

**ANED 2018-19**

**Task 1.2**

**Living independently and being included in the community**

Country: Italy

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## Contents

|     |  |    |
|-----|--|----|
| 1   | Current situation and direction of travel.....   | 2  |
| 1.1 | Numbers and proportions of disabled children and adults residing in institutional care or community-based settings .....   | 2  |
| 1.2 | Overall spending on institutional care versus support services for living independently and being included in the community, including information about proportion/amount of funding provided from EU funds ..... | 5  |
| 2   | Government commitments on living independently and being included in the community, including the transition from institutional care to community-based living.....  | 9  |
| 2.1 | In which document(s) are Government commitments and plans concerning support for independent living in the community set out? .....  | 9  |
| 2.2 | What are the aims and objectives of the relevant strategies, including the relevant targets and milestones? Are they linked to European Structural and Investment Funds (ESIF)? .....                              | 9  |
| 2.3 | Please summarise the planned approach and the actions to be taken in relevant strategies .....   | 10 |
| 2.4 | What budgetary commitments are made to support these strategies, for both domestic and EU funds?.....  | 11 |
| 2.5 | What is the (official) involvement of persons with disabilities and/or their representative organisations in the development of the strategies and plans? .....  | 11 |
| 3   | Implementation and monitoring .....  | 11 |
| 3.1 | Summary of relevant calls for proposals.....   | 11 |
| 3.2 | Summary of relevant projects funded .....  | 13 |
| 3.3 | Overview of other relevant measures since 2013.....  | 13 |
| 3.4 | Monitoring mechanisms and approaches .....   | 13 |
| 4   | Impact and outcomes .....  | 13 |
| 4.1 | Progress against explicit targets and milestones .....   | 13 |
| 4.2 | What is replacing institutional care? .....  | 14 |
| 4.3 | Satisfaction levels among persons with disabilities.....   | 14 |
|     | PART B – Critique and evaluation .....   | 15 |
| 5   | Observations and recommendations of official bodies .....  | 15 |
| 5.1 | Observations by the UN Committee on the Rights of Persons with Disabilities on Article 19.....   | 15 |
| 5.2 | Recent observations by other official European and international bodies.....   | 15 |
| 5.3 | Observations and recommendations by national human rights bodies.....  | 16 |
| 5.4 | Observations and recommendations by national or regional/devolved Parliaments and assemblies.....  | 17 |
| 6   | Views and perspectives of civil society including DPOs.....  | 17 |
| 6.1 | UNCRPD civil society shadow and alternative reports .....  | 17 |
| 6.2 | ‘Grey literature’ at the national level.....   | 19 |
| 6.3 | Pan-European and international civil society organisations.....  | 20 |
| 7   | Academic research .....  | 20 |
|     | PART C – Key points.....   | 22 |
| 8   | Positive developments, including promising practice examples .....   | 22 |
| 9   | Negative developments including examples of poor practice.....   | 24 |
| 10  | Recommendations .....  | 24 |

## PART A – Factual information and statistical data

### 1 Current situation and direction of travel

#### 1.1 Numbers and proportions of disabled children and adults residing in institutional care or community-based settings

##### 1.1.1 Current figures

##### Overall state of affairs

In 2015, there were 270 505 residents with disabilities or who were categorised as 'non-self-sufficient' (*non-auto-sufficienti*)<sup>1</sup> in residential care facilities providing both social and health care services.<sup>2</sup>

Of those, 262 691 (97.11 %) were in institutional care, while 7 479 (2.76 %) were in community-based facilities.<sup>3</sup>

##### Distribution by age and type

- Among the residents, 2 839 were children,<sup>4</sup> 1 818 were males (64.04 %), and 1 021 were females (35.96 %); 2 162 were in institutional care (76.15 %), with 669 in community-based facilities (23.56 %); 49 046 were adults between 18 and 64<sup>5</sup> with disabilities or psychiatric conditions; 29 214 were males (59.56 %), and 19 832 were females (40.44 %); 45 791 were in institutional care (93.36 %), and 3 207 were in community-based facilities (6.54 %).
- A total of 218 620 residents were adults aged 65 and over;<sup>6</sup> 214 738 were in institutional care (98.22 %), with 3 603 in community-based facilities (1.65 %).

In the residential care facilities providing both social and health care services, there were 69 065 elderly non-self-sufficient residents out of a total of 287 685 residents; there were 74 444 males (25.8 %) and 213 241 females (74.12 %). No differentiation is made between older people with age-acquired or pre-existing disabilities.

##### 1.1.2 Trend since 2013

<sup>1</sup> 'Non-self-sufficient' is a classification of beneficiaries that, in Italy, is considered as a specific target. The target is a person who needs intensive support because she/he has a high level of assistance dependency. This term is a legislative category and it is used by the national and regional legislation and by the resulting regulation. Only people who fall within this category can obtain specific funds for deinstitutionalisation, as we have analysed below.

<sup>2</sup> ISTAT (the Istituto Nazionale di Statistica / Italian National Institute of Statistics) defines institutional care facilities as 'community', and it defines facilities provided by an organisation that replicates the characteristics of life in a family as 'family based'.

<sup>3</sup> Those percentages can be affected by a minimal amount of questions not answered or data not categorised.

<sup>4</sup> Children with a physical, psychiatric or sensory disability.

<sup>5</sup> Adults between 18 and 64 years who have a physical, psychic or sensory disability, who have multiple disabilities or who have psychiatric problems.

<sup>6</sup> Non-self-sufficient elderly persons over 65, i.e. persons in a permanent state of invalidity or who suffer from chronic diseases and who consequently have a reduced level of independence, leading to a need for constant help from other people in order to perform essential daily activities.

## Methodological note

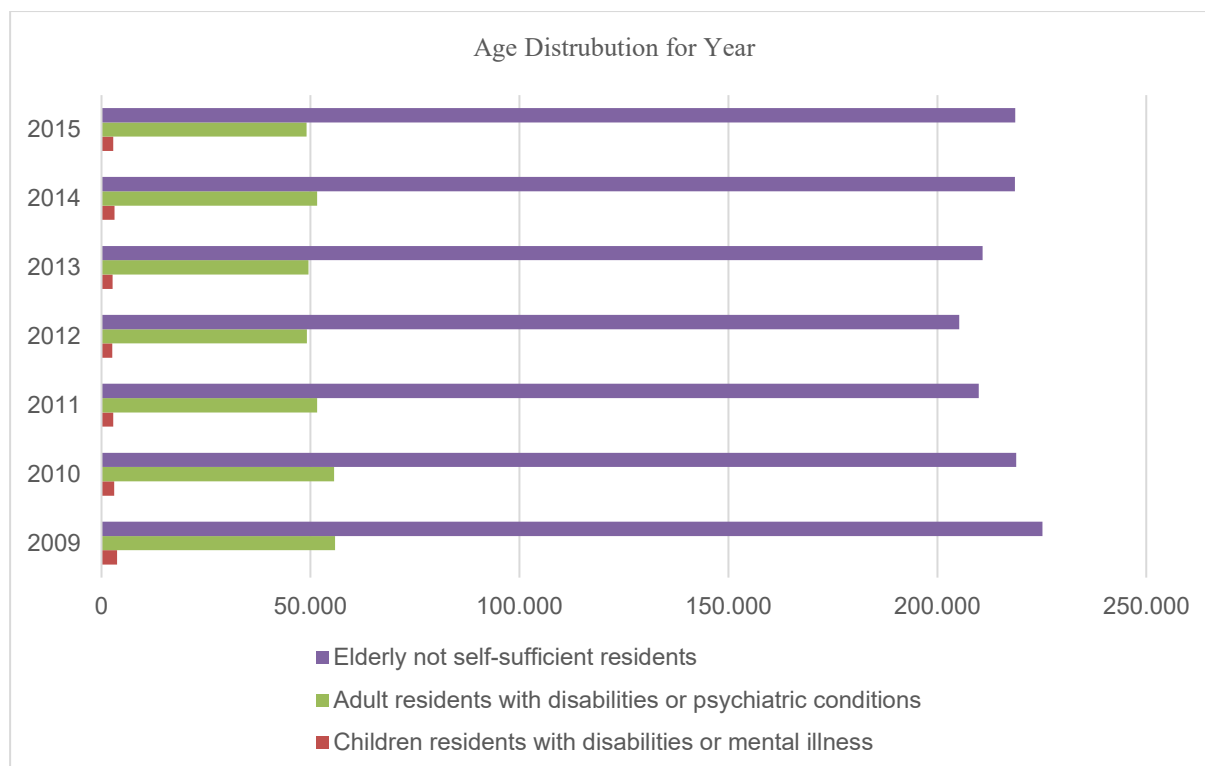
The sequence of official data generated by the Istituto Nazionale di Statistica (ISTAT, the Italian National Institute of Statistics) on residential care facilities that provided both social and health care services stopped in 2015. In October 2017, ISTAT announced the start of a new annual survey, although the data from this are not yet available. Since the official statistical series stopped in 2015, we have examined trends since 2009, which is the year in which Italy ratified and implemented the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol.

