

# From institutions to community living: drivers and barriers of deinstitutionalisation

Case study report: Italy  
2018

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## INTRODUCTION

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of all persons with disabilities to live independently and be included in the community. Although the CRPD does not specifically mention deinstitutionalisation or address the transition process from institutional to community-based support, the Committee on the rights of persons with disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling Article 19.

Achieving deinstitutionalisation is not limited to phasing out certain living arrangements. It entails a profound shift from environments characterised by routine and an ‘institutional culture’, to support in the community where persons with disabilities exercise choice and control over their lives. Realising the right to live independently for persons with disabilities therefore stretches beyond closing institutions and requires development of a “range of services in the community [...], which would prevent the need for institutional care”.<sup>1</sup>

### FRA’s project on the right of persons with disabilities to live independently and be included in the community

To explore how the right to independent living is being fulfilled in the EU, the European Union Agency for Fundamental Rights (FRA) launched a multi-annual research project in 2014. The project incorporates three interrelated activities:

- Mapping types of institutional and community-based services for persons with disabilities in the 28 EU Member States.<sup>2</sup>
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD.<sup>3</sup>
- Conducting fieldwork research in five EU Member States – Bulgaria, Finland, Ireland, Italy and Slovakia – to better understand the drivers and barriers of deinstitutionalisation.

#### **From institutions to community living – commitments, funding and outcomes for people with disabilities**

In 2017, FRA published three reports exploring different aspects of the move from institutions towards independent living for persons with disabilities:

- [Part I: commitments and structures](#) highlights the obligations the EU and its Member States have committed to fulfil.
- [Part II: funding and budgeting](#) looks at how funding and budgeting structures can work to turn these commitments into reality.

<sup>1</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012), [Common European Guidelines on the Transition from Institutional to Community-based Care](#), p. 27.

<sup>2</sup> FRA (2017), [Summary overview of types of institutional and community-based services for persons with disabilities](#).

<sup>3</sup> Indicators are available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>. The indicators are based on the human rights model developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR). See: UN, OHCHR (2012), [Report on Human rights indicators: A Guide to Measurement and Implementation](#), HR/PUB/12/5.

- [Part III: outcomes for persons with disabilities](#) focuses on the independence and inclusion persons with disabilities experience in their daily lives.

The series complements the Agency's [human rights indicators on Article 19 of the CRPD](#).

Other relevant reports previously published by FRA include:

- [Choice and control: the right to independent living](#)
- [Involuntary placement and involuntary treatment of persons with mental health problems](#)

## Reality check? Local-level research on drivers and barriers of deinstitutionalisation

FRA's fieldwork aimed to give actors involved in the deinstitutionalisation process the opportunity to share their knowledge, experiences and perceptions of what drives the process forward, and the barriers that hold it back. It focused in particular on implementation of deinstitutionalisation at the local level, an area little covered by previous research.

The fieldwork was conducted by FRA's in-country research network, FRANET,<sup>4</sup> in five EU Member States that are at different stages of the deinstitutionalisation process. It was divided into two parts:

- In 2016, interviews and focus groups were conducted in each Member State with various stakeholders from the national and local level (municipalities or cities). The findings led to the identification of one case study locality in each Member State.
- In the first half of 2017, interviews and focus groups took place with a range of stakeholders in the selected case study locality.

This report incorporates findings from both parts of the fieldwork. More information on the research methodology is available in the Annex and the main report presenting the results of the research.<sup>5</sup>

### Why this report?

This report presents the findings of FRA's fieldwork research in Italy. Separate national reports capture the results from the four other fieldwork countries.<sup>6</sup>

The report starts by summarising the national context of deinstitutionalisation, including the legal and policy framework and funding, as well as how individuals involved in the deinstitutionalisation process understand some of the key terms and concepts. The rest of the report is structured according to five features emerging from the research as being essential for the deinstitutionalisation

<sup>4</sup> See: <http://fra.europa.eu/en/research/franet>.

<sup>5</sup> FRA (2018), *From institutions to community living for persons with disabilities: perspectives from the ground*, Luxembourg, Publications Office.

<sup>6</sup> The national case study reports are available at: <https://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies>.

process (see table 1). Firstly, the report presents the drivers and barriers of the deinstitutionalisation process in Italy, as experienced by participants in the research. It then looks at what participants believe is needed to make deinstitutionalisation a reality.

A comparative report bringing together the research findings from the five fieldwork countries was published in December 2018.<sup>7</sup>

**Table 1: Key features of a successful deinstitutionalisation process**

1.	Commitment to deinstitutionalisation
2.	Availability of guidance to support the deinstitutionalisation process
3.	Active cooperation between the people involved in the deinstitutionalisation process
4.	A change in attitudes towards persons with disabilities
5.	Practical organisation of the deinstitutionalisation process

Source: FRA, 2018

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<sup>7</sup> FRA (2018), [From institutions to community living for persons with disabilities: perspectives from the ground](#), Luxembourg, Publications Office.

## 1. CONTEXT OF DEINSTITUTIONALISATION

### 1.1 Legal and policy framework for deinstitutionalisation

#### 1.1.1 National legal and policy framework for deinstitutionalisation

In August 1977, Parliament adopted Law No. 517 on 'Norms on the evaluation of pupils and the abolishment of resit exams and other norms modifying the school system'.<sup>8</sup> This reform of the school system made it possible and compulsory to include children with any type of disability in mainstream schools during the mandatory education years, with individualised support from a dedicated teacher. In 1982, the role of this support teacher (*insegnante di sostegno*) was defined in Law No. 270 on the 'Revision of the regulation on the enrolment of school teachers for the pre-school, primary and secondary grades as well as the restructuring of personnel and the adoption of measures to avoid precariousness amongst personnel'.<sup>9</sup> In April 2017 – after the first stage of the fieldwork was completed – Decree No. 66 on 'Norms for the promotion of school inclusion of students with disabilities' reformed the procedures for inclusion in school, reinforcing the concept of inclusive education.

In May 1978, Parliament approved Law No. 180 on 'Voluntary and compulsory healthcare checks and treatments', the so-called Basaglia Law.<sup>10</sup> The law imposed the closure of psychiatric hospitals and regulated compulsory health treatment for people with psychosocial disabilities. The implementation of the law affirmed the principles of deinstitutionalisation (DI), as well as it highlighted mistreatment in psychiatric hospitals. These hospitals treated many people with mental health problems, as well as people with physical disabilities, in inappropriate conditions.

In February 1992, Parliament approved Law No. 104, 'Framework law for the assistance, social integration and rights of disabled people'.<sup>11</sup> Among others, this law made it compulsory to include children with disabilities in any type of educational setting with individualised support from a dedicated teacher. The law also enabled relatives of people with disabilities to obtain care leave from their employers. In addition, the law promoted professional training for people with disabilities to facilitate their integration into the labour market. On the whole, the law acknowledges the importance of economic autonomy and social integration of persons with disability through personal empowerment and the promotion of independence.

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<sup>8</sup> Legge n°. 517 del 4 agosto 1977, [Norme sulla valutazione degli alunni e sull'abolizione degli esami di riparazione nonché altre norme di modifica dell'ordinamento scolastico.](#)

<sup>9</sup> Legge n°. 270 del 20 maggio 1982, [Revisione della disciplina del reclutamento del personale docente della scuola materna, elementare, secondaria ed artistica, ristrutturazione degli organici, adozione di misure idonee ad evitare la formazione di precariato e sistemazione del personale precario esistente.](#)

<sup>10</sup> Legge n°. 180 del 13 maggio 1978, [Accertamenti e trattamenti sanitari volontari e obbligatori.](#)

<sup>11</sup> Legge n°. 104 del 5 febbraio 1992, [Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate.](#)

In March 1999, Parliament approved Law No. 68 on 'Dispositions on the right to work for persons with disabilities'.<sup>12</sup> This law provides a duty for public and private employers with more than 15 employees to hire persons with disabilities. The law also stipulates that public and private employers are required to secure the jobs of employees who acquire a disability as a result of their employment, whether because of an accident or of sickness.

In November 2000, Parliament approved Law No. 328, 'Framework law for the implementation of the integrated system of social interventions and services'.<sup>13</sup> This law establishes the possibility to design individual projects to promote the social inclusion of all people with disabilities.

With the entry into force of Law No. 18 of 3 March 2009, Italy ratified the CRPD and instituted the National observatory on the conditions of people with disabilities (hereafter, the Observatory), which includes disabled persons' organisations (DPOs).<sup>14</sup> The Observatory is responsible to draft the biennial programme of action to promote the rights and the integration of persons with disabilities.

