pensions to families and users, to pay for their own care solutions.<sup>31</sup> This mostly took the form of *indennità di accompagnamento* (accompanying pensions), set at €520.29/month per PWDs for 2020, paid by the National Institute for Social Security (INPS) in cases of complete non-self-sufficiency due to health reasons.<sup>32</sup>

### Local authorities' payment for direct provision of services

As of 2016 data, local authorities cover 83% of costs of the social services for PWDs they offer: the rest is paid by National Healthcare Service (13%) and users (4%),<sup>33</sup> though other ISTAT sources place users' share at 10%, and providers from regions with highly-privatized services estimate it at up to 20%.<sup>34</sup> Of the costs covered by authorities, 61.8% are municipalities or supra-municipal authorities' own funds, 17.8% are Regional Funds for Non-Self-Sufficiencies or other Regional social funds' contributions to municipalities' social expenditure, 9% is government social funds, 7.4% EU or other government funds, 2.7% other public authorities funds, and 1.3% private donations.<sup>35</sup> Southern municipalities rely more on central funding due to lack of own funds.<sup>36</sup> As to regions, they spend on average €987/year per PWDs: 78% in outpatient healthcare costs and supported/independent living (though no exact split is available), 22% in day care or long-term care facilities (LTC).<sup>37</sup>

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A visual split of local funding can be seen in **Annex 1, Figure 2 and 3, and Table 2.**

### Direct purchase of services from private providers via accreditation

Interviews with providers show that despite regional variations, **public-funded care services are generally funded through "accreditation"**: a service provider supplies authorities with "units of service" (Long-Term Care or day care places, number of visits in domestic care, ...) based on a contract allowing authorities to choose providers based on territorial proximity and service needed, without having to do a public tender every time. Though accredited structures sometimes compete to become suppliers and access public budget, providers are usually selected based on proximity to the user.<sup>38</sup> This is possible because compared with facilities merely authorized to sell services privately, **accredited facilities must fulfil tighter standardized quality requirements**, especially healthcare-wise.<sup>39</sup> They must also guarantee continuity and range of services for longer than the average public tender.<sup>40</sup> Local authorities purchase services from accredited providers if and when a territory's health or social needs require it, as determined by territorial planning, and based on budget and demographic trends.<sup>41</sup> Providers thus enjoy stable funding for part or all of their activity for several years, but they can still "sell" privately the part of services that authorities did not commit to buy.<sup>42</sup> Purchasing authorities

31 2019 data (internal ISTAT document provided by authorities). Definitions as per ISTAT 2012.

32 INPS 2020. *Indennità di accompagnamento per invalidi civili*. [www.inps.it/nuovoportaleinps/default.aspx?itemdir=50194](http://www.inps.it/nuovoportaleinps/default.aspx?itemdir=50194) Accessed 17 Aug 2020.

33 ISTAT 2019, p. 136-137.

34 Data shared by expert from *Osservatorio Disabilità*; interview with staff of ATSP Valle Camonica, 15 Jul 2020.

35 ISTAT 2019, p. 136-137.

36 ISTAT 2019, p. 137.

37 ISTAT 2019, p. 19

38 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

39 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul, 5 Aug; interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

40 Regione Emilia-Romagna 2019. *Autorizzazione e accreditamento dei servizi socio-sanitari e sociali*. 1 Mar 2018, updated 3 Dec 2019. [salute.regione.emilia-romagna.it/ssr/strumenti-e-informazioni/autorizzazione-e-accREDITAMENTO/servizi-socio-sanitari-e-sociali](http://salute.regione.emilia-romagna.it/ssr/strumenti-e-informazioni/autorizzazione-e-accREDITAMENTO/servizi-socio-sanitari-e-sociali). Accessed 17 Aug 2020.

41 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

42 Interviews with national experts and with providers in Lombardy, Trentino and Piedmont.

are then responsible for controls. A survey of recent calls for accreditation shows similar mechanisms across regions and types of care.<sup>43</sup>

Accreditation typically involves a non-profit organization whose services, requested by a supra-municipal authority based on needs defined by local councils and on available budget, are paid half by authorities, half by users (using funds from state pensions if available).<sup>44</sup> Authorities purchase units of service using municipalities or supra-municipal authorities' budget for social services, or Regional Funds for Non-Self-Sufficiency for healthcare services or health parts of mixed ones.<sup>45</sup> Municipalities can reimburse part of the families' fee, if the budget allows it.<sup>46</sup> Remaining units of service can be sold to users at full price, if contracts with authorities allow it, but all interviewed providers note that nearly all places and funding (70% or more, with providers in Piedmont reaching up to 90%)<sup>47</sup> are "in accreditation".

### Payments for services from accredited providers via vouchers

Local authorities allocate funds as reimbursements earmarked for specific services, providing "vouchers" to families who spend them for the desired services. **Table 3, Annex 1** shows authorities' expenditure for

vouchers. However, as regions and municipalities set vouchers amounts differently based on available budget and family income, average figures per user are only indicative. Municipalities' income inequalities cause **vast differences in what users receive, especially between North and South**; all providers interviewed in all regions report that municipalities prioritize support for users with no income and family support.

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**Annex 2, In-depth sheet 3** provides a detailed analysis of regional inequalities

### Central funds for disability

Several central funds, often bound to specific types of projects or areas of care, supplement local authorities' budgets. Funds are divided by region and managed locally by healthcare districts (for healthcare services) or municipalities (for social care). The main fund is the *Fondo nazionale per la non autosufficienza* or FNA (National Fund for Non-Self-Sufficiency), created in 2006 to support regional and municipal efforts to avoid institutionalization of people with very severe disabilities and non-self-sufficient older people.<sup>48</sup> The fund received €100m for 2007 and after fluctuations over the years it reached €621m for 2020.<sup>49</sup>

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- 43 Comune di Saronno 2020. *Bando per l'accreditamento del servizio di assistenza domiciliare anziani e disabili*. 11 May 2020. [comune.saronno.va.it/servizi/notizie/notizie\\_fase02.aspx?ID=16768](http://comune.saronno.va.it/servizi/notizie/notizie_fase02.aspx?ID=16768); Città di Bagheria 2020. *On line avviso per la domanda di accreditamento per i servizi di assistenza domiciliare a favore di anziani disabili minori e donne in difficoltà*. 8 Jul 2020. [comune.bagheria.pa.it/on-line-avviso-per-la-domanda-di-accreditamento-per-i-servizi-di-assistenza-domiciliare-a-favore-di-anziani-disabili-minori-e-donne-in-difficolta/](http://comune.bagheria.pa.it/on-line-avviso-per-la-domanda-di-accreditamento-per-i-servizi-di-assistenza-domiciliare-a-favore-di-anziani-disabili-minori-e-donne-in-difficolta/); ASPA Asolano 2018. *Patto di accreditamento per il servizio assistenza domiciliare*. [www.aspa-asola.it/attachments/article/413/PATTO%20ACCREDITAMENTO%20SAD.pdf](http://www.aspa-asola.it/attachments/article/413/PATTO%20ACCREDITAMENTO%20SAD.pdf); Comune di Alcamo 2020. *Bando:Accreditamento di Enti fornitori di Prestazioni Socio-Assistenziali, a mezzo di Voucher*. 15 May 2020. [www.comune.alcamo.tp.it/it/news/accreditamento-di-enti-fornitori-di-prestazioni-soc](http://www.comune.alcamo.tp.it/it/news/accreditamento-di-enti-fornitori-di-prestazioni-soc); Unione dei comuni della Planargia e del Montiferru occidentale 2019. *Bando per l'istituzione dell'albo dei soggetti accreditati*. [www.regione.sardegna.it/allegati\\_bandi/Bando\\_Accreditamento\\_2019\\_2020\\_5cb10a63da925.pdf](http://www.regione.sardegna.it/allegati_bandi/Bando_Accreditamento_2019_2020_5cb10a63da925.pdf); Comunità Montana Montagna Marsicana 2018. *Avviso per l'Accreditamento dei Fornitori di prestazioni di assistenza domiciliare per anziani e disabili, assistenza scolastica specialistica e telesoccorso*. 23 Aug 2018. [www.comunedortucchio.it/images/HOME/368-avviso-accreditamento-servizi-piano-di-zona.pdf](http://www.comunedortucchio.it/images/HOME/368-avviso-accreditamento-servizi-piano-di-zona.pdf); Regione Emilia-Romagna 2019; Regione del Veneto 2020. *Autorizzazione e accreditamento delle strutture sanitarie, socio-sanitarie e sociali*. 10 Feb 2020. [www.regione.veneto.it/web/sociale/autorizzazione-e-accreditamento](http://www.regione.veneto.it/web/sociale/autorizzazione-e-accreditamento). All accessed 17 Aug 2020.
- 44 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.
- 45 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020; Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.
- 46 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020, and staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020; Interview with provider Enza Picca (Turin province), 4 Aug 2020.
- 47 Interview with provider Enza Picca (Turin province), 4 Aug 2020.
- 48 ISTAT 2019, p. 184
- 49 Camera dei deputati 2020. *Le misure a sostegno della famiglia e i fondi per le politiche Sociali*. Rome: Camera dei deputati, Servizio studi XVIII Legislatura. [temi.camera.it/leg18/temi/t118\\_misure\\_sostegno\\_famiglia.html](http://temi.camera.it/leg18/temi/t118_misure_sostegno_famiglia.html). Accessed 29 Jun 2020. p. 7

Other funds include: *Fondo Dopo di Noi* (After us), which amounts to €56.1m for 2019 and €58.1m for 2020,<sup>50</sup> destined for supported/independent living projects for PWDs after their parents' deaths; *Fondo per il caregiver familiare* (Fund for care giving relatives), of €25m for 2019 and 2020;<sup>51</sup> *Fondo per la disabilità e la non autosufficienza* (Fund for Disability and Non-Self-Sufficiency) of €200m for 2021 and €300m for later years.<sup>52</sup>

Sometimes **paradoxes may emerge when central funding is bound to specific areas** of intervention: local administrators are put in a condition of being unable to use such portion of central funds if their territory does not have the specific need they are destined for; and, since dedicated funding cannot be “transferred” freely to solve problems different from those for which they were destined, other and more pressing needs that the territory may have will remain unaddressed.<sup>53</sup>

Amounts and trends in national funds are shown in **Table 4, Figure 4 and Figure 5, Annex 1.**

## Private donations

Private donations can be **individuals' donations and bequests**, or **grants and project-based funding** from Foundations. Individual donations can be spent by recipients based on need, except in the case of bequests bound to specific goals.<sup>54</sup> Foundations' funding

can be operational or project-based and is accessible both to public and private non-profit providers.<sup>55</sup> Banks' Foundations dominate the Italian foundations landscape and are especially active in Lombardy.<sup>56</sup> Private donations cover only 1.3% of local authorities social expenditure for PWDs,<sup>57</sup> but are more important for non-profit organizations. Such donations are estimated to cover 7% of the budget of *healthcare and social services non-profit organizations*.<sup>58</sup> For *disability-focused non-profit organizations*, ISTAT suggests that 7.2% of budget comes from yearly donations from members, 4.4% from other individual donations and bequests, and 4.2% from “other private sources” (It is unclear how much of this refers to foundations), for a total of 15.8%.<sup>59</sup> This can reach up to 25% thanks to Foundations grants in regions where private-public cooperation is more solid.<sup>60</sup>

## Chronology of introduction of funding models used in the three sectors

Personal budgets with integration from state pensions always played a role in Italian care: pensions for work injuries date back to the birth of INAIL in the 1880s, while *accompagnamento* was established in 1968.<sup>61</sup> The accreditation model in public provision of services arose in the 1990s, replacing the public welfare one of the 1970s-1980s.<sup>62</sup> Regions begun adopting it in

50 Camera dei deputati 2020, p. 8

51 ISTAT 2019, p. 185-187.

52 Camera dei deputati 2020, p. 1.

53 Email exchange with provider, local policymaker Mattia Signorelli (Bergamo and Brescia), 17 Oct 2020.

54 Interview with provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020.

55 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020; Exchange with social services office employee, Belluno Province, 10 Sept 2020.