## Timeline showing overall situation

| Year | Residents with disabilities or who are not self-sufficient in residential care facilities | Residents with disabilities or who are not self-sufficient in institutional care facilities | % of residents with disabilities or not self-sufficient in institutional care facilities | Residents with disabilities or who are not self-sufficient in community-based facilities | % of residents with disabilities or who are not self-sufficient in community-based facilities |
|------|---|---|--|--|---|
| 2009 | 284 775   | 269 885   | 94.77  | 7 603  | 2.77  |
| 2010 | 277 541   | 268 577   | 96.77  | 6 484  | 2.34  |
| 2011 | 264 378   | 257 249   | 97.30  | 6 272  | 2.37  |
| 2012 | 257 009   | 249 302   | 97.00  | 6 870  | 2.67  |
| 2013 | 263 048   | 254 341   | 96.69  | 7 977  | 3.03  |
| 2014 | 273 316   | 265 582   | 97.17  | 7 409  | 2.71  |
| 2015 | 270 505   | 262 691   | 97.11  | 7 479  | 2.76  |

## Distribution by age

| Year | Children | Adults aged 18 to 64 | Adults aged 65 or over |
|------|----------|----------------------|------------------------|
| 2009 | 3 718    | 55 875               | 225 182                |
| 2010 | 3 028    | 55 662               | 218 851                |
| 2011 | 2 842    | 51 591               | 209 945                |
| 2012 | 2 593    | 49 159               | 205 258                |
| 2013 | 2 658    | 49 536               | 210 854                |
| 2014 | 3 147    | 51 593               | 218 576                |
| 2015 | 2 839    | 49 046               | 218 620                |



The time series analysis shows a slight 9.5 % decrease in the overall usage of residential facilities between 2009 and 2012, a 6.34 % increase between 2013 and 2014, and a very slight 1.03 % decrease between 2014 and 2015.

Thus, the situation did not significantly change overall over those years. The decrease recorded between 2009 and 2012 did not give rise to the beginning of a cycle, and the slight fluctuations are not related to political choices.

The data on the usage of residential facilities are extremely stable, in particular concerning residential facilities providing institutional care. Even if the regulatory fragmentation in Italy makes it difficult to reconstruct a clear and homogeneous picture of the usage of residential facilities across the country, it is evident that the community-based settings represent a marginal option in the Italian welfare system.

### Update note — 2018

Some indirect indexes seem to confirm a stable picture up to the end of 2018. The main index concerns the reception capacity of the facilities, which can be obtained from the residential facilities Register Office managed by the National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty (GNPL) by cross-checking the data from various national and local databases. The data show a high level of stability in the amount of available sleeping accommodation in residential facilities in 2018 with respect to previous years. Furthermore, the geographical distribution of sleeping accommodation seems fairly stable from a macro standpoint. The type of usage of residential facilities is also stable. The Register Office of the GNPL is not publicly accessible, but it is tasked with monitoring the health and social care institutions. Some differences in the percentages can arise due to the fact that regions and municipalities, which are the main sources of data for the Register Office, do not

update their databases on official residential facilities at the same time. Nonetheless, these tools are useful for obtaining a picture of the present situation, given the lack of data coming from ISTAT or from Government ministries.

## Analytical summary

During 2017, Italy permanently ended the process of abandoning judicial psychiatric institutions (OPGs), which had been replaced with residences for the execution of security measures (REMS). Admission to residential social and health care facilities replaced home care, day care or hospitalisation in judicial psychiatric hospitals. REMS are solutions of last resort, since the current legislation prefers solutions other than institutionalisation.<sup>7</sup>

This change is just the latest event in a long process of deinstitutionalisation and criticism of the culture of segregation, which led, in 1977, to the abolition of specific classes devoted to students with disabilities<sup>8</sup> and, in 1978, to the abolition of the system of state mental institutions.<sup>9</sup>

Nevertheless, in Italy the institutionalisation of persons with disabilities is still an essentially accepted practice, which particularly concerns persons with intellectual and/or psychosocial disabilities and non-self-sufficient elderly people.<sup>10</sup>

## 1.2 Overall spending on institutional care versus support services for living independently and being included in the community, including information about proportion/amount of funding provided from EU funds

### 1.2.1 Current figures

There are neither national data with respect to overall spending on institutional care nor data concerning the overall spending on support services for living independently and being included in the community. Thus, there are no available data on the proportion/amount of funding provided out of EU funds.

In 2013, the *Programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità* (Biannual National Action Programme on Disability) planned three actions related to Article 19 of the CRPD.<sup>11</sup> The Ministry of Labour and

<sup>7</sup> See 'Minority Reports: Cultural Disability Studies' No 3, a special issue of *the deposition of criminal lunatic asylum*, 2016.

<sup>8</sup> See Act No 517 of 4 August 1977, <http://www.gazzettaufficiale.it/eli/id/1977/08/18/077U0517/sq>.

<sup>9</sup> See Act No 180 of 13 May 1978, <http://www.gazzettaufficiale.it/eli/id/1978/05/16/078U0180/sq>.

<sup>10</sup> The present report does not deal with the situation and the problems related to psychiatric institutions. In Italy there is an historic and pronounced split between the field of mental health and the field of disability, so much so that the field of mental health uses different collection and monitoring systems. Recently, however, there have been signs of convergence between the two fields, as may be noticed, for example, from draft law No 180, Disposizioni in materia di tutela della salute mentale volte all'attuazione e allo sviluppo dei principi di cui alla legge 13 maggio 1978, which is explicitly placed within the framework of the CRPD. This draft law is not currently being examined by the Parliament (see <http://www.senato.it/leg/17/BGT/Schede/Ddliter/48103.htm>).

<sup>11</sup> See Decree of the President of the Republic of 4 October 2013, *Adozione del programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità*, <http://www.gazzettaufficiale.it/eli/id/2013/12/28/13A10469/sq>.

Social Policy planned for the funding of pilot programmes, as proposed by regions and autonomous provinces, to adopt a uniform model of intervention for support for living independently and for the inclusion of persons with disabilities throughout the country (see section 3.1). This programme, with a budget of EUR 15 million, was mainly funded from the Fondo Nazionale per la non autosufficienza (the FNA, the National Fund for Non-self-sufficiency). This represented 3.75 % of the annual fund.

The only other available data on this topic concern the expenditure of municipalities on institutional facilities and home care. The expenditure on home care is simply an index with respect to policies supporting services for living independently.

The most recent definitive data on the expenditure by municipalities on residential facilities and on home care concern 2014. In January 2019, ISTAT made available provisional data concerning 2016, but they are still not available with respect to a disaggregated representation of types of expenditure.

The contributions of municipalities to residential expenditure for persons with disabilities vary between 30 % and 60 % and come to 50 % for elderly people; the remaining share goes towards the National Health Service and, in proportion to salary, to users. Thus, the contribution of municipalities to the total expenditure on residential facilities is only partial and is usually minor.

In 2014, the expenditure of municipalities on residential facilities amounted to EUR 809.4 million with 313 million was devoted to disability and EUR 469.3 million for elderly people.