The first biennial programme was adopted by Presidential decree on 4 October 2013, following a proposal by the Ministry of Labour and Social Policies (MLPS). This programme included seven areas of intervention, with the third one relating specifically to policies, services and organisation models for independent living and inclusion in society. "The general process of deinstitutionalisation is favoured [under this line of intervention] on the one hand, and the development of projects of 'living in autonomy' involving small groups of people, on the other."<sup>15</sup> Still in October 2013, the MLPS published guidelines on funding for experimental projects to support independent living and inclusion in society of persons with disabilities.<sup>16</sup> The second biennial programme was adopted in October 2017 (after the fieldwork for this research was completed), with the first line of action concerning preventing isolation and segregation and promoting deinstitutionalisation.<sup>17</sup> The MLPS issued new guidelines for the funding of independent living projects in December 2017.<sup>18</sup>

Parliament adopted Law No. 112 on 'Dispositions concerning the assistance to persons with severe disabilities deprived of family support' – the so-called 'After Us' law – in June 2016, after the national level interviews were conducted for this research.<sup>19</sup> This law aims to foster the wellbeing, social inclusion and autonomy of persons with disabilities. The goal of the legislation is to guarantee the highest

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<sup>12</sup> Legge n°. 68 del 12 marzo 1999, [Norme per il diritto al lavoro dei disabili](#).

<sup>13</sup> Legge n°. 328 dell'8 Novembre 2000, [Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali](#).

<sup>14</sup> Legge n°. 18 del 3 marzo 2009, [Ratifica ed esecuzione della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità, con Protocollo opzionale, fatta a New York il 13 dicembre 2006 e istituzione dell'Osservatorio nazionale sulla condizione delle persone con disabilità](#).

<sup>15</sup> Decreto del Presidente della Repubblica, 4 ottobre 2013, [Adozione del programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità](#).

<sup>16</sup> Ministero del lavoro e delle politiche sociali (2013), [Linee guida per la presentazione di progetti sperimentali in materia di vita indipendente ed inclusione nella società delle persone con disabilità](#).

<sup>17</sup> Decreto del Presidente della Repubblica, 12 ottobre 2017, [Adozione del secondo programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità](#).

<sup>18</sup> Ministero del lavoro e delle politiche sociali (2017), [Linee guida per la presentazione di progetti in materia di vita indipendente ed inclusione nella società delle persone con disabilità](#).

<sup>19</sup> Legge n°. 112 del 22 giugno 2016 [Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno famigliare](#).

autonomy and independence to persons with disabilities with their active involvement, allowing them, for example, to continue living in their own homes or in facilities managed by associations, avoiding a support approach based on traditional healthcare assistance. This law also covers those who still have their parents but who no longer receive their support.

The law's implementation decree fosters the creation of facilities for no more than 10 persons with disabilities, entailing compulsory participation in forms of DI. The law introduces a specific fund, as well as the possibility to benefit from resources provided by private entities and associations. As stipulated in Article 1, the law provides for "the facilitation of funding by private parties, the stipulation of insurance policies and the establishment of trusts [...] also in favour of third sector organisations and of people with serious disabilities".

The fund is financed by the regions, local authorities and third-sector entities. Its resources amounted to 90 million EUR in 2016, 38.3 million EUR in 2017 and 56.1 million EUR in 2018. A manager of a social cooperative (that is, a non-profit community organisation bringing together providers and beneficiaries of a social service) expressed doubts, shared by DPOs, about the implementation of the law:

*"I consider the financial provisions [of the law] are poor, if not very poor. Five-hundred million in Italy for "After Us" is enough to solve things in two regions." (Employee of a community-based service)*

Nevertheless, the role of the law in promoting DI has been welcomed by DPOs, although some highlighted that its implementation relies on private funding if public authorities are unable to provide adequate financial resources.<sup>20</sup>

### 1.1.2 Local legal and policy framework for deinstitutionalisation

Within the national framework, both regional and local authorities have competence in policy implementation. However, disputes may occur or interventions can overlap due to a lack of coordination. The main cause is not related to the specific policy issue (disability) but to the complex governance structure of the Italian state, which is regulated by Chapter 5 of the Italian Constitution. It states that local government is organised around four scales: municipalities, provinces, regions, and the state. Municipalities and provinces are administrative bodies. Typically, administrative tasks are the responsibility of municipalities, but they also manage to a great extent policies and services implemented at local level, such as waste, public transport, social assistance, local police, school buildings, etc. Inter-municipal coordination and planning is up to the provinces, which manage the services that cannot be managed by single municipalities on their own.

Regions are the only sub-national government that, according to the Constitution, have legislative power (like the State). This power covers a wide set of matters. Power is divided into two types: concurring and exclusive. The first one concerns

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<sup>20</sup> Redazione di disabili.com, ["Quella sul dopo di noi è una buona legge?"](#), *Disabili.com*.

all the matters in which regional legislative power is subordinate to state framework laws. Among them are the fields of economy and production (transport and communication, energy, territorial management, research & development) and welfare measures (health, protection and safety of labour, education). Exception are made for social security (solely up to the State) and social assistance (solely up to the Regions). The second pertains matters in which regions' legislative power is not constrained by the state – constitutional, EU and international rules and duties excepted. Regions can legislate autonomously on all matters which are not explicitly the competence of the State or concurring.

The State has sole legislative power over the definition of minimum standards of measures concerning civil and social rights, on the principles of education and on the functions bestowed to sub-national authorities (municipalities, provinces, metropolitan areas). These competences became crucial after the constitutional reform of 2001: they played an important role in the delicate relationship between decentralisation and universal, countrywide citizenship rights. This balance is also fundamental because of the long-lasting economic and social divide between different regions.

The different layers of competencies at different governance levels contribute to a differentiation in the provision of community-based services and the degree to which DI is achieved in localities. This is because different authorities at regional and local level may be more or less committed to promoting the transition and invest more or less resources in terms of budget, personnel and professionalisation. However, the recent adoption of the National Guidelines on Independent Living 2017 which, among other things, encourage the involvement of DPOs, clearly define the role of the personal assistant, and provide rules for monitoring and evaluation should help to harmonise approaches across localities.<sup>21</sup>

The Tuscany Region has been among the most advanced in the implementation of DI. It has promoted the implementation of home-based care and directly financed independent living projects since the year 2004, through the *Independent Living Project*. At that time, a pilot project in five districts started and, subsequently in 2009, was extended to all 34 regional health-social districts. The policy was made permanent in 2012. Since 2014, the Tuscany Region has devoted 9 million EUR every year to fund projects for independent living. The overall average number of beneficiaries is 760 persons, with an average age of 46, and who receive an average monthly contribution of 1,000 EUR. Currently the initiative is regulated by the Regional Committee resolution 'Strategic guidelines for projecting independent living paths No.1329' issued on 29 December 2015.<sup>22</sup>

Tuscany has been at the forefront of pilot independent living and DI projects since 2009. These later inspired the 'After Us' legislation. The regional commitment to enhancing the supply of community based services was formalised by Decision

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<sup>21</sup> The [Guidelines](#) were issued on 27 December 2017 and apply to the financing of regional independent living projects.

<sup>22</sup> Delibera n°. 1329 29 dicembre 2015, [Linee di indirizzo per la progettazione dei percorsi per la Vita Indipendente](#).

No. 11 of the Regional Committee of 7 April 2015, which provides the Guidelines for systemic actions and strategies for the improvement of socio-health services for policies in the field of disability.<sup>23</sup>

Regional reform of the overall organisation of the two pivotal policy areas of healthcare and social care, enacted by the Regional Law No. 84 of 28 December 2015 on 'Reorganisation of the institutional and organisational structure of the healthcare regional system', has further enhanced the provision of community-based services and home-based assistance for people with disabilities.<sup>24</sup> The reforms provide for: integrated paths of assistance; independent living; 'After Us' projects; information points on disability; a regional information and documentation centre; the promotion of exchanges of good practices.<sup>25</sup>

The healthcare system and the system of social policies are integrated in the case study locality, as in the whole Tuscany Region. Healthcare and social assistance services are coordinated by so-called High Integration Units (*Unità di alta integrazione*) to ensure that people with disabilities can access services provided in the locality, according to personalised plans of assistance.

There is a policy tradition and a cultural context favourable to DI in the case study locality. The cultural legacy of the Basaglia reform has played a significant role in this. In the locality, there is a foundation inspired by the principles behind the Basaglia reform, which is committed to the democratisation of the national health service. It organises training opportunities for professionals and awareness-raising initiatives for local policymakers and this has improved the attitude of many policy actors in the area.

The commitment of policy makers in the locality gave an impetus to the DI process during the first decade of 2000. Currently, professionals (doctors and carers) working in social cooperatives and in large institutions are very active in promoting the DI process in collaboration with each other.

## 1.2 Organisation of deinstitutionalisation

The effective implementation of the second National Plan on disability is hindered by the complexity of the governance around disability in Italy. This complexity leads to the overlapping of responsibility and conflicts over competence among actors and governance levels. It also leads more generally to a heterogeneous provision of benefits and services across the country. At the central level, the Ministry of Health and the MLPS share responsibilities with distinct roles which are not always clearly defined.