56 Milner, A. 2017. “The State of European Philanthropy”. *Alliance*, 24 Jan 2017. [www.alliancemagazine.org/opinion/state-european-philanthropy/](http://www.alliancemagazine.org/opinion/state-european-philanthropy/). Accessed 11 Sept 2020; Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020

57 ISTAT 2019, p. 136-137.

58 Barbeta, G. P., Canino, P., Cima, S., Verrecchia, F. 2018, “Entry and Exit of Nonprofit Organizations. National, Sectorial, and Geographic Trends with Italian Census Data”. *Nonprofit Policy Forum*, Aug 2018, p. 2

59 ISTAT 2019, p.147

60 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

61 Milazzo, R. 2000. “Le pensioni di invalidità civile nel periodo 1980-1997”. In ISTAT, *Contributi – Anno 2000*. Rome: ISTAT. [www.istat.it/it/archivio/219432](http://www.istat.it/it/archivio/219432) Accessed 10 Sept 2020.

62 Barbeta, G. P., Canino, P., Cima, S., Verrecchia, F. 2018, p. 3

the 2000s,<sup>63</sup> during the transition of the delivery of services from Public Institutes of Care and Charity to supra-municipal authorities. This is the **main change in funding models in recent decades across all types of care** (Some public Institutes of Care and Charity still exist but tend to deliver services via public tender).<sup>64</sup> A reform of the non-profit sector was initiated with Enabling Act 106/2016 but has not yet implemented.<sup>65</sup>

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**Annex 2, In-depth sheet 2** provides a detailed assessment of quality and reach of care

**Annex 3, In-depth sheet 4** details the impact of funding models for working conditions

## Future Plans

A key trend in all regions and areas of care is the growth of *private* funds to offset gaps and unreliability in public funding, and obtain innovation goals.<sup>66</sup> Experts expect them to grow in importance: some see community foundations as a viable future funding model.<sup>67</sup> Private donations, especially bequests, “weigh” more for Church-affiliated organizations.<sup>68</sup>

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**Annex 3, In-depth sheet 5** provides a detailed discussion of future challenges.

## Day Care

### Accessibility

Places for younger PWDs in day care are few: this is worrying as day care acts as “daily *respite* care”, crucial to allow parents to work.<sup>69</sup> One user notes that in some *rural* areas, day care centres may have too few users to be financially sustainable and face closure, leaving families without support.<sup>70</sup> Users that cannot access services are generally assisted at home, often with private caregivers (“*badant*”).<sup>71</sup>

### Amount of state funding – specific to day care services

Based on a 2019 ISTAT report, municipalities’ day care outlays are stable at around €200-250mIn, but have declined in percentage: 21% of social care expenditure for PWDs in 2004, 18% in 2010, 17% in 2016 (2017 data).<sup>72</sup> In 2020, a *Fondo di sostegno per le strutture semiresidenziali per persone con disabilità* (Support fund for PWDs day care structures) was established to help day care centres that had to restrict their activities due to COVID-19.<sup>73</sup> This fund (€40mIn for 2020) is centrally-managed: providers can apply for help directly.<sup>74</sup>

63 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020, and with provider Devis Ghirardelli (Brescia province), 29 Jul 2020.

64 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

65 *Legge 6 giugno 2016, n. 106 - Delega al Governo per la riforma del Terzo settore, dell’impresa sociale e per la disciplina del servizio civile universale.* (GU Serie Generale n.141 del 18-06-2016). [www.gazzettaufficiale.it/eli/id/2016/06/18/16G00118/sg](http://www.gazzettaufficiale.it/eli/id/2016/06/18/16G00118/sg). Accessed 27 Aug 2020. Camera dei deputati 2020b. *Riforma del Terzo settore*. Rome: Camera dei deputati, Servizio studi XVIII Legislatura. [www.camera.it/temiap/documentazione/temi/pdf/1105128.pdf](http://www.camera.it/temiap/documentazione/temi/pdf/1105128.pdf). Accessed 6 Aug 2020, p. 9.

66 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020; interview with provider Enza Picca (Turin province), 4 Aug 2020.

67 Casadei, B. 2019. “La vera missione per il terzo settore: promuovere il dono”. *Vita*, 16 Jan 2019. [vita.it/it/blog/rifondazioni/2019/01/16/la-vera-missione-per-il-terzo-settore-promuovere-il-dono/4641/](http://vita.it/it/blog/rifondazioni/2019/01/16/la-vera-missione-per-il-terzo-settore-promuovere-il-dono/4641/); Casadei, B. 2018. “Intermediari filantropici e fondazioni di comunità”. *Vita*, 13 May 2018. [vita.it/it/blog/rifondazioni/2018/05/13/intermediari-filantropici-e-fondazioni-di-comunita/4527/](http://vita.it/it/blog/rifondazioni/2018/05/13/intermediari-filantropici-e-fondazioni-di-comunita/4527/). Accessed 21 Aug 2020.

68 Interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020; interview with provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020.

69 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020

70 Interview with user caring for a mentally and physically disabled relative (Ancona province), 21 Aug 2020.

71 Email communication with Alessandro Solipaca, 14 Aug 2020

72 ISTAT 2019, p. 132-133

73 Camera dei deputati 2020a. *Politiche sociali per fronteggiare l’emergenza coronavirus*. Rome: Camera dei deputati, Servizio studi XVIII Legislatura. [www.camera.it/temiap/documentazione/temi/pdf/1215181.pdf?\\_1593502011792](http://www.camera.it/temiap/documentazione/temi/pdf/1215181.pdf?_1593502011792). Accessed 30 Jun 2020. p. 8

74 Camera dei deputati 2020a, p. 8

## Quality of day care services

Despite coverage issues, interviewed stakeholders agree that the quality of day care is very high, both in accredited structures and public ones, although innovation depends heavily on local authorities' income: **this deeply disadvantages Southern ones**.<sup>75</sup> One user in a central province assesses local day care services as fairly basic, though "nothing one can complain about".<sup>76</sup> Key issues affect **mountain areas nationwide and Southern rural areas** with poor road networks, where transporting PWDs to day care centres is arduous;<sup>77</sup> unfortunately, national funds do not allocate additional resources to cover for higher logistic costs.<sup>78</sup>

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**Annex 2, In-depth sheet 3** provides a detailed analysis of regional inequalities.

**Annex 3, In-depth sheet 6** provides additional details on day care services.

## Independent/Supported Living

### Amount of state funding – specific to supported/independent living services

Municipalities' social expenditure for supported/independent living for PWDs grew from €131m (14%) in 2004 to around €273m (19%) in 2010 and 2016.<sup>79</sup> However, this remains an under-invested area of care, which is why central planners allocated a fixed part of the National Fund for Non-Self-sufficiency for independent living projects.<sup>80</sup>

### Accessibility and quality of supported/independent living services

It is impossible to determine how many PWDs use supported/independent living care, as this service is counted with "integrated home assistance", a health-and-social service not limited to PWDs.<sup>81</sup> Vast regional and sub-regional gaps exist, beyond the usual North/South divide;<sup>82</sup> regions like Lombardy report a vast coverage,<sup>83</sup>

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75 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020, provider Maria Rosa Dossi (Trento Province), 9, 10 and 15 Jul 2020, provider Enza Picca (Turin province), 4 Aug 2020, high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020, provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020.

76 Interview with user caring for a mentally and physically disabled relative (Ancona province), 21 Aug 2020.

77 Interview with providers in Lombardy, Piedmont and Trentino-South Tyrol; interview with national expert Alessandro Solipaca, 6 Aug 2020

78 Interview (email) with national expert and State-Region relations specialist, 24 Aug 2020.

79 ISTAT 2019, p. 133.

80 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020; interview with national expert Alessandro Solipaca, 6 Aug 2020. For plans, see Ministero del lavoro e delle politiche sociali 2019. *Piano per la non autosufficienza 2019-2021*. [www.cisl.it/attachments/article/14296/Piano%20non%20autosufficienza.pdf](http://www.cisl.it/attachments/article/14296/Piano%20non%20autosufficienza.pdf). Accessed 27 Aug 2020.

81 ISTAT 2019, p. 138

82 Redazione AboutPharma Online 2019 "Assistenza domiciliare, in Italia solo tre anziani su cento ne beneficiano". *AboutPharma*, 12 Mar 2019. [www.aboutpharma.com/blog/2019/03/12/assistenza-domiciliare-in-italia-solo-3-anziani-su-cento-ne-beneficiano/](http://www.aboutpharma.com/blog/2019/03/12/assistenza-domiciliare-in-italia-solo-3-anziani-su-cento-ne-beneficiano/). Accessed 26 Aug 2020..

83 Bosco, F. 2019. "Assistenza domiciliare privilegio per il 3% degli anziani. Bernabei (Italia Longeva): «Dotazione di servizi comica»". *Sanità Informazione*, 13 Mar 2019. [www.sanitainformazione.it/salute/assistenza-domiciliare-bernabei/](http://www.sanitainformazione.it/salute/assistenza-domiciliare-bernabei/). Accessed 26 Aug 2020.

but one former policy-maker from the region dismisses this as “useless”, claiming that local statistics count the users reached *without weighing the hours delivered against those needed*: users who receive insufficient care still appear as “reached”.<sup>84</sup> One interviewee from another high-income region notes that the bureaucratic burden to activate home assistance is dishearteningly heavy.<sup>85</sup>

The **low coverage forces families to organize home care on their own**, especially for older PWDs. They do so in three main ways: through work leaves, taken up mostly by women;<sup>86</sup> with help from relatives, usually women,<sup>87</sup> who often cannot set aside enough retirement contributions;<sup>88</sup> or with the help of *badanti*, private caregivers with or without professional qualifications, usually Eastern European migrant women,<sup>89</sup> widely seen as vital for the system of care: without them, care for older people, older PWDs, and some PWDs under 65 would collapse, as it would cost the State an estimated €15bn/year to provide residential care instead.<sup>90</sup> The few available estimates of families’ spending for *badanti* are likely to be massive underestimations, as they do not account for undeclared payments.

## Working conditions of staff of providers of supported/independent living services

Working conditions of operators (in all areas of care) depend on identical, national contracts that ensure workers rights protection. **Badanti however face a different situation**, as they fall in the under-regulated area of domestic workers, 57-60% of whom are estimated to work illegally.<sup>91</sup> Legally-employed *badanti* have a right to a half-day off in the middle of the week, one day off per week (usually Sunday), and, if they reside at the PWD’s home, two free hours per day, but they often prefer to work these as off-books extra time.<sup>92</sup> Although they usually work day and night, they tend to have job security only for 25-30 *official* working hours, for around €650/month gross (enough to secure pension, sick leave, holidays, severance indemnities, bonuses and other rights, but *below the taxable income threshold*); additional hours are paid off-books, usually much more in Northern regions than Southern ones.<sup>93</sup> *Badanti* also get varying degrees of help from Regionally-funded domestic care support.<sup>94</sup>

84 Interview with user and local policymaker (Brescia and Trento provinces), 26 Aug 2020.

85 Interview with relative of people with severe cognitive deterioration (Vicenza Province), 4 Sept 2020.

86 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020; European Commission 2018, p. 18 and 31.

87 Interview with user caring for a mentally and physically disabled relative (Ancona province), 21 Aug 2020.

88 ISTAT 2019, p. 171.

89 SafAcli 2018. *Osservatorio sui lavoratori domestici – dati 2017*. [www.safaccli.com/news/lavoratori-domestici-dati-2017/](http://www.safaccli.com/news/lavoratori-domestici-dati-2017/). Accessed 15 Aug 2020; 88.5% of regularly-employed *badanti* are women. In Southern regions, due to the limited employment possibilities, many positions of domestic carer are taken up by Italian women (VITA 2019. *Colf e badanti: in Italia 865mila regolari su 2 milioni di lavoratori domestici*. 15 Jan 2019. [www.vita.it/it/article/2019/01/15/colf-e-badanti-in-italia-865mila-regolari-su-2-milioni-di-lavoratori-d/150336/](http://www.vita.it/it/article/2019/01/15/colf-e-badanti-in-italia-865mila-regolari-su-2-milioni-di-lavoratori-d/150336/). Accessed 15 Aug 2020)

90 Milano, F. 2018. “Senza le badanti gli anziani costerebbero allo Stato 15 miliardi di euro”. *Il Sole 24 ore*, 23 Oct 2018. [www.ilsole24ore.com/art/senza-badanti-anziani-costerebbero-stato-15-miliardi-euro-AEOkMdTG](http://www.ilsole24ore.com/art/senza-badanti-anziani-costerebbero-stato-15-miliardi-euro-AEOkMdTG). Accessed 16 Aug 2020; Galeazzi, G. 2020. “L’Italia senza badanti”. *In Terris*, 10 Jan 2020. Available from: [www.interris.it/la-voce-degli-ultimi/sociale/litalia-senza-badanti/](http://www.interris.it/la-voce-degli-ultimi/sociale/litalia-senza-badanti/).