Municipal expenditure for home care in 2014 amounted to EUR 678.1 million, with EUR 223 million devoted to disability and EUR 455.1 million for elderly people.

Expenditure for home care for disabled persons includes EUR 147.9 million for social assistance home care, EUR 25.7 million for home care integrated with health services (ADI), and EUR 49.4 million for vouchers, care allowance and social health vouchers.

Expenditure for home care for elderly people includes EUR 312.3 million for social assistance home care, EUR 64.7 million for home care integrated with health services (ADI), and EUR 78.1 million for vouchers, care allowance and social health vouchers.

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The decree of the President of the Republic of 12 October 2017, *Adozione del secondo programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità*, moves from action line 3 by expanding it. See <http://www.gazzettaufficiale.it/eli/id/2017/12/12/17A08310/SG>.

## 1.2.2 Trend since 2013

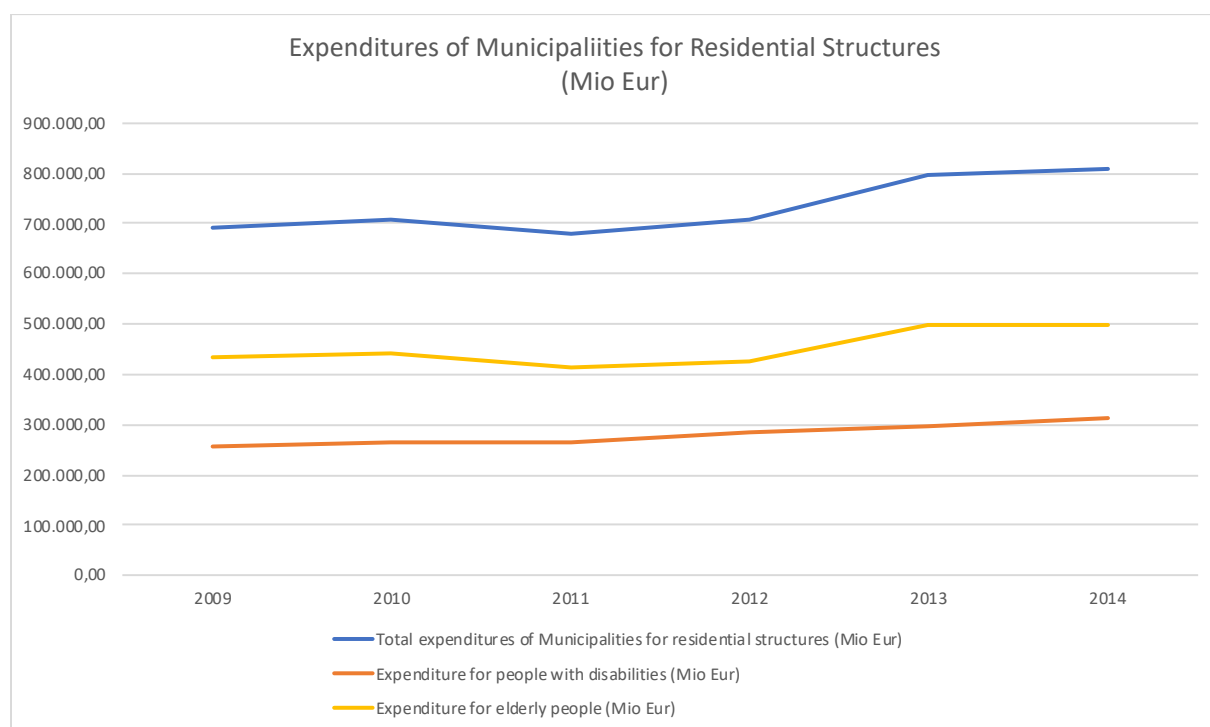
In this case as well, due to the reasons stated in the methodological note in 1.1.2, we assume a broader time horizon.

### Funds from the ministerial programme

The pilot programme received EUR 10 million of funding for 2014-15 and EUR 15 million between 2016 and 2018 (3.1).

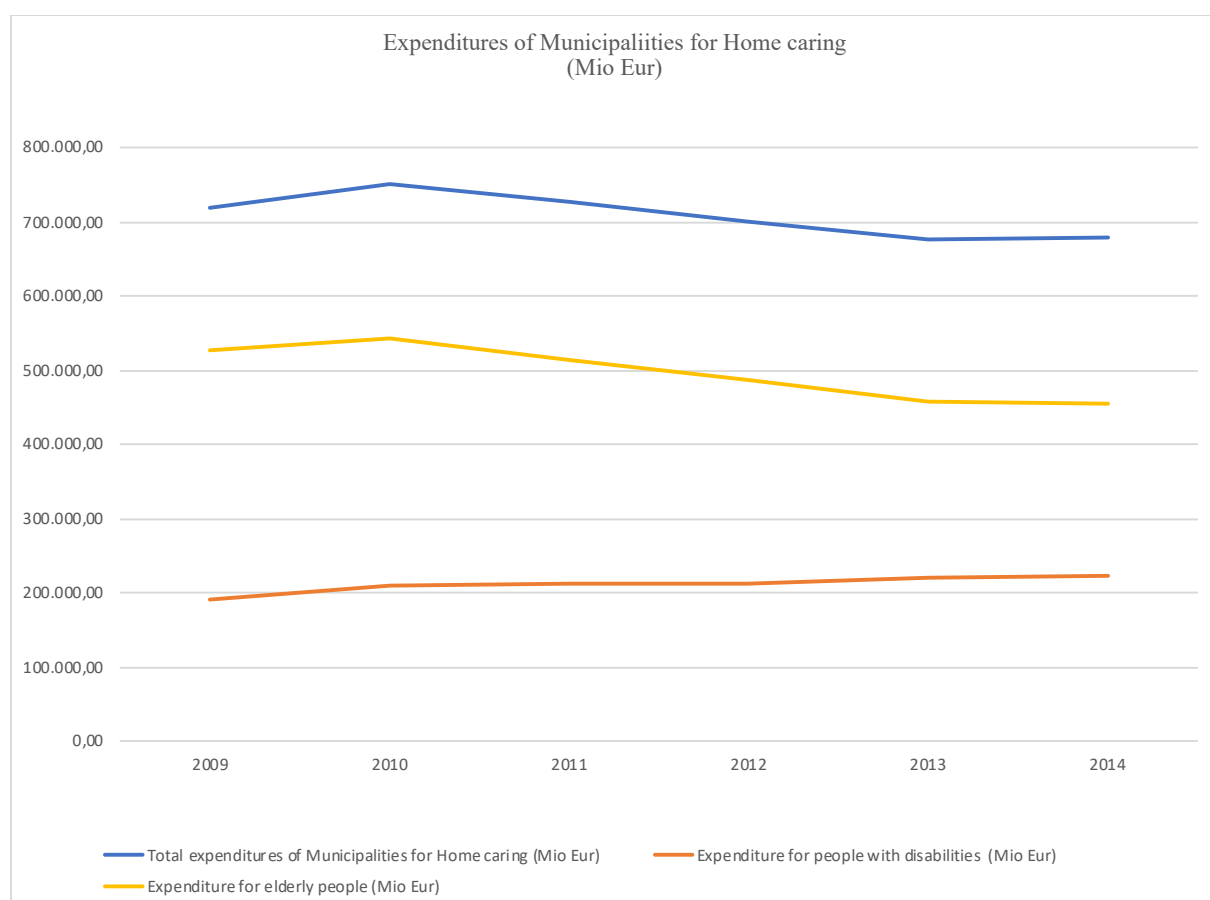
### Expenditure on residential facilities

| Year | Total expenditure by municipalities on residential facilities (million of €) | Expenditure on people with disabilities (million of €) | % of total expenditure on people with disabilities | Expenditure on elderly people (million of €) | % of total expenditure on elderly people |
|------|--|--|--|--|--|
| 2009 | 691 549.75   | 256 681.67   | 37.12  | 434 868.08                                   | 62.88                                    |
| 2010 | 707 308.78   | 264 361.34   | 37.38  | 442 947.44                                   | 62.62                                    |
| 2011 | 678 295.93   | 264 224.52   | 38.95  | 414 071.41                                   | 61.05                                    |
| 2012 | 706 976.23   | 282 840.60   | 40.00  | 424 135.63                                   | 60.00                                    |
| 2013 | 795 910.10   | 297 668.02   | 37.40  | 498 242.08                                   | 62.60                                    |
| 2014 | 809 360.85   | 313 013.10   | 38.67  | 496 347.75                                   | 61.33                                    |