The Ministry of Health is responsible for the national health system together with the regions, and provides healthcare to people with disabilities. The coordination

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<sup>23</sup> Delibera della Giunta Regionale n°. 11 del 7 aprile 2015, [Azioni di sistema e strategie per il miglioramento dei servizi socio sanitari nell'ambito delle politiche per la disabilità](#).

<sup>24</sup> Legge regionale n.° 84 del 28 dicembre 2015, [Riordino dell'assetto istituzionale e organizzativo del sistema sanitaria regionale](#).

<sup>25</sup> This indicates personal, tailored, long-lasting interventions providing different types of support. They might include: healthcare, social assistance, labour and social inclusion activities.

between central and regional competences takes place by means of the Essential Levels of Assistance (*Livelli Essenziali di Assistenza, LEA*), which are minimum standards for healthcare services that have to be provided to all citizens for free or with the payment of the minimum healthcare fees. These standards are established by the national legislator and implemented and guaranteed at the regional and local levels according to regional legislation. An LEA for DI has not yet been defined, and so the implementation of initiatives in this area is left to the regional level and its local articulation (health districts).<sup>26</sup>

The MLPS plays a monitoring and national coordination role of regional policies in the design and provision of social assistance services. The authority and the actual organisation of the services is mostly up to municipalities, under the coordination of the regions. Municipalities often delegate their competence in social services provision to other intermediate authorities, like associations of municipalities, provinces, and health districts, as they do not have the organisational and financial capacity to provide benefits and services.

In addition, a national coordination tool named Essential Levels of Provisions (*Livelli Essenziali delle Prestazioni, LEP*), enables the national legislator to establish minimum standards and criteria for the provision of social assistance. Nonetheless, the LEP as a coordinating tool does not have the same enforcing strength as in the health system. The national level establishes that a service has to be provided so the regions and the local authorities have to design policies to provide the service. However, the national level can only tell regions that the service has to be provided and provide funding for specific initiatives, but is not in a position to push regions to enforce it.

As to the implementation of social assistance which might also support DI or independent living, the involvement of regions varies as the law regulating it (Law No. 328 of 8 November 2000, Framework law on the implementation of the integrated system of social interventions and services) allows for different types of organisation.<sup>27</sup>

Another relevant public institution is the Unit for Disability within the MLPS. It coordinates the policies implemented at national level (the National Plan) on disability including DI and independent living. The unit, which is active in promoting DI, cooperates with other units in the MLPS, such as those in charge of policies for children and the labour market. It can contribute to the promotion and implementation of DI thanks to the distribution of funds for independent living measures through calls for proposal for projects at regional level.

Finally, an important role in the provision of services at the local level is played by social cooperatives. They are private actors that participate in calls for tender organised by the public actors for the implementation of services in the area of social care, including disability, and so participate in the implementation of DI.

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<sup>26</sup> This is also acknowledged in the Guidelines for Independent Living issued by the Ministry of Labour and Social Policy on 27 December 2017 (see for instance the guideline n.° 16) and that apply to the newly nationally financed projects for Independent Living.

<sup>27</sup> Legge n.° 328 dell'8 novembre 2000, [Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali](#).

Social cooperatives sometimes actively take part in the DI process as they might be connected to NGOs for people with disabilities – including DPOs – or associations of relatives of people with disabilities. In these cases, social cooperatives are the means by which these stakeholders try to pursue their aims. These might include DI, but associations do not have similar perspectives and sometimes they radically diverge and may even oppose DI. In these cases, social cooperatives not only rely on public funding but they also look for additional private resources from foundations, banks and private companies to support activities fostering DI. This complex and rich network leads to the multiplication of services offered in the locality and relies on committed people who can influence political decisions and potentially enhance the DI process.

The overlap in different responsibilities at different governance levels makes the implementation of the DI process very complex. For instance, the provision of home-based care services is not uniformly available across the country. This relates to the fact that social services are provided by municipalities and so their provision depends on local conditions, including budget requirements and local policy priorities.

*“Services are unable to cope with full deinstitutionalisation.”* (National official)

People with disabilities, NGOs, families, and service providers participating in this research have different perceptions of the roles played by authorities at national, regional, and local levels. National level stakeholders see the Welfare and Health Ministries, as well as regional authorities, as responsible for the implementation of DI. Stakeholders at local level do not perceive national authorities as an interlocutor in the implementation of the DI process. Local authorities are perceived as the most important interlocutors by people with disabilities, families and staff of community-based services, who regularly cooperate with local authorities. People with disabilities perceive assistants, educators and other professionals who support them in the transition from institutions to communities or shared homes, and who currently support them in their daily lives, as the most important reference point. A wider and critical perspective is more likely to be found among people with physical impairments.

Staff of community-based services and of institutions committed to DI underline the importance of being aware of the role these organisations can play in bringing together persons with disabilities and the community.

### 1.3 Funding for the deinstitutionalisation process

The DI process is funded through a variety of financial resources. There is not a common framework at either the legislative or administrative level, and so it is difficult to determine the overall amount of resources the DI process can count on each year. Moreover, the financial crisis and austerity policies have caused a general reduction in public welfare spending at both the central and regional levels, including financing of health policies incorporating independent living and DI measures. In this scenario, it is unlikely that additional public resources will be destined for the implementation of DI.

The available national funds include:

- National health system funds for socio-health assistance;
- State funds for health and social policies;
- National Fund for Non-self-sufficiency (*Fondo nazionale per le non auto-sufficienze*); a specific part of this fund is provided by the MLSP to independent living policies;
- Stability Law 2016, which financed the implementation of Law No. 134 of 18 August 2015 concerning 'Dispositions on diagnosis and healing of persons with impairments belonging to the autism spectrum and on the support to their families';<sup>28</sup>
- National fund for Social Policies allocated by the MLSP (*Fondo Nazionale per le Politiche Sociali*);
- National Fund for Rare Diseases provides funding from the national health system for care of people affected by specific diseases (*Fondo nazionale per le malattie rare*);
- Funds introduced by the 'After Us' Law.

National funds are distributed to the regions and, consequently, to health districts and local administrations (municipalities). These are used to foster health assistance projects destined for people with disabilities; social assistance and social services. At the local level, funds are also available from regional sources and local funds provided by municipalities.

One national government official reflected on the efficiency of allocating funds according to specific projects at national level:

*"That's the way it should be, because the mosaic is very complex. [...]. Taken together, all these [funding] components certainly contribute to supporting measures to foster [deinstitutionalisation]."* (National official)

The overall amount of financial resources destined to people with disabilities at national level is very difficult to calculate by analysing the allocations in the national budget. In addition, the provision of socio-health assistance by the national health system requires individuals with disabilities to apply for assistance. This varies depending on the region. Participants highlighted an overall lack of resources at national level. This should be considered in light of the wider picture of the critical economic and financial situation Italy continues to face.

Since 2015, the Tuscany Region allocates 9 million EUR a year to support independent living. It also allocates funds to the Regional Fund for non-self-sufficient people and to specific interventions for adults with disabilities (below the age of 65), among the 34 health districts. This contribution amounts to 3.9 million EUR per year. These financial resources are managed by the Multidisciplinary Assessment Units (*Unità di Valutazione Multidisciplinare, UVM*), operating at the district level.

Additionally, the region allocates:

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<sup>28</sup> Legge , n°. 134 del 18 agosto 2015, [\*Disposizioni in materia di diagnosi, cura e abilitazione delle persone con disturbi dello spettro autistico e di assistenza alle famiglie.\*](#)

- Around 10 million EUR provided by the MLSP to the districts/companies of health of Tuscany with the aim to meet the demand for home-based care for people with severe disabilities.<sup>29</sup> With these contributions, relatives of persons with severe disabilities are able to hire a caregiver to support their assistance needs.
- 3.8 million EUR through the regional healthcare system with the purpose of supporting the demand for home-based care for persons with Amyotrophic lateral sclerosis (ALS). These resources aim to finance projects that have been already implemented, or that are going to be implemented.<sup>30</sup>

In the system of 'health societies' (*Società della Salute*) developed by the Tuscany Region, financial resources of the healthcare sector (under the responsibility of the region) and the social policy sector (under the responsibility of the municipalities) are integrated to reduce legislative and financial fragmentation.<sup>31</sup>

These are public non-profit bodies based on the voluntary participation of municipalities in the same district-area and the local ASL to share the management of some local social and health activities. Each health society includes the following bodies:

- the participation committee, which includes representative members of the local community, service users, and associations, as long as they are not service-providers;
- the third-sector council, which gathers the voluntary and third-sector associations which offer services;
- the health Agorà, which organises two annual meetings open to the local population aimed at fostering a direct exchange of needs, opinions and criticisms.

The integration enabled by the health societies is a crucial element in responding to the needs expressed by persons with disabilities. This integration has not been completed in all districts and consequently the system is not homogeneous. This leads to difficult situations in the region, for example problems in meeting all the needs of persons with disabilities; this is not, however, the case in the chosen locality.