91 VITA 2019; Galeazzi, G. 2020.

92 Views from *badanti* from various Italian regions, reported during interview with user and local policymaker, 16 Aug 2020; additional clarifications and review from EASPD Board Member Fabrizio Fea, 2 Nov 2020. As Assessor for Social Services in a town in the North-West, the interviewee interacted at work with tens of *badanti* who worked in multiple regions in the South, the North-West, and the North-East of Italy.

93 Interview with user and local policymaker (Brescia and Trento provinces), 16 Aug 2020.

94 Interview with user and local policymaker (Brescia and Trento provinces), 16 Aug 2020.

## Future plans in financing/ governance of supported/ independent living services

**Supported/independent living services see slow increases in funding**, but as one provider from Lombardy laments, this is not enough and will not avoid future cuts in services.<sup>95</sup> One provider from Piedmont notes that regions fail to adapt funding to new conditions: the funding that they provide via Healthcare Districts is often frozen to levels of 10-15 years ago.<sup>96</sup> Moreover, public administrators sometimes ignore the circumstances providers have to work in, and interact unprofessionally with them, demanding the same standards of care despite failure to adapt funding to inflation.<sup>97</sup> Domestic care also faces the same logistical issues in rural/mountain areas as day care.

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**Annex 3, In-depth sheet 6** provides additional details on independent/supported living.

## Long-Term Institutional Care

**Institutional LTC is increasingly health-focused** due to Italy's ageing population: interviewed providers and experts from all regions agreed that the growth in the percentage of *older* PWDs who suffer from dementia and/or physical impairments places an unmanageable burden on the system of care. Providers now report disability rates of up to 100%.<sup>98</sup> facilities never meant to cater to large

numbers of older PWDs, such as *Residenze sanitarie-assistenziali* or RSA (Healthcare residencies) now have almost only users with severe ailments or disabilities, and must shift from social care for lonely people to a health-and-social care for PWDs.<sup>99</sup> Social care and health-and-social care LTC facilities are estimated to house 288,000 older people, of which 218,000 classified as "non-self-sufficient".<sup>100</sup> 28,000 (4.5%) of PWDs under 65 attend municipal or accredited residential facilities.<sup>101</sup>

## Amount of state funding – specific to long-term institutional care

**Long-term care is seen as underfunded**, with only limited projected increase for the next 15 years.<sup>102</sup> (Funding splits are shown in **Table 3, Annex 1**). According to a meta-study of literature on LTC, the key issue is *insufficient funding for local welfare services*, rather than insufficient personal budgets.<sup>103</sup> Residential facilities for PWDs under 65 absorbed around 17-18% of municipalities' social expenditure for PWDs in 2004-2016.<sup>104</sup> 38% of Municipal funds for care for older people went in residential facilities in 2016.<sup>105</sup>

Accredited *health-care* residencies received around 50% of funds from regions, but families are being asked to pay more, at which point it is up to municipalities to help them, if they can.<sup>106</sup> This reflects a key issue reported during interviews with regard, but not limited to, long-term institutional care for older PWDs: the division of funding

95 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020.

96 Interview with provider Enza Picca (Turin province), 4 Aug 2020

97 Interview with provider Enza Picca (Turin province), 4 Aug 2020

98 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020; interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020;

99 Interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020; interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul and 5 Aug 2020.

100 Galeazzi, G. 2020.

101 ISTAT 2019, p. 133

102 European Commission 2018, p. 35

103 Gori, C. 2017.

104 ISTAT 2019, p. 133

105 ISTAT 2019, p. 136

106 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul, 5 Aug 2020; interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020.

responsibilities between regions and municipalities sees an **“attempt by the health-care system to devour funding for the social care one”** due to the fleeting boundary between the two.<sup>107</sup> While regions are supposed to cover “health” costs and municipalities “social” ones, in practice the definition of the split is largely left to the discretion of the regions, which often under-estimate the health burden of a service, reducing its weight on the region’s budget, and forcing municipalities and families to pay for health expenses as “social care”.<sup>108</sup>

## Funding of providers of long-term institutional care

For older PWDs in residential facilities, even for places in accreditation, **a large portion of funding derives from families’ budgets.** Budget transfers from the central government help only minimally: The average facility costs €1.500–€3.000/month (depending on the region and the range of services offered), against €520 in *accompagnamento*.<sup>109</sup>

## Accessibility and quality of long-term institutional care

**Quality guaranteed by the accreditation model is high, but coverage is insufficient.**<sup>110</sup> The Ministry of Health’s residential health-and-social care data show vast regional coverage inequalities: from 4 places per 1,000 people with severe disabilities in residential LTC in Sicily to around 18/1,000 in Lombardy, with most regions falling in the 5-10/1,000 range.<sup>111</sup>

## Links between funding models and changes in access, quality, working conditions

The accreditation model raises a key challenge for the sustainability of facilities: healthcare-heavy residential facilities are paid by regions for a certain number of “units” of care (days per user); once these are delivered, such structures, differently from day care or domestic assistance providers, cannot stop delivering services, unless by expelling users: they thus have to cover costs by asking for more funding, or, when this is not available, face deficit.<sup>112</sup> This can force facilities to cut costs and quality to ensure continuity of service.

## Future plans for financing/governance of long-term institutional care

Funding for residential services for PWDs under 65 is seen as sustainable, but the same is not true for older PWDs’ residential facilities, which in some provinces **struggle to return to normal users counts due to staggering death rates due to COVID-19:** in the first months of the COVID-19 crisis, authorities agreed to keep paying the full cost of services despite the death of large numbers of users (50% or more in some parts of Lombardy), but this will inevitably cease as 2020 progresses, at which point providers fear that they may have to cut on staff and services.<sup>113</sup> One provider is “struggling to imagine a future, with a Region that is simply not prepared to understand the needs of the moment and is utterly unprepared to come up with suitable legislation”.<sup>114</sup>

107 Quote from interview with national expert and State-Region relations specialist, 24 Aug 2020.

108 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020, 5 Aug 2020; interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020.

109 Galeazzi, G. 2020; Interview with provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020.

110 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

111 ISTAT 2019, p. 140

112 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

113 Interviews with provider and regional expert Enzo Raco (Brescia province) and with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

114 Interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020;

Private funds in coordination with increased public investment may help offset the resources crisis; experts tend to refer to private insurance funds, rather than grants or donations, but do not agree as to whether this will suffice to solve existing problems.<sup>115</sup> There is a concern that insurance funds will only benefit higher income families.<sup>116</sup> For LTC for older non-self-sufficient people, one solution could lie in more public funds in coordination with private ones, but there is limited political will to increase public spending.<sup>117</sup>

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**Annex 3, In-depth sheet 6** provides additional details on long term institutional care.

## Respite care

Accessibility and quality of long-term institutional care and respite care

For respite care, figures on coverage and funding are unclear. Amounts can be estimated (**Table 3, Annex 1**) by assuming that “Summer day care” and “Summer or winter care structures” are pure respite care; however, much respite care is temporary placement in residential or supported/independent living structures all year long, and its funding is therefore indistinguishable from other care types. A typical respite care service for older PWDs is approved by local social services and takes the form of up to 30 days/year of placement at reduced cost (half of that of a long-term facility) funded by Regional funds (when healthcare is present).<sup>118</sup> Respite care for PWDs under 65 often takes the form of summer camps, generally paid by vouchers funded with Regional funds.<sup>119</sup>

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115 Interview with national expert Alessandro Solipaca, 6 Aug 2020; Gori, C. 2017, p. 24-25.

116 Gori 2017, p. 25

117 Gori 2017, p. 25-26

118 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

119 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo), 4 Aug 2020; interview with regional and national expert and former provider Dario lanes, 11 Aug 2020.

## Interviews

- ★ Prof. Alessandro Solipaca, National Expert on Disability and Health, Scientific Director of the National Observatory on Health, Catholic University of Milan, Interviews on 6<sup>th</sup> of August, 2020 and 14<sup>th</sup> of August, 2020
- ★ Dr. Alfredo Ferrante, National and European expert, Coordinator of the Service for Family Policies at the Presidency of the Council of Ministers, Interview on 6<sup>th</sup> of August, 2020
- ★ Prof. Dario Ianes, National and Regional Expert, Professor of Pedagogy and Specialized Teaching, Free University of Bozen-Bolzano, Interview on 11<sup>th</sup> of August, 2020
- ★ Devis Ghirardelli, Provider (private sector), Managing Director of *Fondazione Angelo Maj* RSA providing services for older PWD, Interview on 27<sup>th</sup> of July, 2020
- ★ Enza Picca, Provider and Employee, High-ranking Manager and “socio-lavoratore” (member-employee) of *Cooperative Zenith*, providing services for people with mental disabilities, Interview on 4<sup>th</sup> of August, 2020
- ★ Enzo Raco, Regional expert, High-ranking Manager of an RSA delivering services to older PWD with severe disabilities, mental degenerative disorders and psychiatric conditions, Interview on 3<sup>rd</sup> of July, 2020
- ★ Maria Rosa Dossi, Provider (public and private sectors), Social service work and 10 years of experience in care for older PWD, Interviews on 9<sup>th</sup> of July, 2020, 10<sup>th</sup> of July, 2020 and 15<sup>th</sup> of July, 2020
- ★ Staff of ATSP Valle Camonica, Provider (public and private sectors) and Employee, Interview on 15<sup>th</sup> of July, 2020
- ★ Mattia Signorelli, Local Policymaker, Provider (public sector) and Employee, responsible for social services planning and delivery and decision making through the planning at one of the territorial areas of Mountain Community *Alto Sebino*, Interviews on 3<sup>rd</sup> of August, 2020 and 17<sup>th</sup> of October, 2020
- ★ Anonymous National Expert and State-Region Relations Specialist, High-ranking Officer at the Social Policies Commission of the State-Regions Conference and at the Social Policies Planning Office, Interview on 24<sup>th</sup> of August, 2020
- ★ Anonymous National Fundraising, Marketing and Communication Expert and Strategic Consultant for NPO, Interview on 21<sup>st</sup> of August, 2020
- ★ Anonymous High-ranking Staffer of a public provider, Social Worker with several years of experience in a day-care for PWD, Coordinator of day-care services for one of the SMAs, Interview on 3<sup>rd</sup> of August, 2020
- ★ Anonymous Private Provider and High-ranking Manager at an RSA facility (retirement home) and user, in charge of care for three PWD, two children and one elder (over 65 years), Interview on 23<sup>rd</sup> of August, 2020
- ★ Anonymous Provider (private sector) and Local Expert, Sociologist and High-ranking Manager at a Foundation delivering various services for PWD, Interviews on 23<sup>rd</sup> of July, 2020 and 5<sup>th</sup> of August, 2020
- ★ Anonymous Provider (private sector) and Local Expert involved in local decision making, president and “*Socio-Lavoratore*” (member-employee) of a local NPO (Cooperative) delivering all types of services to PWD under 65 years, Interview on 4<sup>th</sup> of August, 2020
- ★ Anonymous Private Provider, Director and “*Socio-Lavoratore*” (member-employee) of an NPO active in experimental care services for PWD under 65 years, Civil Society and Advocacy Activist, Interview on 17<sup>th</sup> of August, 2020
- ★ Anonymous Employee and Operator in a day-care centre for young PWD, Interview on 19<sup>th</sup> of August, 2020
- ★ Anonymous User and Local Policymaker with the experience of caring for two older PWD, Consultant for local administrators, Interviews on 15<sup>th</sup> of July, 2020, 16<sup>th</sup> of August, 2020 and 26<sup>th</sup> of August, 2020
- ★ Anonymous User, relative caring for and living with a mentally disabled adult PWD, Interview on 24<sup>th</sup> of August, 2020
- ★ Anonymous User, relative caring for and living with a mentally and physically disabled young adult PWD with degenerative condition, Interview on 21<sup>st</sup> of August, 2020