## Expenditure on home care

| Year | Total expenditure by municipalities on home care (million of €) | Expenditure on people with disabilities (million of €) | % of total expenditure on people with disabilities | Expenditure on elderly people (million of €) | % of total expenditure on elderly people |
|------|---|--|--|--|--|
| 2009 | 717 918.95  | 191 032.96   | 26.61  | 526 886.00                                   | 73.39                                    |
| 2010 | 751 004.41  | 209 472.66   | 27.89  | 541 531.75                                   | 72.11                                    |
| 2011 | 726 512.78  | 212 508.32   | 29.25  | 514 004.45                                   | 70.75                                    |
| 2012 | 699 125.94  | 211 658.87   | 30.27  | 487 467.07                                   | 69.73                                    |
| 2013 | 676 765.68  | 219 667.02   | 32.46  | 457 098.66                                   | 67.54                                    |
| 2014 | 678 080.82  | 223 012.13   | 32.89  | 455 068.69                                   | 67.11                                    |



From the time series analysis of the expenditure on residential facilities, it is possible to observe moderate fluctuations until 2012, a significant increase in 2013 (+12.58 %) and a further increase in expenditure in 2014. This increase has to be mainly attributed to the increase in expenditure for residential facilities for elderly people.

During the same period, municipalities' expenditure on home care shows the same trends, characterised by an increase in 2010, followed by a progressive and constant decrease until 2013, which stabilised in 2014.

Considering the fact that municipal expenditure represents just part of total expenditure on residential facilities, a significant structural disequilibrium is evident in expenditure on institutional care.

## **2 Government commitments on living independently and being included in the community, including the transition from institutional care to community-based living**

### **2.1 In which document(s) are Government commitments and plans concerning support for independent living in the community set out?**

As well as having an advisory role, the National Observatory on the Condition of Persons with Disabilities, established by the Ministry of Labour and Social Policy under Act No 18 of 3 March 2009, has an additional role of providing technical and scientific support for the development of national policies on disabilities.<sup>12</sup> On 18 October 2016, the Observatory approved the *Secondo programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità*<sup>13</sup> (Second Biennial National Action Programme on Disability). The title of action line 2 of the programme is 'Politiche, servizi e modelli organizzativi per la vita indipendente e l'inclusione nella società' (Policies, services and organisational models for living independently and inclusion in society).

In Italy, the regions have primary legislative competence and regulatory power in planning and coordinating health and social services, in compliance with the minimum levels of service with respect to civil and social rights which have to be secured throughout the country, as established by the state.

In this regulatory system, some regions have approved or are in the process of discussing laws or measures inspired by the principles of living independently. These acts vary with respect to their conceptual structure, the solutions foreseen and the potential recipients. At time of writing, those regions that have issued measures on the topic are Abruzzo, Emilia-Romagna, Friuli-Venezia Giulia, Lazio, Lombardy, Marche, Molise, Piedmont, Tuscany, Umbria and Veneto.

### **2.2 What are the aims and objectives of the relevant strategies, including the relevant targets and milestones? Are they linked to European Structural and Investment Funds (ESIF)?**

Action line 2, 'Politiche, servizi e modelli organizzativi per la vita indipendente e l'inclusione nella società' (Policies, services and organisational models for independent living and inclusion in society) of the Second Biennial National Action Programme on Disability of the National Observatory on the Condition of Persons with Disabilities considers six programmatic actions:

- Tackling isolation and segregation in order to favour deinstitutionalisation;

<sup>12</sup> See <http://www.osservatoriodisabilita.it>.

<sup>13</sup> Adopted by decree of the President of the Republic, 12 October 2017, <http://www.gazzettaufficiale.it/eli/id/2017/12/12/17A08310/SG>.

- Providing services and facilities for the community which should be available to persons with disabilities by taking into account their needs and in accordance with the principle of parity;
- Promotion of living independently in houses;
- Providing stronger, more effective models of self-managed personal support;
- Sharing and disseminating the principles and tools of personal design and their application;
- Legal protection of persons with disabilities and their self-determination.

### **2.3 Please summarise the planned approach and the actions to be taken in relevant strategies**

The Second Biennial National Action Programme on Disability is based on an articulate, consistent and synergistic approach. All the actions in it converge on the implementation of the rights ratified by the CRPD.

The action programme, both in its writing and in its implementation phase, involves the main state institutions, local authorities, disabled persons' organisations (DPOs) and social partners, using a working method that is extremely cooperative and respectful of the provisions of the CRPD.

Within those actions proposed in action line 2, we highlight the following in particular:

- take UNI standard 11010/2016, 'Servizi socio sanitari e sociali - Servizi per l'abitare e servizi per l'inclusione sociale delle persone con disabilità (PcD)— Requisiti del servizio' (Health and social services - Independent living services and social inclusion services of persons with disabilities. Requirement for services) as a reference point for all future conventions or the institutional accreditation of facilities, and for prohibiting institutional accreditation — and, consequently, any form of direct or indirect funding to facilities that may potentially be segregated.
- on the basis of agreed indexes, which should be identified with large participation, proceed to make a complete and systematic survey of the potentially segregated facilities by fixing a deadline for the appropriate and suitable release of the segregated persons on the basis of personal plans.
- review the *Nomenclature degli interventi e servizi sociali* (Nomenclature of interventions and social services).
- identify service objectives for housing support, based on personal plans.
- develop and promote assignment models for 'personalised budgets' (care budgets, health budgets or however they are designated), which should provide a quantitative and qualitative definition of the economic, professional and human resources needed to activate a process whose goal must be the return of the person to proper social functioning by means of a personal plan, which should require the active participation of the persons with disability themselves, their families and their communities, optimising the integrated use of common resources along homogeneous lines.
- propose a change in the Civil Code, which should introduce the potential abrogation of disqualification and incapacitation, maintaining administrative support as the sole means of legal protection, adjustable in various ways.

- instigate ad hoc advertising and promotion of learning and upgrading processes for magistrates through the Consiglio Superiore della Magistratura (Higher Judicial Council) and the Scuola Superiore della Magistratura (Higher Judicial School).

## **2.4 What budgetary commitments are made to support these strategies, for both domestic and EU funds?**

None of the programme's interventions requires additional costs. On the contrary, the outcomes can lead to a significant qualification (improvement in the way of spending) of public expenditure.

Data on investments by regions and municipalities, aggregated over deinstitutionalisation measures and independent living plans, is not available.

## **2.5 What is the (official) involvement of persons with disabilities and/or their representative organisations in the development of the strategies and plans?**

The National Observatory on the Condition of Persons with Disabilities, which is responsible for the implementation and monitoring process of the CRPD and the biannual action programme, has a total of 40 members, including 14 representatives of DPOs. At the local and regional levels, DPOs are involved in independent living policies.

## **3 Implementation and monitoring**

### **3.1 Summary of relevant calls for proposals**

One of the seven action lines of the *Primo programma biennale di azione sulla disabilità*, action line 3 (which is also presented in a more encompassing form in action line 2, 'Vita Indipendente e inclusione nella società' ('Independent living and inclusion in society'), of the Second Biennial National Action Programme on Disability), mainly concerns policies, services and organisational models for independent living and the inclusion of persons with disabilities in society, with the goal of defining some common lines for the implementation of Article 19 of the CRPD by fixing the guiding principles for the granting of funds, interventions and service planning, as well as the drafting of individualised plans. In order to proceed with planning in this direction, the Ministry of Labour and Social Policy started to fund pilot programmes, submitted by regions and autonomous provinces, for the implementation of a uniform intervention model throughout Italy to support independent living and the social inclusion of persons with disabilities. This was done by means of five calls<sup>14</sup>, funded by the FNA. In these calls, it was expected that regions had to activate/make specific announcements directed towards the area of social spheres (under Act 328/2000), with funding of EUR 100 000 per 12 months and with the area social spheres in charge of a co-financing share of

<sup>14</sup> This call is funded by the government; the funds are transferred to the regions. Regions make a call to the territorial social services that present a project of independent living activities; finally the territorial social services open a call for candidature of persons with disabilities to have access to a selection of individualized projects. The term call is used to describe in synthesis this process.