At the individual level, allowances are provided by the National Institute for Social Security (*Istituto Nazionale della Previdenza Sociale*, INPS) to people with disabilities who are unable to work. There are different types of allowance provided to people with specific impairments. This policy is in force across the country.

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<sup>29</sup> According to Decision No. 342 of 18 April 2016 on the National Fund for non-self-sufficiency in case of severe disability. Approval of guidelines concerning the provision of contributions and distribution of resources ([Delibera n°. 342 del 18 aprile 2016, Fondo Nazionale per le Non Autosufficienze per le gravissime disabilità. Approvazione delle Linee di indirizzo per l'erogazione dei contributi e assegnazione risorse](#)).

<sup>30</sup> See: [www.toscana-notizie.it/-/la-toscana-per-disabilita-e-non-autosufficienza-le-ultime-misure-adottate](http://www.toscana-notizie.it/-/la-toscana-per-disabilita-e-non-autosufficienza-le-ultime-misure-adottate).

<sup>31</sup> More information is available at: [www.regione.toscana.it/sst/organizzazione/societa-della-salute](http://www.regione.toscana.it/sst/organizzazione/societa-della-salute).

#### 1.4 The status of deinstitutionalisation

There are several positive experiences of projects and services scattered across Italy. They mirror the most advanced theoretical perspectives on DI and are rooted in the tradition of the Basaglia law. However, the fragmented governance of the healthcare and the social care systems hinders uniform implementation of the second National Plan for disability, including relevant inputs on DI.

The second national plan encourages DI and indicates what services are needed to properly achieve DI. It also promotes independent living. However, the national level lacks the strength to implement it, as the governance system attributes responsibility for the implementation of policies to regions and local authorities. It leaves room for reliance on the good will of policymakers and stakeholders at regional and local level.

The locality chosen is at the forefront of DI in Italy. It cannot be considered as typical but is rather a good practice example. This is due to:

- the cultural environment, which is close to the Basaglia movement;
- the integrated, effective and efficient management of social policies and health services in the field of disability by the Tuscany Region;
- the development of advanced social services in the region, using innovative tools – such as home automation experimentations, independent living projects and labour market integration strategies – thanks to the proactive work of social cooperatives linked to the Basaglia movement;
- the presence of associations of people with disabilities and their families who actively promote DI;
- regional networking, which allows effective cooperation between all the local stakeholders committed or involved in the DI process, including public authorities, associations, NGOs, social cooperatives and private companies.

The DI process seems to be part of a cultural, political and social attitude in the case study locality. There is a general consensus about this among participants in the research, whether they are staff or managers of cooperatives or institutions or family members. One staff member expressed well how much the work of the community has brought about significant integration in the locality:

*“Here it was the community to do it, here we had deinstitutionalisation. It was born from a political and social agreement, an alliance between citizens and services.”* (Employee of a community-based services)

## 2. UNDERSTANDING OF DEINSTITUTIONALISATION AND INDEPENDENT LIVING

### 2.1 Key terms and concepts

A common understanding of DI emerges among participants in the research. All agree that DI is a process entailing, in the long term, the reduction of the size of institutions until they are completely closed. This allows more people with disabilities living in institutions to access different forms of independent living, such as autonomous flats, assisted apartments and family shelters, etc. These options are, in participants' view, subject to the needs of the individual, depending on the degree of achieved and potential self-determination and skills, which should be assessed with the help of clinical experts.

For this reason, DI is both an individual – transition from the institution to other living solutions – and a policy process – closing institutions and transitioning towards small-scale facilities like independent living apartments and group homes designed for persons with disabilities for whom independent living projects face implementation difficulties because of the high intensity of support and care they need.

Participants share the view that DI is a process closely connected to citizenship. Citizenship includes welfare rights including: affordable and accessible housing, labour, and opportunities to be included in the local community, as expressed by an employee of a community-based service:

*“Autonomy goes beyond [disability] services, because active employment, housing, social and integration policies [are found] where one lives, not within services [...] The community has to grow in terms of opportunities it can offer [...] for different needs [...] I think we should talk about citizenship rights: I mean, in the end, the people we support on this pathway are ultimately asking for the right to health, the right to housing, the right to work, the right to love, the right to a family, the rights to citizenship.”*  
(Employee of a community-based service)

This perspective on the DI process is shared with minimal nuances by all respondent groups involved in this research, including: representatives of institutions, staff and families who have long wished for their children to become full citizens.

For participants in this research, 'independent living' is considered a broad concept concerning all the different forms of autonomous living which may or may not require external support provided by the available services and specifically trained staff. Independent living concerns the person's whole life and entails a comprehensive approach. It includes working, housing issues and participation in social life. It is possible for persons with physical and intellectual disabilities, including those with severe impairments, as long as they are adequately supported.

As regards a definition of institutions, there is a lesser degree of agreement among participants. Employees of social cooperatives perceive institutions as facilities that limit the individual choice. However, employees of institutional services think this limit is necessary to protect people with disabilities from their fears when learning how to manage their autonomy. This applies to modern institutions that have started along the path to DI. In the other institutions where this path to DI is not implemented, individuals do not have the opportunity to make choices, because everything is ready, easier and available and they are not offered any opportunities to live their life, with the result that they often lose their identities.

Among families, the perception of institutions is more differentiated. Many share the interpretation of a place that does not enhance autonomy. But for some others – especially those who were not able to adequately support their relatives because of the severity of their impairment, which was difficult to cope with – institutions have a positive connotation. They are places of containment, in which their relatives can feel secure and protected. For this group of families, it is possible to start independent living only from an institutional setting, since the process to achieve independence needs to be gradual and under the supervision of professionals.

Community-based services are considered by all participants as crucial to achieving autonomy and independent living. They include not only home services but also community facilities, including also labour and social activities. For all participants, community-based services are first of all a possibility which can be provided to any person who wants to determine him/herself and express his/her choices and desires, no matter what they are. Staff members of both community-based services and some of the institutions focus their work on the achievement of sufficient autonomy in persons with disabilities to make use of community-based services, and promote relationships with others, social inclusion and labour market integration.

Representatives of local public authorities, representatives of institutions and/or community-based services and persons with disabilities consider community-based services as pivotal for effective implementation of DI. Representatives of local public authorities and representatives of institutions and/or community-based services agree that the adequate provision of community-based services allows people with disabilities to live autonomously in the community so they might have opportunities to meet other people and improve their social life to prevent isolation, which is one of the main negative effect of living in institutions.

Persons with disabilities see the provision of community-based services positively as they allow them to enjoy a more autonomous life. They see community-based services as synonymous with sociality and the end of their experiences in institutions.

The institutions that are involved in the DI process do exactly this. They implement activities and opportunities outside the institution, for example in the case study locality, and the institution itself enhances the creation of social cooperatives to

involve people with disabilities living in institutions in the labour market and develops leisure activities and services to foster their social inclusion.

Participants from local authorities agreed that different types and degrees of impairments correspond to different and specific needs which have to be considered and adequately addressed by designing tailored interventions. A minority of these participants clearly stated that serious impairments and forms of disabilities, including those related to degenerative diseases, are not compatible with independent living and the DI process in general. They believed that this is because they require continuous assistance and healthcare that can be provided only in institutions, at least at the moment, wherein those receiving care are attended to 24 hours a day. This point of view was supported by a representative of social services, who said:

*“It is impossible to do this for everyone, I mean there are some situations for whom the institutional or semi-residential solution remains the more appropriate one.”* (Local official)

Participants from institutional and community-based services have a different position. They agree that each type and level of impairment is different and entails a variety of needs which require an adequate response. This adequate response can be provided by community-based services which are more flexible and can be tailored according to the individual's choices and needs. Staff and management of community-based services and institutions said that some forms of DI can be implemented even in the most cases of severe intellectual disability. A professional from an institution supported this perspective:

*“Persons with severe disabilities need to have an ad hoc setting, because it is not necessarily the case that a person who can't talk or accomplish tasks [...] cannot take advantage of the benefits of a life in a smaller facility, a family shelter, an apartment.”* (Employee of an institutional service)

Conversely, for people with motor or sensory disabilities, there is a wide consensus across categories: the DI process can be considered easier.

## 2.2 Impact of deinstitutionalisation

Generally speaking, the impact of the DI process is perceived by all participants as positive.

Families reacted positively to the DI process. After initial concerns, due to the difficulties in seeing their relatives outside the institution with no 'protection', they clearly saw the skills and abilities that their relatives could express and they actively took part in this new reality. However, there are difficulties in promoting labour inclusion for people with disabilities, especially those with intellectual impairments, which in some cases have a discouraging effect on families.