- ★ Anonymous User, relative caring for and living with a mentally disabled older PWD with degenerative condition, Interview on 20<sup>th</sup> of August, 2020
- ★ Anonymous User, relative of a mentally and physically disabled young adult PWD taken care of at home, Interview on 20<sup>th</sup> of August, 2020
- ★ Anonymous Employee at the Conversation with Social Services Office, the Municipality of Belluno, Interview on 10<sup>th</sup> of September, 2020

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# Annex 1

## In-depth sheet 1: Legal framework and management of services

### Assessment of the legal framework for governance and delivery of services

On paper, Italian laws are cutting-edge, but *implementation* has not been: to date, 28.7% of families with one PWD face material deprivation, against a national average of 18%.<sup>120</sup> “The tools deployed have not achieved the expected results, merely reducing inequalities [between families with and without PWD], or preventing their widening”, relying too much on institutionalization and *alleviation* of problems, rather than *fulfilling PWD’s capabilities and functioning*.<sup>121</sup> One Genoa-based operator is quoted criticizing this trend by saying: “I feel as if we took [PWDs] and we brought them to a highway. They travel comfortably, sure. They need something? We get it at a service station. There’s everything they need. But at the end of the day, we’re still driving there, on the highway. The real life is outside”.<sup>122</sup>

In assessing the legal framework, it is important to consider that Special Statute Regions and Autonomous Provinces have more discretion in defining their policies of care than Regular Statute Regions, and some defined local funding models before national law.<sup>123</sup> Assessing the suitability of the legal system is also made complex by the fragmentation of legal provisions across regions, not all of which have a single unified legal text to regulate the issue. For example, some regional laws, such as Lombardy’s Law 6/1989,<sup>124</sup> while not focused on care, directly fund users’ domestic needs, resulting in funding for independent living.<sup>125</sup>

### Management of Care Services

Among the supra-municipal authorities that deliver the services planned within each *ambito* mentioned in the factsheet, the main types are *Comuni capofila* (Larger municipalities that take charge of the delivery of services on behalf of smaller ones in the area), *Consorzi* (Consortia), *Comunità montane* (Mountain communities),<sup>126</sup> *Aziende territoriali per i servizi alla persona* or ATSPs (Territorial Authorities for the Delivery of Services to the Person), *Aziende Sociali* (Social Authorities), or *Comunità di Valle* (Valley Communities).

Some of these authorities (Consortia, Territorial Authorities for the Delivery of Services to the Person and Social Authorities) are created *ad hoc* by the municipalities of a given *ambito* for the provision of services as per Law 328; Mountain Communities and Valley Communities however pre-date the law and were chosen because already well-established in the territory, where they played key roles in civil protection and environmental protection for mountain areas.

In recognition of the complexity of planning services in the context of severe infrastructural limitations, and of the small size and large territorial extension of many mountain municipalities, in mountain areas *ambiti* can be smaller in terms of number of inhabitants than in other areas of the country; this, however, is reported to exacerbate the difficulties in building economies of scale and circulating best practices.<sup>127</sup>

120 ISTAT 2019. *Conoscere il mondo della disabilità. Persone, relazioni e istituzioni*. [www.istat.it/it/files//2019/12/Disabilit%C3%A0-1.pdf](http://www.istat.it/it/files//2019/12/Disabilit%C3%A0-1.pdf). Accessed 18 Aug 2020, p. 21

121 ISTAT 2019, p. 22 (quote), 123-153. ISTAT refers to capabilities and functionings as in Sen, A. 1999. *Development as freedom*. New York: Knopf Press.

122 Genoa-based operator cited during interview with provider (Trento province), 17 Aug 2020.

123 Interview with regional and national expert and former provider Dario lanes (11 Aug 2020). An example is Provincial Law 35/1983 of the Province of Trento (*Legge provinciale 31 ottobre 1983 n. 35 - Disciplina degli interventi volti a prevenire e rimuovere gli stati di emarginazione* (B.U. 15 Nov 1983, n. 58), [consiglio.provincia.tn.it/leggi-e-archivi/codice-provinciale/Pages/legge.aspx?uid=1163](http://consiglio.provincia.tn.it/leggi-e-archivi/codice-provinciale/Pages/legge.aspx?uid=1163). Accessed 12 Aug 2020.

124 *Legge regionale 20 febbraio 1989, n. 6. Norme sull’eliminazione delle barriere architettoniche e prescrizioni tecniche di attuazione* (B.U. 22 Feb 1989, n. 8, 1 suppl. ord.), [www.gazzettaufficiale.it/eli/id/1989/12/23/089R0501/s3](http://www.gazzettaufficiale.it/eli/id/1989/12/23/089R0501/s3)

125 Interview with user and local policymaker (Brescia and Trento provinces) (15 Jul 2020). The user received funds for house renewal, and could thus adapt their home to the independent living needs of two older PWDS.

126 Local administrative units that unite mountain municipalities to tackle shared issues in a coordinated way.

127 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020.

## Figures and tables

FIGURE 1 | Overview of authorities' roles in social care for PWDs in Italy

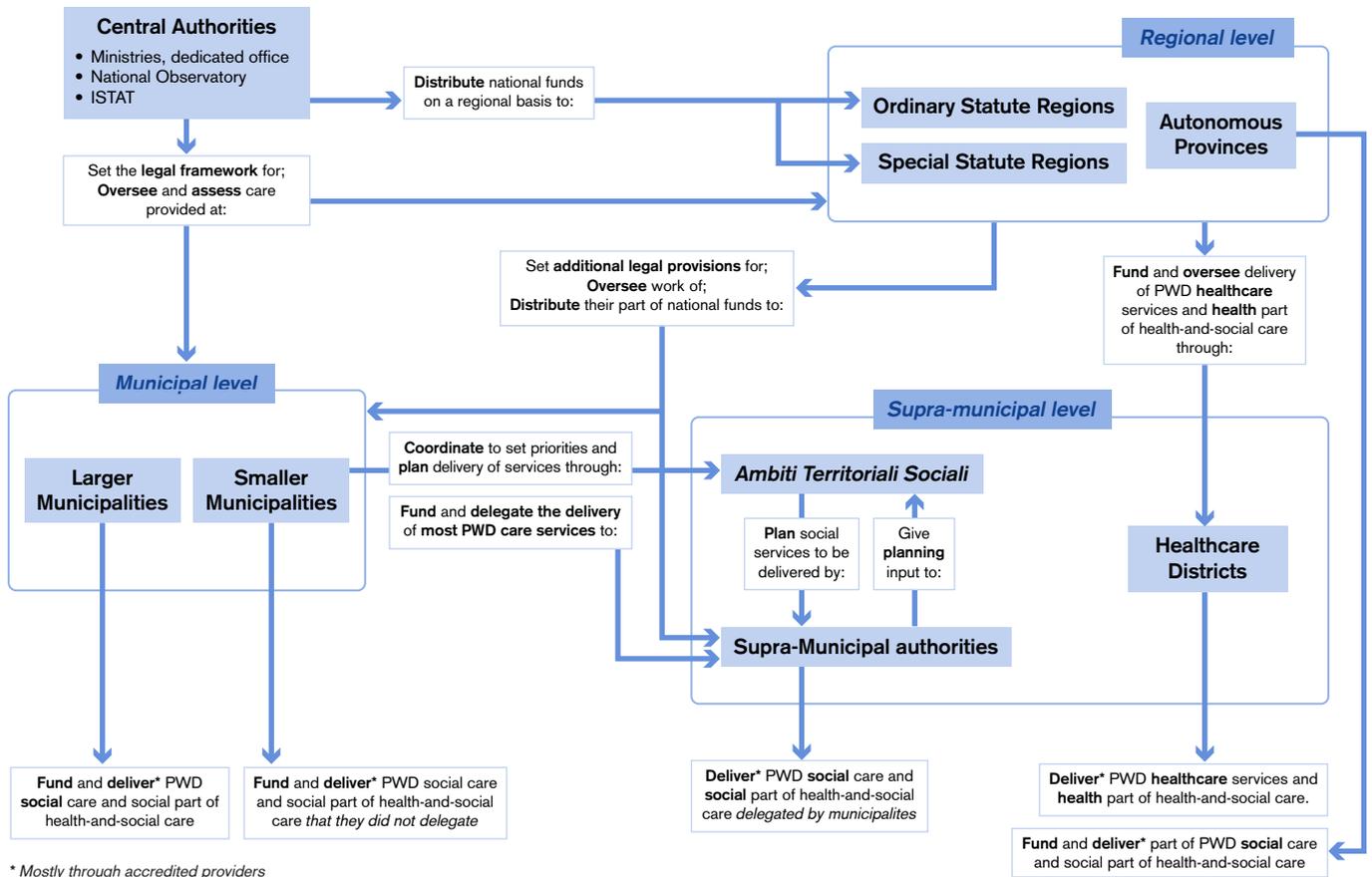


TABLE 1 | Distribution of structures delivering services for PWDs and their employees in Italy by macro-region and type of structure (2016 data).

Structures delivering services for PWDs	North-West	North-East	Centre	South	Islands	Total
<b>Public structures</b>						
N. of structures	1,623.00	1,587.00	1,073.00	428.00	434.00	<b>5,145.00</b>
%	8.3%	11.7%	7.6%	3.2%	4.6%	<b>7.4%</b>
Employees	23,150.00	36,236.00	11,472.00	4,759.00	5,845.00	<b>81,462.00</b>
%	9.7%	17.6%	8.2%	5.9%	9.0%	<b>11.2%</b>
<b>For-profit structures</b>						
N. of structures	5,532.00	3,511.00	3,860.00	4,078.00	3,054.00	<b>20,035.00</b>
%	28.4%	25.8%	27.4%	30.7%	32.3%	<b>28.7%</b>
Employees	95,763.00	72,886.00	57,773.00	34,794.00	28,020.00	<b>289,236.00</b>
%	40.2%	35.4%	41.3%	43.1%	43.1%	<b>39.6%</b>
<b>Non-profit structures</b>						
N. of structures	12,334.00	8,502.00	9,158.00	8,761.00	5,968.00	<b>44,723.00</b>
%	63.3%	62.5%	65.0%	66.0%	63.1%	<b>64.0%</b>
Employees	119,573.00	96,534.00	70,571.00	41,162.00	31,127.00	<b>358,967.00</b>
%	50.1%	46.9%	50.5%	51.0%	47.9%	<b>49.2%</b>
<b>Total</b>						
N. of structures	19,489.00	13,600.00	14,091.00	13,267.00	9,456.00	<b>69,903.00</b>
Employees	238,486.00	205,656.00	139,816.00	80,715.00	64,992.00	<b>729,665.00</b>

Data: ISTAT 2019, p. 142

TABLE 2 | Distribution of social expenditures of local authorities—Municipalities and Supra-Municipal Authorities—by type of authority and area of need (2016 data).

Type of authority	PWDS (€)	Older people (€)	PWDS (%)	Older people (%)
Municipalities	1,109,597,210.00	721,960,247.00	61.7	58.7
Districts/ <i>Ambiti</i> /Social areas	210,095,232.00	166,014,407.00	11.7	13.5
Mountain Communities	12,898,130.00	7,231,157.00	0.7	0.6
Consortia	141,768,627.00	104,869,975.00	7.9	8.5
Local healthcare authorities	169,992,620.00	38,687,296.00	9.5	3.1
Unions of Municipalities	44,437,219.00	44,627,283.00	2.5	3.6
Other supra-municipal auth.	108,195,080.00	147,894,036.00	6	12
<b>Total</b>	<b>1,796,984,118.00</b>	<b>1,231,284,401.00</b>	<b>100</b>	<b>100</b>

Data: ISTAT 2019, p. 142

**TABLE 3 | Distribution of local authorities' social expenditures (Municipalities and Supra-Municipal Authorities) by type of service for PWD and older people (2016-2017 data).**

Note: ISTAT separates services for PWDs from those for people over 65, but do not show how many of the latter are also PWDs. Moreover, ISTAT splits figures by type of service provided, but many of these (e.g., "social workers", "recreative activities", "transportation", "other") are not clearly assignable to one specific type of care; in some cases it is not possible to define whether a service contributes to "care" at all. Almost 10% of expenditures go into "other" categories or otherwise unspecified areas. No total number of users is indicated by groups of services because the same user may access multiple services.