EUR 20 000. The number of territorial scopes (administrative areas) which could be funded in each region was identified on the basis of the resident regional population aged between 18 and 64. The calls required to be discussed with associations of persons with disabilities. Since 2016, a criterion has been introduced in these calls, according to which a 15 % share of the funds for the area social spheres in the regions has had to be devoted to work on training and information systems and to specific actions such as peer counselling activities in some regions.

Call 1 – Guideline for the presentation by the regions of a proposal to join the intervention model trial for independent living and the inclusion in society of persons with disabilities in 2014,<sup>15</sup> with the FNA devoting EUR 9 987 721.28 to 129 regional territorial scopes.

Call 2 – Guideline for the presentation by the regions of a proposal to join the intervention model trial for independent living and the inclusion in society of persons with disabilities in 2015,<sup>16</sup> with the FNA devoting EUR 9 987 721.28 to 128 regional territorial scopes.

Call 3 – Guideline for the presentation by the regions of a proposal to join the intervention model trial for independent living and the inclusion in society of persons with disabilities in 2016, with the FNA devoting approximately EUR 10 million to 187 regional territorial scopes.

Call 4 – Guideline for the presentation by the regions of a proposal to join the intervention model trial for independent living and the inclusion in society of persons with disabilities in 2017,<sup>17</sup> with the FNA devoting approximately EUR 15 million to 187 regional territorial scopes.

Call 5 – Guideline for the presentation by the regions of a proposal to join the intervention model trial for independent living and the inclusion in society of persons with disabilities in 2018,<sup>18</sup> with the FNA devoting approximately EUR 15 million to 187 regional territorial scopes. This has not yet been activated.

The passing of Act 112/2016<sup>19</sup> made it possible to identify interventions for persons in greater need of support who do not have family help. The law provides for ‘micro-apartments’ with a management structure similar to that provided for family accommodation. Alternatively, people may continue living in their own environment if they have adequate support. The initial endowment, in 2016, was of EUR 90 million, which went down to EUR 38.3 million in 2017 and then reached a stable level of € 56.1 million from 2018 onwards. On the basis of the resident population and other heterogeneous criteria, regions issued their own announcements, for which there is still no monitoring process.

<sup>15</sup> See [http://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Vita-indipendente/Documents/Vita%20indipendente\\_Bandi%202014.pdf](http://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Vita-indipendente/Documents/Vita%20indipendente_Bandi%202014.pdf).

<sup>16</sup> See [http://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Vita-indipendente/Documents/Vita%20indipendente\\_Bandi%202015.pdf](http://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Vita-indipendente/Documents/Vita%20indipendente_Bandi%202015.pdf).

<sup>17</sup> Directorial Decree No 808 of 29 December 2017, <http://www.lavoro.gov.it/notizie/Pagine/Linee-Guida-Vita-Indipendente-anno-2017.aspx>.

<sup>18</sup> Directorial Decree No 669 of 28 December 2018, <http://www.lavoro.gov.it/notizie/pagine/linee-guida-vita-indipendente-anno-2018.aspx/>.

<sup>19</sup> Act No 112 of 22.6.2016, Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno familiare, <http://www.handylex.org/stato/l220616.shtml>.

## 3.2 Summary of relevant projects funded

The Act No. 112 of 2016 finances personalised projects for persons with high level of condition of disability, where the family not have yet the capacity to assist, to prevent institutionalisation; Sardinia region invest €110 million for 35.000 personalised projects; Umbria region utilise 2,4. million from the EU structural funds to reform the regional welfare towards independent living support. These are the main projects:

- Ministry of Labour and Social Policy: *Vita Indipendente* programme (see point 3.1);
- Act No 112/2016: funding to support persons with serious disability without family support (3.1);
- Sardinia: personalised plans for persons with disabilities in need of a high level of care, in accordance with national Act No 162/1998(8);
- Sardinia: *Ritornare in famiglia* programme under regional Act No 4/2006(8);
- Umbria: 'Vado a vivere da solo' project on European structural funds (8).

## 3.3 Overview of other relevant measures since 2013

Beyond those already mentioned, there are no specific significant measures, either national or regional.

## 3.4 Monitoring mechanisms and approaches

### 3.4.1 Monitoring mechanism(s)

Italy has neither developed nor implemented a specific monitoring system for policies and deinstitutionalisation actions or, more generally, to fulfil the requirements of Article 19 of the CRPD, in accordance with Article 31 of the Convention (4.1).

### 3.4.2 Measurement and data collection

The available data that may be used in some way in relation to Article 19 of the CRPD come from different institutions, are collected in different ways and, as a rule, are collected using methods and systems whose goal is the simple quantitative monitoring of public expenditure (4.1).

## 4 Impact and outcomes

### 4.1 Progress against explicit targets and milestones

The present policies on the topic, both national and regional (FNA, Act No 112/2016, Sardinian regional legislation, etc.), are directed mainly towards persons in greater need of support (see section 6.1 box), but they are not part of a national strategy of deinstitutionalisation or of preventing institutionalisation. Moreover, no valid data are available on the effectiveness of single interventions, since the plans have very few monitoring tools, or sometimes none at all; as a rule, only the number of funded individualised plans is recorded. There is no attention to the quality of the expenditure, such that the achievement rate is generally not monitored, not even in the short or medium term.

This state of affairs largely stems from the fact that these programmes are methodically activated in a ‘trial’ form, and they are almost always funded on a yearly basis.

This operating model makes it impossible to implement stable processes to support independent living. The same individualised plans, activated via announcements under the Ministry of Labour and Social Policy’s trial programme, come with no guarantees that they will continue at the end of the funded year. Only some regions, such as Puglia, activated dedicated regional resources to guarantee the continuity of the plans beyond the trial year. Beyond the doubts concerning effectiveness, this poses an important ethical issue.

## **4.2 What is replacing institutional care?**

4.2.1 At the point when persons with disabilities are moved out of institutional care facilities, what types of accommodation and support are they being moved into?

For the same reasons that were pointed out in 4.1, there are no homogenous, reliable data on the types of accommodation and support that replace institutional care facilities: in some cases, there is a predominance of accommodation in small groups, while in others the individuals go back to their original accommodation. Finally, in a very limited number of cases, new, independent accommodation is provided. It is very difficult to assess to what extent the freedom of choice of the individual, as required by Article 19 of the CRPD, is actually safeguarded.

4.2.2 What services, support and measures are being developed and established to build long-term support for people’s right to live independently and to be included in the community?

The only tool which has been shown to be effective is the personalised budget, which can be described using different names (e.g. ‘care budget’ or ‘health budget’.) in the different places where it is implemented. Essentially, it is a matching mechanism. This mechanism allows for the integrated use of the economic, professional and human resources needed to begin a process whose goal is that of giving individuals back their proper social function by means of personal plans, which are shared with the individuals with disabilities themselves, along with their families and their communities.

## **4.3 Satisfaction levels among persons with disabilities**

Every institution that hosts persons with disabilities must be endowed with a service charter that allows users to make complaints. However, there are no studies or data concerning the effectiveness of this tool that support the fact that this is not merely an abstract and purely formal possibility.

## **PART B – Critique and evaluation**

### **5 Observations and recommendations of official bodies**

#### **5.1 Observations by the UN Committee on the Rights of Persons with Disabilities on Article 19**

*Concluding observations on the initial report of Italy* of 6 October 2016, relevant to Article 19:<sup>20</sup>

41. The Committee is concerned that the remit of the mandate of the national preventive mechanism does not extend to psychiatric institutions or other residential facilities for persons with disabilities where they are deprived of their liberty.
42. The Committee recommends that the national preventive mechanism immediately visit and report on the situation in psychiatric institutions or other residential facilities for persons with disabilities, especially those with intellectual and/or psychosocial disabilities.