Staff of community-based services and institutions agree that the DI process is relevant and has a positive impact not only on the individuals but also on the

community because it fosters solidarity, inclusion and the attention towards other people. The impact is on the whole considered positive. In a locality which received and supported the family-shelter group, the clients of the pizzeria and local cafés all appreciated and included these people without particular difficulties. What seems particularly important is the presence of a social worker who helps in overcoming fear, in fostering mutual knowledge and in including people belonging to different realities. Knowledge and overcoming initial reluctance are crucial tools to achieve social inclusion, as a person working at a restaurant where persons with intellectual disabilities work mentioned:

*“Going back to relationships with customers, the interesting thing is that sometimes regular customers highlight: ‘the boy got better since we first came here, the first time he had a crisis and now he seems more professional’.”* (Member employee of a community-based service)

The personal stories of individuals who spent a long time in institutions show a history of important achievements, autonomy and new skills. A good example is that of ‘Adele’ (name is a pseudonym) (see box in section 3.1.2). She has a moderate intellectual disability and has moved from one institution to another since her birth. She underwent a long DI process with activities which were organised at the institution to foster her skills and promote autonomy. As a result, now she lives in a flat with a friend

Another participant with disabilities describes how, once out of the institution, he finally achieved complete self-determination (see also the box ‘Romeo’s story’ in section 4.3).

*“I have a life...having a house feels like I won the lottery.”* (Person with a disability)

For everyone, the institution contributed to creating autonomous conditions and support to achieve independent living.

### 3. ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS

Essential features	Key drivers	Key barriers
<b>3.1 Commitment to deinstitutionalisation</b>	3.1.1 Legislation 3.1.2 Commitment and support of the institution's professional staff to the DI process 3.1.3 Labour market integration	3.1.4 Lack of dynamicity and commitment of public authorities and legislation 3.1.5 Financial and political power of institutions 3.1.6 Hindrances to labour market integration
<b>3.2 Availability of guidance to support the deinstitutionalisation process</b>	3.2.1 National Plan 3.2.2 Exchange of good practices, knowledge and information 3.2.3 Training targeting people who work on the DI process	3.2.4 Re-Training people in order to overcome institutional culture
<b>3.3 Active cooperation between the people involved in the deinstitutionalisation process</b>	3.3.1 Cooperation between the public and private sectors	3.3.2 Lack of consistency and clarity of competences' distribution among the different levels of governance and difficulty in resources allocation
<b>3.4 A change in attitudes towards persons with disabilities</b>	3.4.1 Political cultural change 3.4.2 Everyday-life cultural change 3.4.3 Changing attitude of younger families of children with disabilities	3.4.4 Families' assistance culture 3.4.5 Social stigma concerning disability 3.4.6 Learned helplessness
<b>3.5 Practical organisation of the deinstitutionalisation process</b>	3.5.1 Focus on community-based services rather than on residential institutions 3.5.2 Multidimensional approach to disability combining social and healthcare assistance 3.5.3 Levels of assistance tailored to the needs of people with disabilities 3.5.4 Support to families of persons with disabilities	3.5.5 Lack of financial resources 3.5.6 Short-term planning

### 3.1 Commitment to deinstitutionalisation

#### 3.1.1 Driver 1: Legislation

The framework of legislation on DI in Italy is extremely varied and covers different aspects of inclusion and integration for people with disabilities. This view is shared by most research participants, who consider the existing laws to be drivers of DI, even if they think there is still room for improvement. This is because measures that allow or even favour institutionalisation are still in force and funding for institutionalisation is available.

Despite the ambiguities in the national legislative framework, progress has been achieved for DI in the area of disability. However, many participants in the research ask for a more open and courageous position from the side of public authorities at the national level, as was the case with the closure of psychiatric hospitals following the Basaglia Law. However, it is not easy for policymakers to take a strong political position, either because of the economic interests of private actors (institutions provide jobs) or because families are still not convinced that autonomous living could be a good solution for their relatives.

More specifically, participants from regional and local authorities and managers of institutional and community-based services mentioned the 'After Us' law, which aims to regulate assistance for persons with disabilities who do not get support from their families. The 'After Us' legislation establishes a specific fund for the provision of assistance and support to people with disabilities without family help, as well as facilities for individuals, organisations and associations which are committed to the allocation of resources to people with disabilities. The fund is used by regions, local authorities and organisations belonging to the third sector. It will benefit from a three-year budget of 90 million EUR for 2016, 38.3 million EUR for 2017 and 56.1 million EUR for 2018.

The fund's resources can be used to create "innovative housing programs and interventions" (Article 4) such as co-housing that enhances the independence of people with disabilities in dwellings or groups. These are apartments that reproduce the housing and relational conditions of the family home. This fund will also support projects aimed at fostering the autonomy of people with disabilities deprived of assistance.

Participants particularly stressed the importance of the foundation-model. Foundations manage the resources destined to the DI process and gather all the local stakeholders – such as local authorities, social cooperatives, families associations, private companies and banks – together to develop innovative forms of DI, including co-housing opportunities. Managers of social cooperatives, institutions and public authorities mostly support this model, compared to staff members in general.

Managers of institutions or social cooperatives highlighted the 'After Us' Law not only for its impact on the 'DI culture' by fostering the closure of big institutions; but also for the possibility it entails for direct funding to the DI process. In addition, they also highlighted the importance of the trust model, which is the possibility

for families to leave their inheritance to institutions and social cooperatives to guarantee adequate care to their relatives in the future.

### 3.1.2 Driver 2: Commitment and support of the institution's professional staff to the DI process

Professionals involved in the DI process are the main protagonists of its implementation and the first contact point for people with disabilities. As such, a relevant driver concerns the changes that the DI process entails for staff operating in this field and the promotion of a radical paradigm change in the professional approach.

This driver was stressed by different respondent groups in this research, especially by those professionals who are aware of the importance of the cultural changes going on around them. Persons with disabilities also recognised their value and importance:

*"In the apartment group [...] they helped me in the institution, they hosted me, they supported me through the difficulties [that] we met even in a normal life[.] But help, you also have to accept it. Being aware that you need help, we can say, is one of the first steps forward that someone can take."* (Person with a disability)

Professionals are at the core of this path. They have to face new challenges in their work concerning autonomy and the development of people with disabilities to support them in this difficult path. As the representative of a family association describes:

*"Staff is far more forward-looking than it used to be. It considers the future more, compared even to a family which is more fearful, or to public authorities which don't want to see it because it's not very politically beneficial. Employees have a different approach and many instruments it can apply and dare take more risk."* (Representative of a local non-governmental organisation)

#### **PERSONAL STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?**

##### **Adele**

My story is not easy to tell. I was born in 1957, I don't know why my mother abandoned me, maybe she was poor or maybe she didn't want me. As soon as I was born, I was sent to a catholic institution. I don't remember much of that period, I spent time with the girls, with the other girls. Before going to sleep, we used to pray and chat a bit, but when the nun told us to be quiet we used to fall asleep. Nonetheless, I liked living there, it was a place I liked.

Later on, I was sent to another institution nearby, there were so many of us in there: 180 boys and girls from every part of Italy. Then I moved to another institution, I don't know why, it was 1975 and I was 18, so it might be because

I turned of age. I used to like this institution too and this is where I met the Rossi's, a family I used to visit every now and then: even today I spend Christmas with them and the holidays in general.

When I turned 21, I went to live with Serena and I used to like it a lot. I liked it there because I could do some gardening; I watered the plants and cleaned. I was still the same but every now and then I was willing to do these things. I was so nervous, I felt bad, I can't tell what occasionally happened to me but I started doing things that concerned the others. Once I did something wrong without realising it; Serena got really angry at me because she was worried, she was in charge of me. One day Serena brought me to this institution. As soon as I got there I realised I didn't like it at all, I didn't want to move there; then I met Luisa, one of the people who worked there and I decided to stay.

Everything was different in there, we used to do so many things, really a lot and then the trips outside too, we never did this with the nuns. We visited many places, we even caught the plane. Yes, I did so many things there.

Then one day, I was called and they told me that I could go living in a flat and that I could choose whom to share the flat with and I discarded so many names and then I said yes, and my friend Francesca said yes, that it was fine for her too, and we moved. When we saw it for the first time, the flat was empty but cool, then we chose the colour of the kitchen and I chose a light blue. There was a light blue kitchen just as I wanted it to be and all the other furnishings.

Now I live in this house with Francesca, in the morning we wake up and have a coffee. Before that we tidy our beds, then we get ready and go out and we go by bus to the pizzeria, because I work there. I'm in charge of cleaning and doing some work in the kitchen, too: I wash the salad and cut it before putting it on the plates. Then at about 4.30 p.m. we come back. The bus brings us back home and, as soon as I arrive, I have a shower and I relax watching TV and then, if necessary, I do some shopping or I go out for a coffee at the cafe.

On Saturday and Sunday I visit the Rossi's because I still am in contact with them; otherwise I take part in some activities.