Years/Services	
Group of services	Type of service
<b>Social work</b>	Social workers
	Service of integration within families
	Support with/allocation of housing
	Other
	<b>Total</b>
<b>Social integration</b>	Social integration for fragile people
	Recreational, social, cultural activities
	Other
	<b>Total</b>
<b>Assistance for PWD at home</b>	Home assistance (social care)
	Home assistance (health-and-social care)
	Proximity services
	Remote assistance
	Vouchers for home assistance
	Meals and laundry services
	Other
	<b>Total</b>
<b>Supporting services</b>	Canteens
	Social transportation services
	<b>Total</b>
<b>Vouchers and municipal contributions for the purchase of:</b>	Groceries or meals
	Services to the person (not specified)
	Healthcare contributions
	Users' fees for day care structures
	Users' fees of other semi-residential services
	Users fees for residential structures
	Transportation services
	Loans
	Contributes to housing expenditures
	Work integration
	Integration of family income
	Foster care and related services
	Unspecified funds for associations
	Other
	<b>Total</b>
<b>Day care and other semi-residential structures</b>	Day care centres
	Social aggregation centres
	Summer day care
	Workshops and playrooms
	Other
<b>Total</b>	
<b>Residential care</b>	Residential structures
	Summer or winter care structures
	Other
	<b>Total</b>
<b>Work/school integration</b>	<b>Total</b>
<b>Total of all services</b>	

128 ISTAT 2020. *La spesa dei comuni per i servizi sociali (Tavole spesa sociale dei comuni)*. <https://www.istat.it/it/files//2020/02/Tavole-Spesa-sociale-dei-comuni.xlsx>

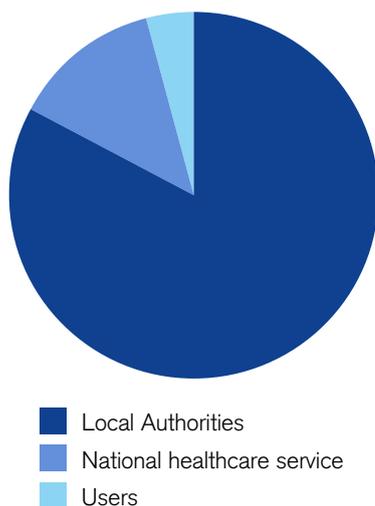
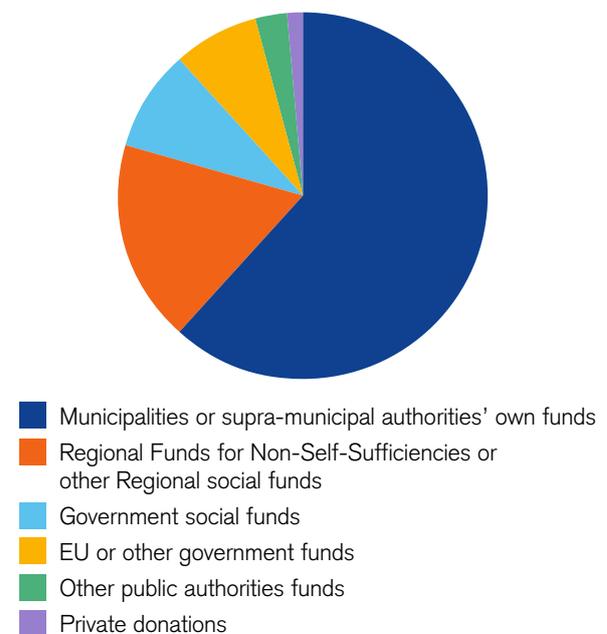
Data: ISTAT 2019 internal document on 2016 municipalities expenditures; ISTAT 2020

2016 split						2017 split					
PWD			Older people			PWD			Older people		
Expenditure (in €)	Number of users	Average per user	Expenditure (in €)	Number of users	Average per user	Expenditure (in €)	Number of users	Average per user	Expenditure (in €)	Number of users	Average per user
62,726,137	242,235	259	92,292,071	565,158	163	65,297,438	279,646	234	92,237,851	584,488	158
1,040,833	1,902	547	1,176,808	1,207	975	1,081,726	3,017	359	762,333	798	955
0	0	0	947,064	1,842	514	0	0	0	1,198,329	1,900	631
0	0	0	3,104,824	21,497	144	0	0	0	2,536,910	21,066	120
<b>63,766,970</b>			<b>97,520,767</b>			<b>66,379,164</b>			<b>96,735,423</b>		
21,276,212	14,541	1,463	6,256,240	11,863	527	25,399,413	16,084	1579	6,612,370	18,393	360
8,039,130	16,326	492	14,851,563	349,599	42	8,540,108	15,941	536	14,191,943	367,088	39
9,050,056	14,735	614	3,036,247	46,177	66	9,031,474	14,360	629	4,188,405	57,205	73
<b>38,365,398</b>			<b>24,144,050</b>			<b>42,970,995</b>			<b>24,992,718</b>		
153,831,887	43,133	3,566	269,054,835	131,876	2,040	159,736,885	43,848	3,643	279,565,169	134,750	2,075
24,789,986	10,587	2,342	73,076,038	75,983	962	26,681,020	12,352	2,160	65,359,745	72,549	901
180,265	1,090	165	6,523,757	10,747	607	220,194	226	974	7,030,043	11,000	639
514,142	9,358	55	4,692,713	40,012	117	289,368	8,784	33	3,500,577	40,014	87
63,927,020	31,693	2,017	65,924,850	49,969	1,319	64,310,662	24,465	2,629	71,877,388	51,401	1,398
1,561,484	1,622	963	24,787,974	37,266	665	1,679,958	1,658	1,013	23,535,827	38,072	618
27,523,881	8,301	3,316	13,192,535	35,356	373	25,754,297	10,169	2,533	10,924,228	38,199	286
<b>272,328,665</b>			<b>457,252,702</b>			<b>278,672,384</b>			<b>461,792,977</b>		
1,264,992	2,915	434	2,372,856	4,188	567	1,017,122	2,733	372	2,028,327	83,314	24
97,525,682	60,459	1,613	18,852,033	100,455	188	94,916,809	66,867	1,419	16,794,196	119,136	141
<b>98,790,674</b>			<b>21,224,889</b>			<b>95,933,931</b>			<b>18,822,523</b>		
504,349	1,540	327	848,330	2,561	331	536,166	3,021	177	649,211	2,628	247
66,215,003	17,839	3,712	40,000,672	16,659	2,401	70,626,598	18,817	3,753	41,265,350	17,415	2,370
20,991,708	9,684	2,168	5,285,427	8,734	605	27,782,899	14,310	1,942	5,805,543	8,356	695
100,698,328	17,134	5,877	7,943,274	5,301	1,498	100,680,965	16,831	5,982	7,920,087	5,105	1,551
19,641,297	4,303	4,565	1,997,992	560	3,568	17,639,274	4,379	4,028	1,722,792	459	3,753
167,446,581	17,137	9,771	213,451,110	59,767	3,571	166,937,440	18,118	9,214	210,623,152	132,721	1,587
12,192,238	12,336	988	1,412,946	13,655	103	11,553,408	11,450	1,009	1,196,143	12,639	95
30,478	53	575	34,366	40	859	18,842	27	698	45,503	28	1,625
3,058,936	2,082	1,469	8,953,351	10,783	830	3,265,495	2,541	1,285	8,588,282	12,766	673
16,130,669	10,619	1,519	0	0	0	15,180,409	9,777	1,553	0	0	0
18,057,555	12,206	1,479	24,731,373	23,014	1,075	19,323,976	11,876	1,627	23,983,212	38,291	626
13,971,550	3,978	3,512	3,189,833	1,353	2,358	17,077,344	4,013	4,256	3,625,833	1,497	2,422
12,250,530	N/A	N/A	14,607,205	N/A	N/A	12,783,872	N/A	N/A	15,316,407	0	0
23,462,026	9,902	2,369	5,125,797	18,052	284	25,888,006	129,130	200	5,258,882	29,943	176
<b>474,651,248</b>			<b>327,581,676</b>			<b>489,294,694</b>			<b>326,000,397</b>		
193,966,949	26,338	7,365	33,413,228	49,067	681	199,047,687	27,447	7,252	29,954,431	55,331	541
0	0	0	11,695,435	208,906	56	0	0	0	10,059,259	0	0
1,516,117	1,267	1,197	0	0	0	1,379,865	1,100	1,254	0	0	0
37,405,529	4,562	8,199	0	0	0	33,621,308	4,654	7,224	0	0	0
8,757,788	3,189	2,746	4,676,783	12,136	385	9,698,029	3,348	2,897	7,568,528	12,516	605
<b>241,646,383</b>			<b>49,785,446</b>			<b>243,746,889</b>			<b>47,582,218</b>		
161,808,769	11,064	14,625	248,536,704	41,620	5,972	172,737,829	11,624	14,860	312,341,307	53,139	5,878
3,187,379	4,057	786	1,052,677	6,708	157	3,038,163	4,097	742	910,808	5,646	161
8,181,774	1,111	7,364	4,185,490	3,566	1,174	9,773,747	1,133	8,626	7,871,845	3,916	2,010
<b>173,177,922</b>			<b>253,774,871</b>			<b>185,549,739</b>			<b>321,123,960</b>		
<b>434,256,858</b>			<b>0</b>			<b>467,966,393</b>			<b>0</b>		
<b>1,796,984,118</b>			<b>1,231,284,401</b>			<b>1,870,514,189</b>			<b>1,297,050,216</b>		

**TABLE 4 | Funding for the National Fund for non-self-sufficiency<sup>129</sup>**

Year	Amount
2007	€ 100,000,000
2008	€ 300,000,000
2009	€ 400,000,000
2010	€ 400,000,000
2011	€ 100,000,000
2012	€ 0
2013	€ 275,000,000
2014	€ 350,000,000
2015	€ 400,000,000
2016	€ 400,000,000
2017	€ 500,000,000
2018	€ 462,200,000
2019	€ 573,200,000
2020	€ 621,000,000

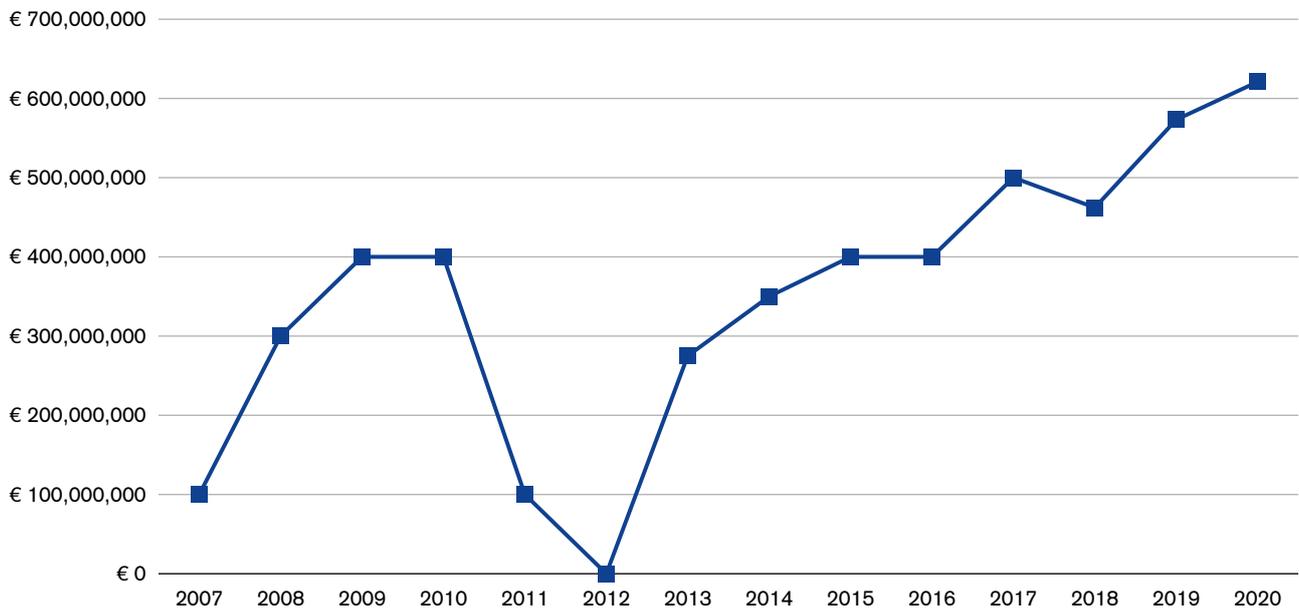
Data: see footnote

**FIGURES 2-3: Overview of sources of funding (local)**
**FIGURE 2 | Sources of funding for services directly provided to PWD by authorities**