*Concluding observations on the initial report of Italy* of 6 October 2016, which concern Article 19 specifically:

47. The Committee is deeply concerned about the trend to re-institutionalise persons with disabilities and that funds are not being reallocated from institutions towards promoting and ensuring independent living for all persons with disabilities within their community. The Committee further notes with concern the gendered consequences of the current policies where women are 'forced' to remain within the family as caregivers of their peers with disabilities instead of being employed in the labour market.
48. The Committee recommends: a) implementing safeguards to retain the right to autonomous independent living across all regions; and, b) redirecting resources from institutionalisation to community-based services and increasing budget support to enable persons with disabilities to live independently across the country and have equal access to services including personal assistance.

#### **5.2 Recent observations by other official European and international bodies**

In December 2018, the European Union Agency for Fundamental Rights (FRA) published two short reports which contain an overview of the European state of affairs on the transition from institutions to community living, together with some general opinions on the obstacles to deinstitutionalisation. These documents contain some information concerning Italy.<sup>21</sup> This study stresses that various forms of in-home support and hospitality are provided locally in several day-care centres to foster autonomy, as well as a number of labour inclusion services for persons with disabilities.

<sup>20</sup> See <https://www.ohchr.org>.

<sup>21</sup> 'From institutions to community living for persons with disabilities: perspectives from the ground', <https://fra.europa.eu/en/publication/2018/independent-living-reality>; and 'The right to independent living of persons with disabilities', <https://fra.europa.eu/en/project/2014/right-independent-living-persons-disabilities>.

These facilities and services tend to be run by social cooperatives that work closely with local authorities, often also in cooperation with regions committed to achieving deinstitutionalisation. It must be noted that the FRA report considers a very specific case study, therefore it is limited in scope.

### 5.3 Observations and recommendations by national human rights bodies

Established in 2013, the National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty (GNPL) became operational in 2016. The GNPL is an independent state body authorised to monitor places characterised by deprivation of freedom by visiting them without prior notification.

As a national preventive mechanism — as per the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment<sup>22</sup> and as per Article 33 of the CRPD — the GNPL monitors residential facilities to ensure that persons with disabilities, in particular intellectual or psychosocial disabilities, shall not be deprived of their freedom illegally or arbitrarily. The objective here is to ensure that disability is not used as a prerogative or excuse for restrictions of freedom or for segregation.

The GNPL's work stems from recommendation No 42 of the *Concluding observations on the initial report of Italy*<sup>23</sup> of 6 October 2016 of the Committee on the Rights of Persons with Disabilities (5.1).

The National Guarantor started monitoring health and social care homes in June 2017.<sup>24</sup> In light of the lack of official data, the GNPL created its own national register of residential and semi-residential facilities. This database allows facilities to be located according to a dedicated information and risk indexing system.

During its monitoring visits, the GNPL often found inadequacies in living and support conditions in the residential facilities, with improper forms of freedom reduction, abuses or treatments that did not respect the dignity of the person, as well as the use of restraint tools.

The main problem is de facto segregation: the process of involuntary institutionalisation that tends to arise after a person voluntarily joins the residential facility, when the social services do not put in place adequate forms of community-based support.

After a period of embargo, the GNPL makes its observations with respect to its monitoring visits publicly available.<sup>25</sup>

<sup>22</sup> Ratified by Italy by Act No 195 of 9 November 2012, <http://www.gazzettaufficiale.it/eli/id/2012/11/19/012G0216/sg>.

<sup>23</sup> See <https://www.ohchr.org>.

<sup>24</sup> The activities of the GNPL are scientifically supported by an operational research protocol on 'Places, forms and ways of segregated disability', which involves a collaboration between GNPL, L'Altro diritto, Centro di ricerca interuniversitario su carcere, devianza, marginalità e migrazioni of the University of Florence, Aypicalab for Cultural Disability Studies of the University of Calabria and the Robert Castel Centre for Governmentality and Disability Studies at the Suor Orsola Benincasa University of Naples.

<sup>25</sup> See <http://www.garantenazionaleprivatiliberta.it/gnpl/it/rapporti.page>.

The GNPL publishes its observations and general recommendations in its annual report to the Parliament.<sup>26</sup>

#### **5.4 Observations and recommendations by national or regional/devolved Parliaments and assemblies**

There are no available documents on this topic.

### **6 Views and perspectives of civil society including DPOs**

#### **6.1 UNCRPD civil society shadow and alternative reports**

This subsection comprises the comments on Article 19 made by the *Forum italiano sulla disabilità* in its report on the CRPD, which is an alternative report to that prepared by the Italian state:<sup>27</sup>

*[Extract from the report]* In the last years regional policies which re-introduce institutional solutions for persons with disabilities have increased, such as those in the regions of Marche, Campania, Tuscany.<sup>28</sup> Italy does not yet offer on its national territory and in a homogeneous way, throughout the regions, appropriate support for guaranteeing persons with disabilities that need more support, the ‘possibility to choose, on an equal basis with others, their own residence and where and with who to live and not obliged to live in a particular accommodation’. In Italy there is a consolidated tradition of admitting adults with disabilities who do not have family support to segregating institutions which are managed mainly by religious bodies. The alternatives to residential solutions (small group homes, supported living units, support measures at home, etc.) are still very few and mainly reserved for persons with mild disabilities.<sup>29</sup> 3.4 % only of people living in residential facilities have access to small family type communities or to community housing. More than 90 % live in institutions.

The reasons cited for maintaining residential services are usually organizational and economic. These reasons, however, are in conflict with the right to choose and on preferences of persons with disabilities, thus violating the inner dignity of persons with disabilities. No positive trend towards community living is occurring after the ratification of CRPD. Individual supports to independent living, including personal assistance, are not equally ensured across regions. Moreover, alternative options to institutionalization in big-size facilities (smaller living communities, home groups, etc.) often maintain an institutional organization, as residents do not have choice and control over their own lives.

Regional policies continue to promote institutionalization of persons with disabilities, and sometimes their re-institutionalization as a consequence of

<sup>26</sup> See [http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub\\_rel\\_par.page](http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub_rel_par.page).

<sup>27</sup> The alternative report can be downloaded at <http://www.superando.it/files/2016/03/fid-rapporto-convenzione-marzo-2016.pdf>.

<sup>28</sup> See [www.superando.it](http://www.superando.it), searching for ‘istituzionalizzazione’.

<sup>29</sup> Beadle-Brown, J. and Kozma, A., *Deinstitutionalisation and community living – outcomes and costs (DECLOC)*, report of a European Study, Vol. 3: Country Reports, Tizard Centre, University of Kent, Canterbury, 2007.

austerity measures. For instance, in the Marche region the Resolution 1260/2013 of the Regional Council establishes that residential units for persons with disabilities must not have less than 20 beds and recommends merging 20-bed units in residential facilities accommodating not less than 40-60 residents. In Tuscany, two big institutions for persons with intellectual and developmental disabilities are under construction: in Empoli and Pisa, the first one providing 20 places in a residential service and?

60 places in a day service, the second one providing 100 places in a residential service and 400 places in a day service.

The average expense for disability varies noticeably according to the type of service, ranging from 3,469 EUR/year/user in Social assistance services (RSA) to 12,201 EUR in Healthcare residential facilities for persons with disabilities (RSD) (net of the user's participation quota).

Access to 'intensive support' by persons with higher needs depends on the availability of specifically allotted funds. The amount of national 'Fund for non-self-sufficiency' is determined from year to year by the Stability Act and is distributed through the regional administrations which in some cases integrate them with their own resources.

Only a few regions adopt and fund independent living schemes, including personal assistance. Persons with disabilities who live in regions that do not offer support for independent living projects are therefore discriminated with regards to other persons who, living in other regions, can benefit from this opportunity. Moreover, personal assistance and other forms of support to independent living, lack portability across regions, thus hindering the mobility of persons with disabilities across the country.