I mean, I like my life at the moment and I wouldn't change it; living in a flat with Francesca is fine. I learnt so many things and I like to do them!

The story of Adele is similar to that of many children at that time in Italy. Her transfers from several different institutions and then to a family shelter are due to reasons which do not concern her needs: in some cases, her restlessness made her difficult to handle; in other cases, her age made her unsuitable for the facility she was living in. In none of these cases, was DI the main goal. She was totally unaware of the possibility of independent living.

Adele is still undergoing this transition. The institution, through the social cooperative society which was created to implement labour integration projects, found her a job. The management of her money is ruled by the administrative department, which is in charge of ensuring that part of her income is given to

her in cash in order for her to face weekly expenses and another part is put aside in her bank account. Adele is also supported by a member of the staff when she goes shopping so that she can have enough to eat and a sufficient variety of food for her nutrition. Every success she achieves provides her great satisfaction. Compared to her life in the institution, this is an important change also because she achieves these results for herself and then she shares them with other people – her flatmate and colleagues. This experience of autonomy gives her a feeling of confidence and empowerment.

### 3.1.3 Driver 3: Labour market integration

It is impossible to build an independent life without economic autonomy and social integration. In Italy there are laws which support this important driver, such as law 104/92 and law 68/99 modified by decree 185/2016.

Staff of social cooperatives and institutions participating in the research report that labour market participation is a very important step on the path towards autonomy for people with disabilities. Nevertheless, not all of them believe that persons with disabilities can be fully integrated into the labour market; this is perceived to be the case, for instance, for people with severe impairments. In any case, even people with severe disabilities might be able to take part in some activities thanks to the support and assistance of social cooperatives and associations committed to the DI process.

People with disabilities and their families stress the importance of working for the full implementation of their autonomy. One father recounted:

*“My son has been doing [...] job market integration for eight years. [...] He is now working [and] manages to get up at six in the morning: takes his scooter, goes to work [and] does his thing. Then he comes back home by scooter, both during winter and summer. He did not have these abilities before, but he achieved them little by little.”* (Family member of a person with disabilities)

### 3.1.4 Barrier 1: Lack of dynamicity and commitment of public authorities and legislation

Legislation was defined by many participants as rigid, obsolete and not flexible enough to respond to the needs of persons with disabilities. Participants from local authorities stressed that very often legislation concerning disability is not flexible enough to keep pace with the evolving needs and requests of persons with disabilities and cannot provide innovative options to fulfil them. Local authorities, when choosing which projects to support, are not able to thoroughly assess the usefulness and content of the projects because they only consider the formal and legal requirements of the proposals and the facilities. One participant from a local authority explained:

*“[Public] authorities are unable to respond. I mean, they provide the general disposition but can't always follow you in this process, because you don't fit in the catalogue of entries.”* (Local official)

### 3.1.5 Barrier 2: Financial and political power of institutions

Participants across respondent groups agree that institutions are not all the same and have different attitudes towards DI. There are 'innovative' institutions that implement innovative solutions and actively promote DI, and other 'conservative' institutions that want to maintain the status quo. The latter exercise some influence in the political sphere in defence of their interests and to guarantee work for their employees through an adequate allocation of resources. This attitude is backed by local political authorities who have often developed over the years a strong political dependence on conservative institutions.

DI is a complex process. Relying on facilities that can host several dozen people is perceived as being easier than listening and funding projects and structures that take a diversified approach to the DI process. At the local level, this barrier was stressed as compromising the DI process, as reported by a participant in the research:

*"I think a big problem we have, is also a very political one, in that financial resources available at the local level shrink constantly. [...] Today, very often, there is also the mentality that small facilities cost much more [than] closing the institution and move young people to protected forms of living, independent living." (Employee of a community-based service)*

### 3.1.6 Barrier 3: Hindrances to labour market integration

The barriers to labour market integration, in particular for people with intellectual disabilities, seem hard to overcome and families complain about the lack of interest from politicians. Law No. 68 showed some limits in the past and was recently amended. More specifically, it did not allow labour market integration for all types of impairment and could damage people with intellectual disability compared to those with physical or sensory impairments. Private companies were not adequately incentivised to hire people with disabilities, and the law did not include mandatory and clear requirements. Recent changes to the law have just started to be implemented to increase integration of people with disabilities in the labour market; no evidence is yet available on the impact of these changes.<sup>32</sup>

As the changes had just started to be implemented at the time the research was conducted, many participants were dissatisfied with the current situation. As a parent of a young person with a disability, stressed:

*"It does not work, because it does not have sanctions. Additionally, it is unacceptable that psychological disability is equated with, say, those who have a hand missing. I mean, my son has neuropsychological disease and the other lacks a hand. If you were an entrepreneur living in today's world, who would you hire?" (Family member of a person with disabilities)*

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<sup>32</sup> Legislative Decree n.° 185 of 24 September 2016, Corrective dispositions and integrations to the Legislative decrees n.°81 of 15 June 2015, n.°148, 149, 150 and 151 according to the art. 1 paragraph 13, of the Law No.° 183 of 10 December 2015, ([Disposizioni integrative e correttive dei decreti legislativi 15 giugno 2015, n. 81 e 14 settembre 2015, nn. 148, 149, 150 e 151, a norma dell'articolo 1, comma 13, della legge 10 dicembre 2014, n. 183.](#)).

Another problem currently emerging in this field is the further reduction of labour market integration possibilities for persons with disabilities in general due to the abolition of the priority that used to be offered by public bodies to B-type social cooperatives. B-type social cooperatives are those where people with disabilities comprise at least 30% of members. Participation in calls for tender has now been extended to all companies, at the European level too. This has created an additional difficulty in the labour market integration process. One parent with a child with disabilities explained that a foreign business won a bid for a local cleaning service:

*“They say that they will keep those who worked for the [B-type] cooperative, but actually this is not going to happen because they will keep them at the beginning, but as soon as these people will need to be accompanied, maybe one morning they will not feel good, they are a bit more fragile, they will deliver less... They will probably be the first to be fired!”* (Family member of a person with disabilities)

## 3.2 Availability of guidance to support the deinstitutionalisation process

### 3.2.1 Driver 1: legislation

The implementation of the CRPD in Italy has played a crucial role as it promoted the involvement of people with disabilities, required the implementation of new legislative measures and fostered the creation of the Observatory. The law which transposed the CRPD into Italian legislation represents the main driver of the DI process in Italy as it promotes the right to live independently and be included in the community, as set out in Article 19 of the convention.<sup>33</sup>

This driver is generally considered in a positive way by managers of institutions and community-based services; in contrast, there seems to be less awareness among staff working for other services.

Local authorities and managers of institutions and community-based services stressed that clear guidelines for the implementation of relevant legislation are required to guarantee the homogeneous implementation of policies and actions across the country and avoid the fragmentation of regional regulations. In this respect, the ‘After Us’ law constitutes a good example of a general legislative framework based on common guidelines that guarantee a common vision of the DI process, able to change the predominant culture towards disability.

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<sup>33</sup> Law No. 18 of 3 March 2009, Ratification and execution of the United Nation Convention on the Rights of People with Disabilities, and its Optional Protocol, done in New York on 13 December 2006, and establishment of the National Observatory on the Condition of People with Disabilities ([Legge n°. 18 del 3 marzo 2009, Ratifica ed esecuzione della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità, con Protocollo opzionale, fatta a New York il 13 dicembre 2006 e istituzione dell'Osservatorio nazionale sulla condizione delle persone con disabilità](#)).

### 3.2.2 Driver 2: Exchange of good practices, knowledge and information

The exchange of good practices is widely identified as a driver fostering real change in the cultural approach to the DI process and enhancing independent living projects.

In particular, according participants from the case study locality, the exchange of good practice concerning the DI process is considered a crucial element for the design of new models of intervention. Probably because of the long tradition of cooperation and networking on the ground, the exchange of experiences concerning projects and intervention models is considered to be fundamental to:

- Put the person with disabilities back at the core of the assistance process;
- Consider his/her needs and wishes first;
- Realise interventions aimed at fostering the self-expression of persons with disabilities, providing room for action and freedom;
- Develop a technical and professional culture aimed at designing independent living projects in order to approach this key area in a scientific way. Even though this is done in practice, the study, analysis and evaluation of the life project are still missing;
- Provide proper financial resources specifically designed to create this culture;
- Create networks not only between the different stakeholders but also aimed at creating real social inclusion, meaning that the person with disabilities is not only considered as the final beneficiary of the services but an active subject;
- Implement real community welfare which requires a serious commitment even after the process begins;
- Make independent living accessible for persons with disabilities according to their needs.