**FIGURE 3 | Split of local authorities' share by source**


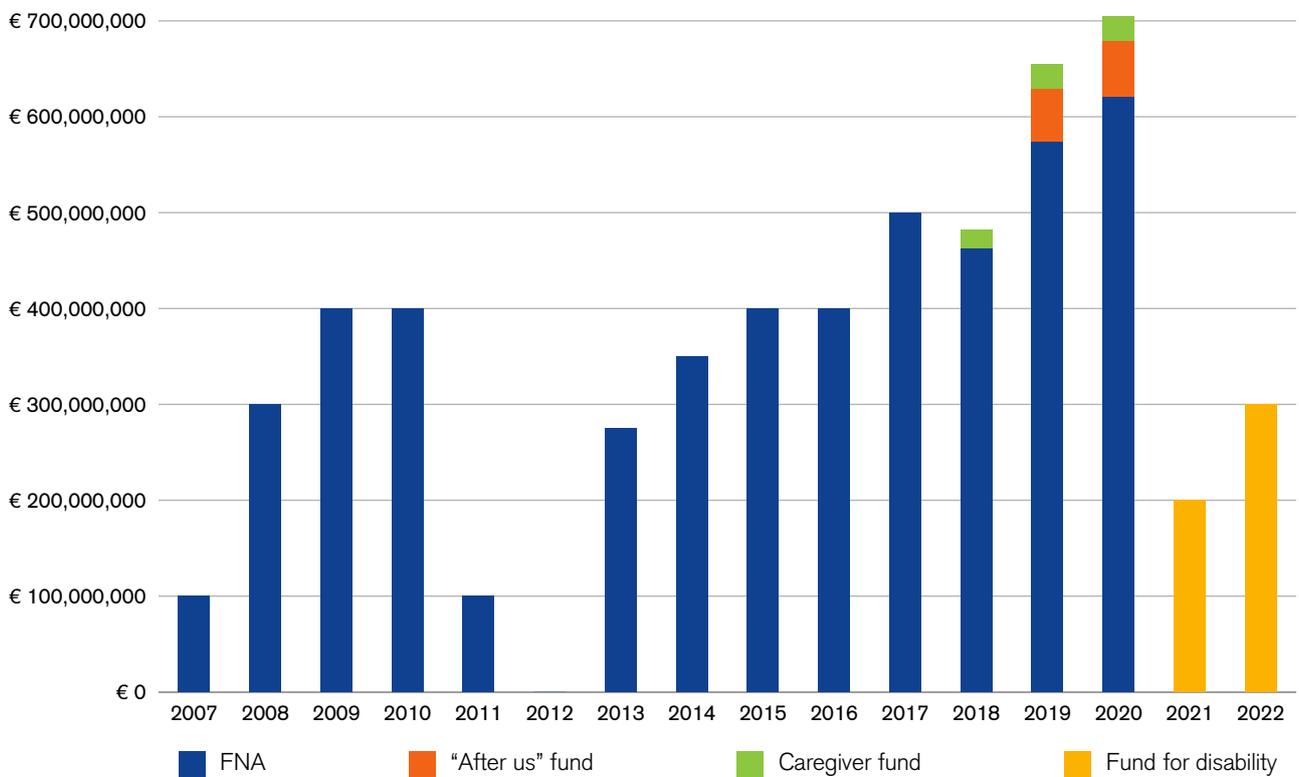
129 2007-2016 figures: Ministero del lavoro e delle politiche sociali 2020. *Fondo nazionale per la non autosufficienza*. [www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Fondo-per-non-autosufficienza/Pagine/default.aspx](http://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Fondo-per-non-autosufficienza/Pagine/default.aspx). Accessed 30 Jul 2020. 2017-2019 figures: ISTAT 2019, p. 185. 2020 figures: Camera dei deputati 2020. *Le misure a sostegno della famiglia e i fondi per le politiche Sociali*. Rome: Camera dei deputati, Servizio studi XVIII Legislatura. [temi.camera.it/leg18/temi/tl18\\_misure\\_sostegno\\_famiglia.html](http://temi.camera.it/leg18/temi/tl18_misure_sostegno_famiglia.html). Accessed 29 Jun 2020. p. 7

**FIGURES 4-5: Overview of sources of funding (national)**

**FIGURE 4 | Trends in funding for the National Fund for non-self-sufficiency**



**FIGURE 5 | Trends in national funds (cumulative)**



(\*) For 2021 and 2022, only the Fund for disability and non-self-sufficiency has already been allocated. The FNA (National Fund for Non-Self-Sufficiency) has, however, become a *structural* fund and is therefore likely to remain stable.

## Annex 2

### In-depth sheet 2: Assessment of quality and reach of care

#### General challenges in the measurement of coverage

Adequacy of financing of care is hard to gauge: there is a severe **under-monitoring and under-reporting** of care itself,<sup>130</sup> but also **lack of precise statistics on needs**: as one former local policymaker explains, services fail to meet most needs, to which families tend on their own in ways not covered in national statistics.<sup>131</sup> Crucially, there is no clear data on families' outlay for *private home carers for older PWD*, a cornerstone of care in Italy.<sup>132</sup> In fact, one regional expert laments that local authorities often ignore even the number of older PWD, as many live marginalized and alone,<sup>133</sup> as confirmed by the National Observatory of Health in Italian Regions.<sup>134</sup> Moreover, as one expert at ISTAT, the National Institute of Statistics, warned, **some costs can be double-counted due to overlap** and difficulty separating regions' accounting of healthcare and health parts of mixed services, and municipalities' accounting of social ones.<sup>135</sup> As most care services are defined as "*assistenza socio-sanitaria*" (health/social care), statistics often do not disaggregate between purely-healthcare services, purely social ones, and mixed ones.

Other issues come from the use of **obsolete categories in national statistics and planning**,<sup>136</sup> differences in how the 7.914 municipalities delegate social care to supra-municipal authorities, and fragmentation of healthcare data between Regions. Moreover, although ISTAT now follows the social criterion in defining PWD as "people with severe limitations in their everyday activities",<sup>137</sup> local authorities seem to assign such status inconsistently: as one user from Syracuse (Sicily) reports, despite her relative's complete non-self-sufficiency due to dementia, she is not recognized as PWD and is ineligible for support.<sup>138</sup>

#### Coverage shortcomings and accessibility issues

**Services paid by local authorities are vastly insufficient to meet needs**,<sup>139</sup> as little of Italy's social care expenditures goes in care for PWD.<sup>140</sup> Politicians keen on cutting costs see this area as low priority.<sup>141</sup> Municipal spending in services for *older* people is even more severely underfunded than that for PWD under 65y.o.,<sup>142</sup> with *disability-prevention* services being especially under-invested in.<sup>143</sup> In fact, "Municipal social service occupies a marginal position in care for [older] non-self-sufficient people, of which it can satisfy only

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130 Interview with national expert Alessandro Solipaca, 6 Aug 2020

131 Interview with user and local policymaker (Brescia and Trento provinces), 26 Aug 2020.

132 Interview with national expert Alessandro Solipaca, 6 Aug 2020.

133 Interview with provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020.

134 Osservatorio nazionale sulla salute nelle regioni italiane 2018. *Persone con Disabilità in Italia lasciate spesso sole, con scarsi aiuti e pochi servizi da un sistema di welfare che destina meno risorse in confronto ai Paesi guida nella UE.* <https://www.osservatoriosullasalute.it/wp-content/uploads/2018/11/3-dicembre-2018-Focus-Disabilit%C3%A0.pdf>. Accessed 2 Sept 2020

135 Interview with national expert Alessandro Solipaca, 6 Aug 2020.

136 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020.

137 ISTAT recognizes that this definition might fail to fully account for all forms of disability (ISTAT 2019, p. 10)

138 Telephone exchange with user (Syracuse province), 20 Aug 2020.

139 Interview with user and local policymaker (Brescia and Trento provinces), 26 Aug 2020.

140 ISTAT 2019, p. 124

141 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020.

142 ISTAT 2019, p. 132

143 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020

a small percentage of demand”.<sup>144</sup> **Bureaucracy also poses a major hurdle:** one user from the Ancona area remarks that the process to access more services or funds for PWD is so convoluted that they prefer to care for their adult relative with disability alone, at home.<sup>145</sup> Another interviewee seconds this, noting that funds or services for psychologically-impaired users sometimes fall victim of “Comma 22” paradoxes of Municipal bureaucracy, whereby the non-self-sufficient PWD is expected to apply for help themselves, despite not being able to do so.<sup>146</sup> One user with policymaking experience notes that even in high-income regions (Lombardy), ad-hoc funds for supported/independent living can take 5-6 years to arrive.<sup>147</sup>

**State contributions to personal budgets also show inefficiencies and severe gaps.** Families’ care costs can be deducted from taxes, thereby costing the state in missed tax revenues.<sup>148</sup> *Accompagnamento* goes partly wasted, as it is non-proportional and is paid also to high-income families that do not need it.<sup>149</sup> Some 52.6% of PWD only receive these funds and have an average gross income of €515/month: insufficient to survive without help but enough to reduce poverty risk rates from 34.4% (or 50% in the South) to 18.9%.<sup>150</sup> Some 47.4% of PWDs add retirement pensions or other social security, which triple their average income.<sup>151</sup> **State pensions are vastly insufficient especially for older**

**PWD:** at €1.200-1.500/month, places in *Residenze sanitarie assistenziali* or RSAs (Healthcare residencies) for long term care (LTC) cost more than what many older PWD receive, and families must fill the gap.<sup>152</sup> In large cities, where RSA places can cost twice as much, the situation is even worse.<sup>153</sup>

**Centralized funding is also insufficient to properly address PWD’s issues.** It also suffers from fragmentation into small funds,<sup>154</sup> which causes massive bureaucratic duplication for local authorities,<sup>155</sup> and from drastic fluctuations (as shown in **Figure 4** and **5**), which make **centrally-funded services unreliable.**<sup>156</sup> For perspective, the initial funding of the National Fund for Non-Self-Sufficiency (€100mln in 2007) accounted to less than 1/3 of the corresponding Regional Fund of one medium-sized region.<sup>157</sup> The budget of one northern Territorial Authority for the Delivery of Services to the Person serving around 100.000 inhabitants is over €7mln,<sup>158</sup> equal to 1/3 of the whole national Caregivers’ Fund. Given their small size, centralized funds’ main virtue is forcing local authorities to follow national standards of care to access them, partially offsetting the institutional fragmentation.<sup>159</sup>

Insufficient pensions, services provision shortcomings and unreliable central funding **put families’ ability to care at constant risk.** A typical case was described by

144 Gori, C. 2017. “Introduzione. L’età dell’incertezza”. In *Network Non Autosufficienza (2017). L’assistenza agli anziani non autosufficienti in Italia. 6° rapporto 2017/2018. Il tempo delle risposte*. Santarcangelo di Romagna: Maggioli Editore, p. 14

145 Interview with user caring for a mentally disabled relative (Ancona province), 24 Aug 2020.

146 Interview with relative of people with severe cognitive deterioration (Vicenza Province), 4 Sept 2020.

147 Interview with user and local policymaker (Brescia and Trento provinces) 16 Aug 2020.

148 Interview with national expert Alessandro Solipaca, 6 Aug 2020.

149 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020.