#### **box - Allocation of funds for non-self-sufficiency**

The Decree for the allocation of the National fund for 'non-self-sufficiency' commits the Regions to use National resources primarily (and in any event 40 % at least) in favour of persons with severe disabilities, according to their definition as 'persons in conditions of vital dependence that need continuous home assistance and socio-health monitoring in the 24 hours, for complex needs deriving from serious psycho-physical conditions, ... needing vigilant assistance by a third person to guarantee their psycho-physical integrity'.<sup>30</sup> Though this definition does not make any reference to age, some regions allocate the funds for non-self-sufficiency mainly to people over 65 years of age.

For example, the fund for non-self-sufficiency in Tuscany established in 2014 for 2015 is made up of a National quota of 27,651,000 Euros, which is integrated by regional resources up to a total of 79,800,000 Euros. The regional Decree concerning the allotment of the total fund for non-self-sufficiency reserves more than 95 % (75.921.324 Euro) of the resources to non-self-sufficient persons aged over 65, that represent 80 % of persons with disabilities. More than 30 % (24.921.324) of the fund is allocated to finance institutionalization in Social assistance facilities (RSA). Less than 5 % of the total non-self-sufficiency fund, equal to 3.878.676, representing only 14 % of the quota of the National fund received for 2015, is allocated to non-self-sufficient persons aged under 65,<sup>31</sup> which represent 20 % of persons with disabilities.<sup>32</sup> Even considering that 80 % of persons with disabilities in Italy are aged over 65, the allotment of the Non-self-sufficiency Fund in Tuscany penalizes persons with severe disabilities aged under 65.

<sup>30</sup> Decree of the Ministry of Labour and Social Policies, 14 May 2015 'Allocation of the tributary financial resources to the Fund for non-self-sufficiency, for the year 2015', art. 3.

<sup>31</sup> Deliberation No 444 of 3 June 2014 (L.R. No. 66 of 2008) 'Establishment of the regional fund for non-self-sufficiency', Year 2014: allocation to the Zone/District of the fund for non-self-sufficiency. – Bollettino ufficiale della Regione Toscana No. 23 of 1 June 2014.

<sup>32</sup> ISTAT, *Disability in Italy: Il quadro della statistica ufficiale*, 2009.

Persons with disabilities in need of high support, if family help is lacking, have no access to non-institutional forms of housing. The lack of planning, development and funding of alternative forms of home support, of alternative services to segregating institutions, such as family type facilities, and of transition processes towards residential arrangements in the community constitutes a concern for the families of persons with intensive support needs. The number of families that complain that they cannot count on anybody's help and grows with the age of the person, together with the parents' concerns about the perspectives of the future life of their children with disabilities after their death. While the number of parents of children or teens with Down Syndrome up to 15 years who think about 'after us' in which their children will have an autonomous or semi-autonomous life varies from 30 % to 40 %, among parents of adults the percentage decreases to 12 %. The number of parents of children and adolescents with autism that imagine an autonomous or partially autonomous future situation for their children (23 %) decreases even more drastically (5 %) among families of adults with autism over 21.<sup>33</sup>

### *Recommendations*

1. **Define, adopt and fund at national level Minimum Standards of residential support and services for persons with disabilities, ensuring homogeneous access to independent living schemes to all persons with disabilities, including those with high support needs (Non-self-sufficiency), as well as small size community – based residential services, according to individually tailored programs, with the respect for the choices and wishes of persons with disabilities, regardless of their place of residence or the level of support needed. Define National guidelines on independent living with the active participation of persons with disabilities through their representative organizations.**
2. Urge the Italian Regions to activate and implement in a reasonable length of time a transition process from segregating residential services to alternative inclusive services by providing a range of living arrangements in the community with the necessary individual support, to persons with disabilities of any age, including to persons with intellectual and psychosocial disabilities and those needing intense support.
3. Develop awareness raising and empowerment actions for persons with disabilities in order to enhance their capacities of choice and self-determination, in partnership with representative DPOs.

## **6.2 'Grey literature' at the national level**

National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty, *Report to the Parliament 2018* (Garante nazionale dei diritti delle persone detenute o private della libertà personale, *Relazione al Parlamento 2018*).<sup>34</sup>

<sup>33</sup> Censis, *Diario della transizione*, issue 3, 2014.

<sup>34</sup> See [http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub\\_rel\\_par.page](http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub_rel_par.page).

National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty, *Report to the Parliament 2017* (Garante nazionale dei diritti delle persone detenute o private della libertà personale, *Relazione al Parlamento 2017*).<sup>35</sup>

In the Annual Report to the Parliament, the National Guarantor explains his own monitoring activities and the areas of criticism identified during visits to the facilities. He also provides guidance on the activities he will undertake during the following year.

Gruppo Solidarietà, *Disability and the life project: How to combat the reinstitutionalisation of services* (*Disabilità e progetto di vita. Contrastare la re-istituzionalizzazione dei servizi*), Castelplanio, GS, 2018.<sup>36</sup>

The Gruppo Solidarietà (Solidarity Group) has been working in Marche in the field of the rights of people with disabilities since 1979. In this book, it encourages inclusive paths that counteract specialist services.

### 6.3 Pan-European and international civil society organisations

The European Coalition for Community Living is a Europe-wide cross-disability initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation. Since 2008, ECCL has been hosted by the European Network on Independent Living (ENIL) and has produced different tools and publications on independent living issues.<sup>37</sup>

## 7 Academic research

In Italy, the amount of scientific research on the forms, types and dynamics of institutionalisation and deinstitutionalisation of persons with disabilities is extremely limited, as is the research on models and practices of community-based living.

During recent years, starting with studies and original research, the following volumes addressed the themes related to Article 19 of the UNCRPD:

Merlo, G., and Tarantino, C., eds., *La segregazione delle persone con disabilità. I manicomi nascosti in Italia*, Maggioli, Santarcangelo di Romagna, 2018.

Starting from research funded by the FISH (Federazione Italiana per il Superamento dell'Handicap (8) — the Italian Federation for the Overcoming of Handicap) that was carried out throughout the country, this volume provides an analysis of the segregation of persons with disabilities in Italy at the present time. This work provides some indexes and measures of segregation. The research concludes with some operating guidelines for fighting institutionalisation and segregation.

Falasca, C., ed., *Il diritto di invecchiare a casa propria. Problemi e prospettive della domiciliarità*, LiberEtà, Roma, 2018.

<sup>35</sup> See [http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub\\_rel\\_par.page](http://www.garantenazionaleprivatiliberta.it/gnpl/it/pub_rel_par.page).

<sup>36</sup> See <http://www.grusol.it/pubblicaN.asp>.

<sup>37</sup> See <http://community-living.info/> on the European Coalition for Community Living. *Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities: Focus report 2009*, see <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf>.

This research provides an analysis of the Italian home care system, which is a pillar of long-term care, starting from an analysis of the available data, primarily those on demographic change and on the quality and quantity of public and private services offered in Italy.

Marchisio, C. and Curto, N., *Costruire futuro. Ripensare il dopo di noi con l'Officina della vita indipendente*, Erickson, Trento, 2017.

This book, starting with many daily experiences, reconstructs which support policies are effective in achieving the goal of independent living.

Francescutti, C. et al., eds., *Disabilità: servizi per l'abitare e sostegni per l'inclusione. Manuale applicativo della norma UNI 11010:2016*, Maggioli, Santracangelo di Romagna, 2016.

This volume presents the first analysis of the UNI 11010:2016 ('Servizi residenziali e semiresidenziali per le persone con disabilità') standard. This standard introduces processes of *certificazione di qualità* (quality accreditation) and *sistemi di accreditamento dei servizi* (service accreditation systems), which drastically reduce the risk of institutionalisation.

The debate on the practices of institutionalisation and deinstitutionalisation in the context of mental health is still lively and widespread.