### 3.2.3 Driver 3: Training targeting people who work on the DI process

The importance of training and fostering change to tackle the challenge of DI was widely highlighted by all participants: a radical change of paradigm needs to be promoted. Providers of both institutional and community-based services stressed the importance of these factors in the implementation of the DI process and the need to increase awareness and capacity among people working with people with disabilities. One employee who works on a daily basis with persons with severe disabilities reflected:

*"First of all we, have to change since we work with them. After that, I think the change will spread. I mean, if we don't change, it is difficult to expect that people on the outside will manage to."* (Employee of a community-based service)

They are aware of their value and their potential to enhance the personal growth of the people they work with, and how much they have to do to remain prepared and up-to-date.

One participant from a local authority suggested an innovative approach to staff training, in that training should also be oriented towards addressing the reality in the field.

*“Training should also be lived in the field, also seeing other experiences. That is, choosing the most significant experiences that are implemented in other places, thereby enabling people to spend time in other contexts. Because this widens perspectives [and] opportunities.”* (Local official)

### 3.2.4 Barrier 1: Re-Training people in order to overcome institutional culture

The barrier represented by the institutional cultural approach to disability among professional workers has been expressed by participants from local authorities and institutional and community-based services. A radical change of paradigm has to be promoted among professionals. One participant from a local authority claimed that, in some cases, the DI process is implemented just as a form of compensation for past institutionalisation, but without the real commitment of the professionals involved:

*“We still have and suffer the idea that independent living rights a wrong that history, the phenomenology of the organisation of services has caused to the disabled population. Independent living then appears and consequently home-based assistance and then the closure of asylums and institutions, no? Because it might right a wrong.”* (Local official)

Another participant from community-based services, with reference to the training of service providers dealing with people with disabilities, mentioned the episodes of violence that sometimes feature on the news and considers them a result of the inadequate training provided to professionals. His view was shared by other participants working in community-based services. According to them, the only antidote to this problem is guaranteeing the continuous training of professionals also from the point of view of their attitudes and psychological perceptions.

The professional approach towards people with disabilities includes respecting their dignity. The principle of respect for the dignity of people with disabilities must always be in the background in professional training. This is a cultural precondition for DI shared by professionals working both inside institutions and in community-based services. An employee of an institutional service stated that institutionalisation is a cultural approach; this is why even the staff needs to work with a new perspective and avoid being stuck in traditional approaches and tools:

*“It is a paradox, but the staff that in that moment was working to send these persons out, they were institutionalised too. It is difficult to get rid of this. So, if the staff doesn’t undergo a reset, we risk to move on and create flats, for example, that are more institutionalised than the institution.”* (Employee of an institutional service)

These views clearly express the importance participants in the research attach to supporting DI through training for service providers which provides new tools for work but also an adequate mental and cultural approach to DI.

### 3.3 Active cooperation between the people involved in the deinstitutionalisation process

#### 3.3.1 Driver 1: Cooperation between the public and private sectors

Cooperation between the public and private sectors is considered a crucial driver for the DI process by all participants. It is thanks to this synergy that it is possible to provide the range of services needed to promote real social inclusion for people with disabilities. Funds destined for the DI process are allocated by public authorities through calls for tender on specific projects to social cooperatives introducing facilities to support the DI process. Social cooperatives also actively participate in national and European calls aimed at financing additional activities. The system of cooperation between the public and the private sectors allows them to offer an independent living system that includes housing opportunities, support in the organisation of leisure activities and job opportunities.

It is worth stressing that participants across respondent groups, and at both the national and local level, mentioned local networks as one of the main drivers of the DI process. Such local networks entail cooperation among social cooperatives, institutions, private companies and associations active in the locality. These networks are relevant for the efficiency of the DI process as they allow a multidimensional approach to be better implemented, which covers all aspects of social inclusion. This approach aims to foster the skills and autonomy of persons with disabilities, involving them in the local community. One representative of a local authority highlighted how networking and cooperation can contribute to overcoming local community resistance:

*“Many localities have designed projects together with voluntary associations, [social] cooperatives, third-sector organisations, professionals, experts in the sector, enterprises represented by Confartigianato [the largest nationwide association of handicraft enterprises] with industrialists. I mean, many interesting things were done to create this safety network.” (Local official)*

Persons with disabilities consider local networks a fundamental driver of the DI process. They report the central relevance of these networks and social cooperatives, which prevent them from being isolated and alone. Involvement in activities deeply grounded in the local area promotes their autonomy and empowerment (see promising practice box).

#### **Promising practice – Social agriculture project**

A families association decided to involve a group of adolescents with autism who had already finished school in a social agriculture project financed by the Tuscany Region. The project was supposed to last three years but has been renewed for two more years. A small enterprise has been created where three of these adolescents continue to work.

During the first phase of the project, some local farmers were involved as tutors for the participants to support them in their activity and teach them how to do it; later the project evolved according to participants' requests and to the farmers' ability to listen to them. Consequently, during the second phase, the adolescents were asked to prepare jams, preserves, dried tomatoes and, with the support of the Provincial authority, had the opportunity to attend training sessions which allowed them to transform food to a business context. A machine for the production of food preserves was purchased thanks to a private donation.

The project participants started selling the products and today they have a small enterprise which is quite well known in the locality. An interesting collaboration has started with a well-known restaurant in a nearby town which started serving one of their jams with a specific kind of cheese. In addition, the project and restaurant collaborate in the production of other products. It is a very relevant experience, which highlights many of the issues concerning the creation of effective local networks: the Region's role, the private sector which directed the resources to an innovative project, the social network which received but also fostered further developments, the enterprises which financed and cooperated on the project. These are actions which can create the basis for preventing institutionalisation for the next generations, creating for them the conditions to develop their skills and live their lives autonomously and with self-determination.

### 3.3.2 Barrier 1: Lack of consistency and clarity of competences' distribution among the different levels of governance and difficulty in resources allocation

This barrier is closely related to the distribution of competence for social policies and healthcare assistance across levels of governance. Governance levels and competencies are ruled by the Italian Constitution; healthcare and social care are ruled by specific laws at national and regional levels. This has an impact on the services provided to persons with disabilities. Very often these competences overlap and, whenever there is a lack of cooperation among the different levels of governance, it becomes very hard for people with disabilities to obtain integrated service provision.

Since both regional and local competence come into play for social care and healthcare, implementation of the DI process varies across Italy. This can constitute a crucial barrier, especially when resources are limited and distributed according to 'historical expenditure' and without considering DI as an aim. Historical expenditure is a criterion providing for the allocation of funding to items in the public budget according to the resources allocated in the past to the same items. It is widely considered inefficient and changing it has often been a subject of public debate. One participant from a local authority highlighted the impact of this issue on providers of social and health services:

*"There is not a unique norm. There are national guidelines that the regions should interpret, and from there move to the entire regional mental health plan, maybe also for other types of disability. But this is a strong barrier;*

*how norms are interpreted, how they are not read. They entail the possibility to design projects, or not!"* (Local official)

At the local level, this issue also makes it difficult for families to understand the different rules and regulations concerning the right to assistance of their relatives and consequently the right to access available funds.

### 3.4 A change in attitudes towards persons with disabilities

#### 3.4.1 Driver 1: Political cultural change

The participants in the research believe that politicians are already aware of the importance of the DI process, but, as noted by a national official:

*"We would need another law that says that we have to close centres for persons with disabilities, or, as the Basaglia Law said, that we must not host new people."* (National official)

The 'After Us' Law is an important incentive for the DI process in real and cultural terms. The decision to close big institutions and to create smaller facilities also fosters a new approach to the assistance to be provided to people with disabilities, thanks to the implementation of new measures such as co-housing and small independent flats, and the increase in community-based services that respond to the needs expressed by people with different types of disability. This means that participation in the DI process is no longer only voluntary but depends on a project which is decided and implemented by the Region to support the creation of facilities that are more similar to a family environment and so support DI.

#### 3.4.2 Driver 2: Everyday-life cultural change

Participants from local authorities and providers of institutional and community-based services agree that cultural change has in the past (concerning the closure of psychiatric hospitals after the 'Basaglia Law') and now today plays an important role in the DI process. This cultural change is an important driver to build social and political consensus.

In particular, professionals are aware of the importance of the cultural change their activities entail for themselves and for the wider community:

*"Integration, inclusion [and] socialisation are crucial[.] There is a very important thing, which is to let the 'locality' come inside the facilities, but it's [also] important to take these facilities into the 'locality' [...], that is, giving life to the social dimension of interaction."* (Employee of a community-based service)

The most important driver is a change of attitude in everyday life culture that can be encouraged through the implementation of initiatives on the ground, such as: labour integration, leisure activities, meeting occasions which foster a real DI process. This is conceived as overcoming the culture of segregation, and the separation between and people with disabilities and wider society by acknowledging that disability belongs to the possibilities of life.