150 ISTAT 2019, p. 18-19 and 129

151 ISTAT 2019, p. 129-130

152 Pesaresi, F., cited in Galeazzi, G. 2020. “L’Italia senza badanti”. In *Terris*, 10 Jan 2020. Available from: [www.interris.it/la-voce-degli-ultimi/sociale/litalia-senza-badanti/](http://www.interris.it/la-voce-degli-ultimi/sociale/litalia-senza-badanti/)

153 Interview with provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020.

154 Lombardy alone has more funding than the entire FNA; interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020.

155 Interview with provider, local policymaker Mattia Signorelli (Bergamo and Brescia provinces), 3 Aug 2020.

156 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020

157 Regione Emilia-Romagna 2007. *Il Fondo regionale per la non autosufficienza. salute.regione.emilia-romagna.it/normativa-e-documentazione/convegni-e-seminari/conferenza-nazionale-cure-primarie/il-fondo-per-la-non-autosufficienza-scheda-di-sintesi*. Accessed 27 Aug 2020.

158 ATSP Valle Camonica 2017. *ATSP, il modello di gestione associata dei servizi sociali in Val Camonica* (Internal document provided during the interview stage).

159 Interview with national and European expert and national policymaker Alfredo Ferrante, 6 Aug 2020

one user from the Ancona province: until 2015, the family could afford professional domestic care, only partially thanks to payments from the state; after one parent lost their job and savings, however, the family could not afford any home care and now has to rely on help from relatives.<sup>160</sup> The reliance on users' contributions to pay for services creates **risks for low-income groups**: One

provider notes that some poorer families caring for PWD with learning disabilities or autism keep them at home to save the full state pension, rather than sending them to day care or LTC, depriving PWD of the professional care they need and exposing them to major psychological stress from the emotional instability common in struggling households.<sup>161</sup>

## In-depth sheet 3: The conundrum of regional inequalities

### Coverage inequalities: North-South divides and regional differences

All experts interviewed report deep gaps between North/Central regions, and South/Island ones: the former (especially in the North-East) show vaster and better coverage, the latter lack social care funding.<sup>162</sup> This is because **municipalities fund social care with local taxation**, which inevitably puts the lower-income South to the disadvantage.<sup>163</sup> As of the latest data available, North-Eastern Municipalities spend €5.080/year per PWD in social services, against €870 in the South.<sup>164</sup> The leading region, Trentino-South Tyrol, spends €12.512/year per PWD; Calabria, €374;<sup>165</sup> within them, Bolzano/Bozen spends €15.000/year per PWD, Vibo Valentia €77.<sup>166</sup> 50% of disability-oriented non-profit organizations are in Lombardy (18%), Lazio (10.8%), Tuscany (10.8%), Piedmont (8.5%) and Emilia-Romagna (8.1%); Sicily and Puglia, the best-served Southern regions, have only 5% each.<sup>167</sup> Some 2/3 of Northern families can afford to buy services; less than half of Southern ones can.<sup>168</sup>

**Inequalities due to uneven municipal tax revenues**

**affect low-income areas all over Italy.** One user from one such areas near the central city of Ancona notes that while regionally-funded healthcare coverage is good, the local supra-municipal authority can only offer 3 hours/week in home care to their disabled son, who needs 24/7 care: while excellent in quality, they judge this service as “absolutely nothing”.<sup>169</sup> By contrast, a high-income district in Emilia-Romagna ensures, at least for older PWD, up to 12 hours/week in home assistance.<sup>170</sup>

**The North-South gap is vast in human resources, too:** The best-staffed Southern region only has 65% of non-profit organizations employees per 10.000 inhabitants than the *worst*-staffed Northern one; the leading Trento Province has 5.5 times more than the least-covered Southern one.<sup>171</sup> Central regions and Northern Autonomous Provinces/Special Statute regions also have 1.067-3.012 *non-profit organization volunteers* every 10.000 inhabitants, against 290-781 in most Southern regions.<sup>172</sup> As to *private employees in PWD care*, leading provinces of Biella and Trento boast a coverage of 31.7

160 Interview with user caring for a mentally and physically disabled relative (Ancona province), 21 Aug 2020

161 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

162 ISTAT 2020b. *La spesa dei comuni per i servizi sociali*. [www.istat.it/it/files//2020/02/Report-Spesa-sociale-dei-comuni.pdf](http://www.istat.it/it/files//2020/02/Report-Spesa-sociale-dei-comuni.pdf). Accessed 6 Aug 2020.

163 Interview with national expert Alessandro Solipaca, 6 Aug 2020.

164 ISTAT 2019, p. 19

165 2016 data from ISTAT data provided during interviews. Aosta Valley spends even less than Calabria but this is a statistical variation due to the minuscule population of the region. Trento, within Trentino-South Tyrol, also leads by structures delivering services to PWD per 10.000 inhabitants: 11.4 against a national average of 6.2.

166 ISTAT 2019, p. 151

167 ISTAT 2019, p. 148

168 ISTAT 2019, p. 21

169 Interview with user caring for a mentally and physically disabled relative (Ancona province), 21 Aug 2020.

170 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

171 Barbetta, G. P., Canino, P., Cima, S., Verrecchia, F. 2018, p. 3-4

172 Barbetta, G. P., Canino, P., Cima, S., Verrecchia, F. 2018, p. 3-4

and 20.6/100 PWD, against 1.3 and 0.6 in Reggio Calabria and Vibo Valentia.<sup>173</sup> *Public employment* also sees the South at a disadvantage: the Provinces of Vibo Valentia, Reggio Calabria and Matera as of 2016 did not have a single public employee in services for PWD.<sup>174</sup> As to *all social services employees* per 100 PWD, the North has 4-5 times the South's coverage rate (see **Table 5** and **6**).<sup>175</sup>

During interviews, while Northern stakeholders noted difficulties ensuring widespread coverage, Southern ones reported a *complete lack* of care. One user from a

low-income rural area in the Southern Pescara Province notes that other than sporadic civil society initiatives and some help for school-age PWD from authorities, there are no care services at all, nor any transportation services to reach towns where they might exist – though the whole province, not just smaller towns, faces major shortages.<sup>176</sup> In the absence of services, care is done at home, with no support for independent living, either.<sup>177</sup> One regional expert reports of an “Italy divided in half”, with a “Wild West” in care for older PWD in Southern regions, with no controls and low quality standards in facilities that profit off people's vulnerabilities.<sup>178</sup>

## Figures and tables

TABLE 5 | Territorial care index (n. of employees in care for PWD per 100 PWD) by sector.

Macro-region of Italy	Public employees	For-profit employees	Non-profit employees	All
North-West	2.6	10.9	13.6	<b>27.1</b>
North-East	5.4	10.9	14.4	<b>30.7</b>
Centre	1.2	6.3	7.7	<b>15.2</b>
South	0.4	2.7	3.2	<b>6.3</b>
Islands	1.0	4.6	5.1	<b>10.7</b>
<b>Total</b>	<b>1.9</b>	<b>6.6</b>	<b>8.2</b>	<b>16.7</b>

Data: ISTAT 2019, p. 143

TABLE 6 | Table 6. Count of employees in PWD care by macro-region and area of care (2015 data)

Split of employees	Employees in residential care			Employees in other areas of care		
	Public authorities	For-profit organizations	Non-profit organizations (*)	Public authorities	For-profit organizations	Non-profit organizations (*)
North-West	9,841	53,553	68,883	13,309	42,210	50,690
North-East	26,479	35,114	47,433	9,757	37,772	49,101
Centre	3,515	26,864	28,758	7,957	30,909	41,813
South	1,684	16,030	15,507	3,075	18,764	25,655
Islands	1,974	13,961	14,286	3,871	14,059	16,841
<b>Total</b>	<b>43,493</b>	<b>145,522</b>	<b>174,867</b>	<b>37,969</b>	<b>143,714</b>	<b>184,100</b>

Data: ISTAT 2019, p. 142. (\*) Data for non-profit organizations is for 2016

173 ISTAT 2019, p. 151

174 ISTAT 2019, p. 150

175 ISTAT 2019, p. 143

176 Interview with user caring for a mentally and physically disabled relative (Pescara province), 20 Aug 2020.

177 Interview with user caring for a mentally and physically disabled relative (Pescara province), 20 Aug 2020.

178 Interview with provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020.

## Annex 3

### In-depth sheet 4: Impact of funding models

#### Working conditions

All private employees' conditions are set by contracts negotiated nationally by Trade Unions. Employees interviewed note that **working conditions tend not to vary by type of care** and depend on Unions' negotiating power rather than on funding models. They report very low salaries across the sector, with one expert noting only a 6% raise in recent years, insufficient to cover inflation.<sup>179</sup> Public employees report better treatment: one public provider in Piedmont comments that "we have so many rights [we] don't even know we have them".<sup>180</sup> However, they also note that non-profit organizations can be much more flexible with the tasks of their staffers, which helps in high-stress sectors of care (such as for PWDs with behavioural issues): employees can be given less stressful tasks to recover energies.<sup>181</sup> Low salaries and job insecurity made non-profit organizations a convenient choice for Italian welfare in recent decades.<sup>182</sup> Even though salaries are low, one national expert comments that the taxation burden remains so high that services are still too expensive.<sup>183</sup>

In the private non-profit sector, **Cooperatives' staffers are usually *soci-lavoratori*** (members-employees) who

partake in the non-profit organization's performance; even those in leadership roles receive similar salaries.<sup>184</sup> One cooperative's manager reports average monthly net salaries of €1.200-1.300 in all sectors of care, minimal seniority benefits, and difficulties getting performance bonuses due to cash shortages; night shift operators may get a bonus of €18/night.<sup>185</sup> This rarely applies to day care operators but is more frequent for independent/supported living or institutional long-term care services.

#### Cost efficiency, ability to address needs: the issue of monitoring

Even though accreditation guarantees sufficient local *quality checks*, gauging services' *cost efficiency* and *ability to tackle needs* in light of funding models or their changes is arduous, due to **lack of aggregated reporting and spending accountability**.<sup>186</sup> A leading fundraising expert notes that Italy's system is "fragmented into an endless number of rivulets of funding",<sup>187</sup> making it impossible to ascribe the impact of services to one funding source or model.<sup>188</sup> In their words, "nobody measures, nobody checks, nobody cares, nobody knows".<sup>189</sup> evaluation and reporting are only starting to be expanded, and mostly only when private donors are

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179 The similar picture across types of care and regions was confirmed by all interviewees. The views about the negotiation of the new contract are from an interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

180 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020.

181 Interview with high-ranking staffer of a public provider (Cuneo province), 3 Aug 2020.

182 Even very high-income regions such as Trentino-South Tyrol increasingly see the involvement of private entities as a way to cut costs (Interview provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020).

183 Interview with national expert Alessandro Solipaca, 6 Aug 2020

184 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

185 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

186 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

187 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

188 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

189 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

involved.<sup>190</sup> The growth of fundraising and private grants will improve monitoring, but negatively affect providers' long-term operational sustainability.<sup>191</sup>

One regional and national expert notes that **the impact of privatization via accreditation differs based on**

**political motives**, and in most regions it is merely a cost-saving process; in regions like Tuscany, Emilia-Romagna and Campania, it has been slowed down by resistance from the public sector; Trentino-South Tyrol stands out, as it still uses the model to foster the birth of innovative, self-organized services from civil society (for now).<sup>192</sup>

## In-depth sheet 5: The system in the face of future challenges

### Innovation needs and challenges for care

A key issue raised during interviews is **innovation**, needed to tackle the challenges of “new disabilities” and the growing needs of an ageing population.<sup>193</sup> A fundraising expert notes that **the accreditation model stifles innovation**, having turned civil society-based cooperatives into providers that can rely on relatively regular funding, or even underperform, as next year's funds will cover budget gaps.<sup>194</sup> As a result, providers who seek to innovate must rely on families' fees, private grants, or investments, often to create new services that they hope the public sector will, later, include as accredited ones.<sup>195</sup> Consortia, Territorial Authorities for the Delivery of Services to the Person and Social Authorities act less stiffly than the old Public Institutes of Care and Charity, and expanded the range of services, but the appointment of their management remains political (even in Lombardy, the country's spearhead of privatization), resulting in changes at the helm with every election.<sup>196</sup>

Only providers from Trentino decisively point at public authorities as promoters of cooperative's proactivity: this is due to specific local planning and funding models that involve non-profit organizations in *defining needs* and *experimenting new services*, in a region that can afford it thanks to a very high-income, a unique local culture of mass volunteering,<sup>197</sup> and the country's highest quality of governance.<sup>198</sup> Unfortunately, neither is easily exportable, if at all. Elsewhere, **innovation may depend on operators' personal initiative**: one day care staffer in the Ascoli Piceno Province notes that lack of innovation depends on lack of exposure to new care methods, which are more often experimented with and more swiftly adopted in Northern regions.<sup>199</sup>

### An ageing population and a system on the edge of crisis

Many interviewed stakeholders agree that the fast growth in the number of *older* PWD (caused by the high

190 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

191 Interview with provider Enza Picca (Turin province), 4 Aug 2020; interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.; interview with provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020.