## PART C – Key points

### 8 Positive developments, including promising practice examples

#### DPO level

The FISH (Federazione Italiana per il Superamento dell'Handicap / Italian Federation for the Overcoming of Handicap) carried out national research on institutional segregation, which ended with a Consensus Conference in June 2017. This research brought the topic to the centre of national focus (7).

#### Regional level

Having applied national Act No 162/1998 since 2000, Sardinia long foresaw the drawing up of personalised plans for persons with disabilities in need of a high level of care.<sup>38</sup> This allowed for an increase from 123 personalised plans in 2000, with a budget of EUR 1.34 million, to 39 356 personalised plans in 2015, with a budget of EUR 117.8 million. EUR 120 million has been budgeted for 2019.

Under regional act No 4 of 11 May 2006, Sardinia activated a programme called *Ritornare in famiglia* (Return to Family) 'with the goal of favouring the return of persons currently in residential facilities of a social and/or medical type to their family and their communities, of overcoming institutionalisation, and of supporting residence in their domicile'.<sup>39</sup> Between 2006 and the time of writing, approximately EUR 600 million has been allocated from regional funds. Around 3 300 plans were funded in 2018. Some recipients were released from institutions; for others, the risk of institutionalisation has been prevented. EUR 49 million was allocated in 2019, with annual funding ranging from EUR 18 000 to EUR 65 000 for each individual plan.

Umbria allocated approximately EUR 2.4 million of European structural funds for activities related to independent living as part of the 'Vado a Vivere da solo' (I am going to live by myself) project,<sup>40</sup> and it set out regional guidelines for independent living on the basis of the trial funded by the Ministry of Labour and Social Policy.

In 2017, Friuli adopted a decision corresponding with the British Care Act of 2014, which started an evaluation process for the living conditions of persons with disabilities benefiting from residential and semi-residential services.<sup>41</sup>

<sup>38</sup> See <https://sus.regione.sardegna.it/sus/searchprocedure/details/420>.

<sup>39</sup> See <https://sus.regione.sardegna.it/sus/searchprocedure/details/409>.

<sup>40</sup> PO Umbria 2014-2020. Asse 2, priorità di investimento 9.1 - Obiettivo specifico RA 9.2, 'Incremento dell'occupabilità e della partecipazione al mercato del lavoro attraverso percorsi integrati e multidimensionali di inclusione attiva delle persone maggiormente vulnerabili', specific intervention, 'Potenziamento delle autonomie possibili. Sperimentazione di Vita Indipendente', <http://www.regione.umbria.it/sociale/vita-indipendente>.

<sup>41</sup> See Friuli-Venezia Giulia Regional Council, *LR 41/1996 Art. 1- Avvio di un percorso per la valutazione delle condizioni di vita delle persone con disabilità che usufruiscono dei servizi a regime semiresidenziale e residenziale*, Delibera No 370, 2017.

In 2015, Tuscany allocated EUR 9 million towards 761 independent living plans,<sup>42</sup> based on the ‘Vita indipendente’ (Living independently) project started in 2004, which was defined as regional policy in 2012, with specific guidelines.

### **Stable local projects**

The Centre for Autonomy in Rome<sup>43</sup> is a territorial service of ASL Roma 2, which, by means of a process of habilitation/rehabilitation, supports persons with serious and extremely serious disabilities in achieving the highest possible degree of self-sufficiency and self-determination.

The Centre for Autonomy of Umbria<sup>44</sup> was created in 2003. Its mission is to guarantee persons with disabilities a lead role in choices relating to them by means of personal and community empowerment tools.

The Centre for Studies on Rights and Independent Living of the University of Turin<sup>45</sup> supports the public service in the acquisition and development of support tools which give equal opportunities to adults with intellectual disabilities for their participation in social life, as well as promoting the protection of the right to choose where and with whom to live as established by the UN Convention.

### **Trial developmental participative local welfare projects**

L-inc (Laboratorio inclusione sociale disabilità<sup>46</sup> — the Social Inclusion Disability Laboratory) is a project that has started to address the difficulties faced by the welfare system in promoting actions of real social inclusion for all persons with disabilities, due to the persistence of the idea of disability as a chronic disease. L-inc was conceived as a laboratory that seeks to change the present costs of care and assistance for persons with disabilities by investing in independent living plans and in the activation of the community. L-inc involves some municipalities located in the northern districts of Milan. This project is promoted and implemented by a collection of various public and private associations, supported by the Fondazione Cariplo. The leading institution is the Lombardy branch of ANFFAS (Associazione Nazionale Famiglie di Persone con Disabilità Intellettiva e/o Relazionale — the National Association of Families of Persons with Intellectual and/or Relational Disabilities).

For some years now, the Habitat-Microaree programme,<sup>47</sup> promoted by the Trieste integrated university health authority, has been trialling innovative forms of territorial interventions, pursuing the ideas of rights promotion, combating institutionalisation and promoting community building, with a special focus on elderly persons, persons with disabilities and children living in areas dominated by public housing.

<sup>42</sup> Regione Toscana, *La disabilità in Toscana: Secondo rapporto - Anno 2016*, Osservatorio regionale sociale, Florence, 2017, p. 80; see <http://www.regione.toscana.it/osservatoriosocialeregionale/attivita/disabilita/le-pubblicazioni>.

<sup>43</sup> See <http://www.centroperlautonomia.it>.

<sup>44</sup> See <http://www.cpaonline.it>.

<sup>45</sup> See <https://www.centrostudiodivi.unito.it/progetti/officina-per-la-vita-indipendente>.

<sup>46</sup> See <http://www.laboratoriolinc.it/>.

<sup>47</sup> See <http://www.secondowelfare.it/governi-locali/habitat-microaree-unesperienza-di-welfare-di-comunita-a-trieste.html>.

## 9 Negative developments including examples of poor practice

### General Index

In the last three years, there has been an increasing number of reports concerning cases of limitation of freedom, mistreatment, abuse and violence towards persons with disabilities in residential and semi-residential facilities. There are no valid data to evaluate whether there has been a quantitative and/or qualitative increase in these incidents in comparison with previous periods. The most realistic hypothesis is that the monitoring action started by the National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty (5.3), along with increased investigative efforts on the part of district attorney's offices and the forces of law and order (in particular the NAS — Nuclei Carabinieri Antisofisticazione e Sanità) as well as the awareness campaign implemented by the FISH (8), revealed some previously hidden cases.<sup>48</sup> On the other hand, this monitoring activity could be lowering the social tolerance threshold to incidents of this sort. However, the number of cases and their distribution around the country hint at the existence of many situations of poor practice.

### A trend towards greater institutionalisation

Some recent acts and regional standards have provided for a significant increase in the number of beds in residential facilities, a signal of an expansion phase in the culture of institutionalisation, at least in some areas of the country (6.1).

One example of this trend is the regional government of Campania's Decreto Dirigenziale No 3 of 3 January 2019, which fixes the maximum capacity of residences for adults with disabilities (social assistance facilities, known as RSA) at 120 beds, divided into units of up to 20 beds.

### Medicalisation

In some regions, such as Lombardy, the welfare system is characterised by an explicit form of medicalisation, because all social policies are absorbed by regional legislation within the organisational health framework. Welfare is determined according to a medical model.

### Second action programme on disability (2017-19)

The second action programme on disability is an action plan, although in many respects it is not supported by policies. It contains the goal to achieve independent living, but this has not yet been implemented.

## 10 Recommendations

- Set out a national programme of deinstitutionalisation of persons with disabilities who live in segregated facilities;

<sup>48</sup> See <http://www.fishonlus.it/segregazione/category/abusi-e-violenze/> and <http://www.fishonlus.it/segregazione/category/segregazione/>.

- Structure a national monitoring and data collection system for collecting data on deinstitutionalisation and on the application of Article 19 of the CRPD;
- Restrict the organisation of policies and public expenditure to the safeguarding of the rights recognised under Article 19 of the CRPD;
- Develop and publicise mechanisms to allocate resources via the personalised budget system;
- Approve the national guidelines on the independent living plans by completely following the lines of the CRPD;
- Develop new assessment criteria for persons applying for independent living plans;
- Run information campaigns on independent living.