192 Interview with regional and national expert and former provider Dario lanes (11 Aug 2020).

193 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020; Gori, C. 2017, p. 24-25; interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

194 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

195 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

196 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

197 Interview with provider and policy advocate (Trento province), 17 Aug 2020, and with provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020. Trento and Bolzano/Bozen's indeed dominate in regional comparisons about numbers of volunteers (Barbetta, G. P., Canino, P., Cima, S., Verrecchia, F. 2018, “Entry and Exit of Nonprofit Organizations. National, Sectorial, and Geographic Trends with Italian Census Data”. *Nonprofit Policy Forum*, Aug 2018, p. 3-4; Terzo Settore Banca Popolare 2015. *I profili del volontariato italiano*. [www.volontariatotrentino.it/sites/default/files/download/Volontariato%20italiano.%20studio.pdf](http://www.volontariatotrentino.it/sites/default/files/download/Volontariato%20italiano.%20studio.pdf). Accessed 21 Aug 2020).

198 QOG 2018, *EQI data* (2010, 2013, 2017). [qog01-p.gu.gu.se/shiny/users/xalvna/qog/eqi\\_map/](http://qog01-p.gu.gu.se/shiny/users/xalvna/qog/eqi_map/).

199 Interview with day care centre operator (Ascoli Piceno province), 19 Aug 2020.

life expectancy, even accounting for the drop caused by COVID-19,<sup>200</sup> and the ageing of the “baby boomers”), is **throwing the Italy care system in a catastrophic crisis**,<sup>201</sup> with no viable solution in sight,<sup>202</sup> despite growth in municipalities’ spending for services for PWD.<sup>203</sup> As one expert put it, “the Italian welfare system is literally falling apart”.<sup>204</sup> Some 63% of PWD are now over 65y.o., and 47% are over 75y.o, in a staggering ageing trend:<sup>205</sup> non-self-sufficient older people are projected to skyrocket to 6.3mIn by 2028.<sup>206</sup> The impending retirement of much of an already “old” medical population,<sup>207</sup> will worsen the crisis for a care system that requires more and more *health-care* for older PWD.

The COVID-19 pandemic adds a further challenge because of comorbidities-induced disabilities among survivors, but also due to the **effect of lockdown measures in accelerating the decline in cognitive faculties** and worsening the psychological health of fragile people over 65. A relative of two such people from a heavily-urbanized area in the Vicenza Province reports that after months of confinement in a small flat, their parents’ psychological health has collapsed, and one has suddenly started showing signs of rapidly-progressing Alzheimer’s disease; despite being still in their 60s, both are now likely to become non-self-sufficient and require care in the near future.<sup>208</sup>

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200 Il Sole 24 Ore 2020. “L’impatto del Covid-19 sulla speranza di vita. La popolazione italiana si ridurrà di tre milioni entro 2035”. *Il Sole 24 Ore*, 20 Jun 2020. [www.infodata.ilsole24ore.com/2020/06/20/limpatto-del-covid-19-sulla-speranza-vita-la-popolazione-italiana-si-ridurra-tre-milioni-entro-2035/](http://www.infodata.ilsole24ore.com/2020/06/20/limpatto-del-covid-19-sulla-speranza-vita-la-popolazione-italiana-si-ridurra-tre-milioni-entro-2035/). Accessed 13 Aug 2020.

201 Interview with provider and regional expert Enzo Raco (Brescia province), 3 Jul 2020; interview with national expert Alessandro Solipaca, 6 Aug 2020; interviews with provider Maria Rosa Dossi (Trento province), 9, 10 and 15 Jul 2020.

202 Interview with national expert Alessandro Solipaca, 6 Aug 2020.

203 ISTAT 2020b. *La spesa dei comuni per i servizi sociali*. [www.istat.it/it/files//2020/02/Report-Spesa-sociale-dei-comuni.pdf](http://www.istat.it/it/files//2020/02/Report-Spesa-sociale-dei-comuni.pdf). Accessed 6 Aug 2020, p. 1-2.

204 Interview with national fundraising expert and consultant for non-profit organizations, 21 Aug 2020.

205 ISTAT 2019, p. 10; Paolini, M. C., Colombo, F. 2020. “I numeri della disabilità in Italia”. *Lenius*, 27 Mar 2020. [www.lenius.it/disabilita-in-italia/](http://www.lenius.it/disabilita-in-italia/). Accessed 12 Aug 2020; ISTAT 2020a. *Disabilità in cifre*. [dati.disabilitaincifre.it/dawinciMD.jsp](http://dati.disabilitaincifre.it/dawinciMD.jsp). Accessed 3 Aug 2020.

206 Galeazzi, G. 2020.

207 Eurostat in *Quotidiano Sanità* 2019. “In Europa esercitano 1,8 milioni di medici. Italia al secondo posto in valori assoluti con 240mila medici ma abbiamo il record per anzianità: il 54% ha più di 55 anni”. *Quotidiano Sanità*, 14 Jan 2019. [www.quotidianosanita.it/lavoro-e-professioni/articolo.php?articolo\\_id=69866](http://www.quotidianosanita.it/lavoro-e-professioni/articolo.php?articolo_id=69866). Accessed 12 Aug 2020.

208 Interview with relative of people with severe cognitive deterioration (Vicenza Province), 4 Sept 2020.

## Annex 4

### In-depth sheet 6: observations about specific areas of care

#### Day Care

Even though datasets for day care often show contradictions and unclear overlap, the **figures they show for PWD using day care are consistently minuscule**, especially for older PWD. The 2017 data for *healthcare-focused or health-and-social day care* count 11.496 mentally disabled people, 25.184 older people,<sup>209</sup> and 13.875 physically disabled people in day care centres, against 11.494, 16.018 and 15.315 places,<sup>210</sup> respectively.<sup>211</sup> Ministry of Health figures *on day care provided by regions* per 1.000 people with severe disabilities range from 1/1.000 (Molise and Calabria) to 16/1.000 (Veneto), with most regions falling in the 2-7/1.000 range.<sup>212</sup> The 2016 data from ISTAT's 2019 report show 43.500 PWD (6.9% of PWD under 65) and 52.000 older people (0.4%) in *Municipal day care*, which should be social-care oriented or mixed.<sup>213</sup> Of the PWD under 65 receiving day care, 59.8% attend Municipal day care, 40.2% enjoys Municipal contributions for accredited ones.<sup>214</sup>

#### Working conditions of staff of providers of day care services

Working conditions follow the dynamics described previously. As to safety, one provider from Piedmont reports of PWDs with behavioural issues attacking day care centres operators.<sup>215</sup> One such operator from Ascoli Piceno seconds this, adding of difficulty in communication between operators and mentally disabled users that can lead to PWDs' families interpreting physical activities or containment measures as aggressions or sexual abuses against their children.<sup>216</sup> In such cases, employees' safety depends on providers' ability to clearly explain to families the nature of the activities conducted.<sup>217</sup>

#### Impact of COVID-19 Pandemic for day care services

**COVID-19 forces a radical review of day care funding:** day care (especially for younger PWD) relies heavily on the use of shared transportation and spaces for socialization, but social distancing now forces centres to halve the number of users, while costs of venues and transport remain identical.<sup>218</sup> The manager of a non-profit organization that provides day care to PWD

209 It is not entirely clear if and how many of these would fall in the category of PWD.

210 Author's elaboration of data provided by expert from *Osservatorio Disabilità*.

211 The presence of more users than places indicates rotation within facilities, also due to death of users, but probably also indicates insufficient supply that creates waiting lists, although existing statistics do not allow to shed light on this (Email communication with Alessandro Solipaca, 14 Aug 2020).

212 Figures in "equivalent places", counted weighing the number of places against the number of days in care per year. ISTAT 2019, p. 140.

213 ISTAT 2019, p. 136; the figures do not fully match with the split provided other ISTAT documents (reflected in Table 3 under day care and vouchers for day care fees), but are a sufficiently precise approximation.

214 ISTAT 2019, p. 133

215 Interview with high-ranking staffer of a public provider (Cuneo Province), 3 Aug 2020

216 Interview with day care centre operator (Ascoli Piceno province), 19 Aug 2020.

217 Interview with day care centre operator (Ascoli Piceno province), 19 Aug 2020.

218 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020, and interview with provider and regional expert Enzo Raco (Brescia province)

under 65y.o. notes that authorities will keep paying for full services (despite the reduced number of users) only until September, after which the outlook is bleak: the risk of their services becoming unsustainable is very high.<sup>219</sup> COVID-19 safety measures also place a heavy bureaucratic burden: to reopen its day care service, the same cooperative had to hire an external consultants to produce the 150 pages of safety protocols required.<sup>220</sup>

### Changes in funding models

As for all types of care, the **key change was the shift to the accreditation model**. One expert and provider from Lombardy adds that even in their high-income and innovation-savvy Region, the funding system is failing to adapt to the new personalized psychological care needed, in particular, for autism, which cannot rely on day care practices based on group work or socialization.<sup>221</sup>

### Independent/Supported Living

#### Amount of state funding – specific to supported/independent living services

Funding for independent/supported living is insufficient, and **even high-income regions struggle**: for example, Piedmont authorities fail to meet demand due to cost cuts;<sup>222</sup> Lombardy focuses on severe disabilities leaving medium severity ones unaddressed,<sup>223</sup> and sometimes underfunds supported living services with health components, forcing providers to cover the gap.<sup>224</sup> Home

assistance for *older* PWDS “faces difficulties defining its role in a context of high severity of older people health conditions and the wide presence of home carers [*badanti*]”.<sup>225</sup>

### Long-Term Institutional Care

#### Working conditions of staff of providers of long-term institutional care

Working conditions for employees in long-term care facilities are **regulated in the same way as other types of care**; there are however more opportunities for bonus payment for night shifts.<sup>226</sup> Perceptions differ widely: staffers in a large supra-municipal authority feel that workers of cooperatives they outsource to enjoy sufficient guarantees, for all types of care.<sup>227</sup> Non-profit organizations’ employees, the bulk of the sector’s workforce, lament lack of career opportunities, massive stress, low salaries, and major gaps with *public sector colleagues*, who earn around 30% more.<sup>228</sup>

Providers’ ability to secure continuity of employment for their staff in the context of the COVID-19 crisis has been put in jeopardy not only in the most severely hit provinces, as described in the main section. Provinces hit less hard (30% death rate) also struggle to recover: COVID-19 safety measures now require perspective users to isolate for 14 days before being admitted, which forces their facility to keep as much as 10% of available rooms empty for perspective users.<sup>229</sup>

219 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020.

220 Interview with provider and local expert - also involved in local decision making (Brescia and Bergamo provinces), 4 Aug 2020; on safety measures: Camera dei deputati 2020a, *Politiche sociali per fronteggiare l'emergenza coronavirus*. Rome: Camera dei deputati, Servizio studi XVIII Legislatura. [www.camera.it/temiap/documentazione/temi/pdf/1215181.pdf?\\_1593502011792](http://www.camera.it/temiap/documentazione/temi/pdf/1215181.pdf?_1593502011792), p. 6-7

221 Interview with provider, local regulator, umbrella organization leader and expert (Brescia and Bergamo provinces), 23 Jul 2020 and 5 Aug 2020.

222 Interview with provider Enza Picca (Turin province), 4 Aug 2020.

223 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020.

224 Interview with provider Devis Ghirardelli (Brescia province), 29 Jul 2020.

225 Gori, C. 2017, p. 15.

226 As confirmed during interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

227 Interview with staff of ATSP Valle Camonica (Brescia province), 15 Jul 2020

228 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

229 Interview with provider from an RSA facility and user (Rimini province), 23 Aug 2020.

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