### 3.4.3 Driver 3: Changing attitude of younger families of children with disabilities

Participants in the research pointed to the importance of an ongoing cultural change. This concerns the attitude of those that have children with disabilities. They are contributing to the transformation of the cultural approach to disability – switching from a mainly medical approach to a more social one – which is a crucial element of the DI process. They conceive persons with disabilities as complete persons with their own needs, desires and aspirations and try to imagine how to guarantee them an adequate future from their early childhood. As one staff member of an institution said:

*“Our perception is that we are not only witnessing a generational change but an epochal one. [...] From childhood [younger persons with disabilities] start thinking about and fighting for what their life situation will be in their adult life.”* (Employee of an institutional service)

This view is shared by all participants, including public authorities, managers of institutional and community-based services, and, in particular, by the staff working daily with people with disabilities. Competent families who pay attention to the development process of their relatives are considered as a resource: they support the DI process and can become a driver of innovation, especially when they create associations. They can also foster additional changes in the autonomy and independent living system. The awareness of younger families entails an increased attention towards people with disabilities, their emotional needs and their relational needs with a view to broader inclusion.

#### **Promising practice – HOME**

“HOME” is an independent living project for teenagers and adults with intellectual and physical disabilities aged between 20 and 50 years. It is financed by contributions from the Ministry of Labour and Public Policies, the Tuscany Region and the families of people with disabilities. The participation of persons with disabilities and their families is voluntary.

The persons who took part in the project were chosen from local services. “HOME” is a facility with three apartments hosting six people with disabilities. Each apartment houses two persons and they have the keys to the flat. A staff member who is not highly specialised but has received specific training is available 24-hours a day within the facility to support the people living there according to their needs. In addition, a professional educator visits the facility for seven hours each day. The facility also has a housing lab, which is an apartment where people with disabilities can experience some hours or days of autonomy during the week in order to figure out if they feel comfortable living without their families. This facility is located in a small town and hosts people with disabilities from the surrounding area. Those receiving care go back home one weekend per month but this rule can be adapted according to each person’s needs.

Participants highlighted the following strengths of the project:

- The cooperation with municipal social services which supported the creation of an individual project for each person;
- A gradual and individual approach which entails respect for the needs of each person with disabilities, for his/her pace and necessities;
- The families who supported and contributed to the design of an individual independent living project for their children.

#### 3.4.4 Barrier 1: Families' assistance culture

This barrier was stressed with different nuances by all respondent groups. Families are considered among the drivers, but specific attention must be paid to families with persons with severe disabilities, in particular to older parents. According to families associations, for these parents the need to cope with a complex assistance system strongly discourages them from caring for their relatives at home, because the daily management is too complex. For this reason, many choose for their loved ones to be cared for in institutions, rather than having to face daily assistance which can become complex and a burden on the family. Therefore, responsibility is shifted to services who provide the assistance they need.

Representatives of institutions highlight that the parents of people with disabilities feel that their relatives are more protected in larger organisations compared to what is the case in semi-autonomous conditions. In some cases, this perception also concerns children with autism or with combined impairments, who need continuous assistance. According to employees of institutions and local services, some parents who have assisted their children for many years find it difficult now to let them go. They have not developed in their children an autonomous attitude and this might expose persons with disabilities to the risk of institutionalisation when their parents die.

In these cases and because of different difficulties, parents generally delegate the assistance and have an attitude which does not foster the DI process. One representative of a local authority reflected:

*"Often the main resistance comes from the family. I mean, there are 50-year-old disabled persons who still sleep in their parents' bed, so whose problem is this? Of the 50-year-old person or of the 80-year-old who can't manage anymore to let go of her/his son?" (Local official)*

#### 3.4.5 Barrier 2: Social stigma concerning disability

Participants from local authorities and institutional and community-based services reported that social stigma can seriously affect the implementation of DI. It contributes to the social isolation of persons with disabilities who are not guaranteed the opportunity to take part in activities or projects – including co-housing experiences – which would contribute to their empowerment and emancipation from their families and institutions.

At local level, too, this form of stigma, especially targeting people with psychosocial or intellectual impairments, is still present according to the

perception of professionals and families associations. Its impact can be perceived in labour integration possibilities and in housing policies. One manager of a social cooperative reflected:

*"Three years ago, colleagues from the service, having to active a project of [...] supported housing, visited every estate agency in [the area]. Now, in [the area] there are 3,000 empty flats[, but] every time we said that it was for mental health, the flat was not available anymore. We searched for one and a half years on the real estate market because no one wanted to rent us a flat, simply because there were mental health issues."* (Employee of a community-based service)

#### 3.4.6 Barrier 3: Learned helplessness

Participants with disabilities reported the 'need of protection' as a barrier to the DI process. In this case, persons with disabilities might find it hard to leave the institution and start their DI process because they feel protected in the institution and are afraid they are not autonomous enough to live on their own or with other people outside the facilities where they have spent most of their lives.

An employee of an institutional service clearly expressed the difficulty of people with disabilities with a long personal history of institutionalisation.

*"It cannot be taken for granted that people who have been living for many years in institutions are going to appreciate living a life of autonomy in a flat with friends. We take it for granted, but sometimes it is not like that, because I think that spending many years in an institution creates dependence on the institutions, which is a real barrier."* (Employee of an institutional service)

### 3.5 Practical organisation of the deinstitutionalisation process

#### 3.5.1 Driver 1: Focus on community-based services rather than on residential institutions

A fundamental driver of DI is the provision of community-based services at the local level. There is consensus on this among participants from all respondent groups. The broad spectrum of services made available in a locality makes it possible to better understand the real levels of social inclusion of people with disabilities.

Participants with disabilities, when asked about the services they generally use, mentioned transport, day-care centres, health assistance etc. as something that commonly belong to their daily routine, implying that these services become reference points in their daily life. For all participants, community-based services are primarily a possibility which can be provided to any person who wants to determine him/herself and express his/her choices and desires, no matter what they are. That is the reason why their activity mainly concerns the development of autonomy skills of persons with disabilities, as well as the promotion of social inclusion which entails also labour market integration and social life.

### 3.5.2 Driver 2: Multidimensional approach to disability combining social and healthcare assistance

This is a very relevant issue for participants from local authorities and for managers of public and private service providers. The integration of social assistance and healthcare in many areas of the country is far from achieved but it is considered fundamental for a successful DI process and more specifically for the implementation of individualised independent living projects.

Participants at the local level – who already live this positive reality – consider this driver to be extremely important in the implementation of the DI process. The integrated Social and Health system allows everyone to have access to all services fluidly because ad hoc support is provided during the whole process, as a result of an individualised service plan being in place.

People with disabilities are assisted by public services from childhood to adulthood and access to this path is through social assistants from both the municipality (the social services) and the healthcare and social systems. They are coordinated by the same unit and work in synergy: if the person with disabilities needs social or health assistance, then social assistants design the individual path according to the individually-tailored projects. To implement an individual path, all the local services are needed – those that are managed by public services and social cooperatives and/or associations – with the authorisation and monitoring of public authorities.

### 3.5.3 Driver 3: Levels of assistance tailored to the needs of people with disabilities

Participants stressed that each type and level of impairment is different and entails a variety of responses. Participants from institutional and community-based services felt that assistance must be provided to support the person in his or her autonomy path with varying levels depending on the needs associated with the type of impairment or their stage of life.

An employee of an institutional service stated that some forms of DI can be implemented, even in the case of severe impairments:

*“We have tried now apartments for persons with low functioning autism with severe intellectual impairments, where the professional is always present. So, this is independent living, that’s true, because you are in a more autonomous context, because you do things on your own.”* (Employee of an institutional service)

In the case study locality, institutions are strongly committed to DI and they actively promote innovative practices to support the development of people with disabilities’ autonomy.

**PERSONAL STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?**

## **Jean**

I am Jean and I'm quadriplegic. It has not been easy to manage my impairment. So when I was five, my father moved with the whole family because he found an institution which might be suitable for me. So when I was five, I moved to a big institution in a big town, Milan. My mother wasn't able to do all that I needed as she had six more children to take care of.

At the beginning it was difficult. I felt disoriented and I missed my family, but later I found my own environment. In the institution I could get in contact with persons living with the same condition and I became aware of the difficulties I was about to face.

I attended primary school in the institution and secondary and high school. Attending school was a positive experience because schoolmates at the beginning had a curious attitude towards diversity, they observed it, made even fun of it but then we found each other.

I graduated as a business secretary. When I was 18, my father died and I needed to work. The disability benefit wasn't enough. We created a cooperative society in order to obtain jobs to do in the institution. In 1982, I found an external job. I wanted to work and I wanted a real job, with other people.

I found the right job for me: a big company where I was in charge of mail distribution. I really enjoyed this job, but unfortunately after three years the company closed. I felt I still needed autonomy. Together with the institution and the support of the staff of an NGO, we found suitable accommodation for me in a community located in the centre of Italy. It was community hosting not only persons with disabilities. It was a completely different experience compared to the institution: there were no time schedules besides the meals and we had to organise our own days. I used to write for a magazine published internally and we also dealt with various social problems...we were very active!

In this community I met my wife, Paola. She came to visit the community with her friends from the institution in Tuscany. I went to Tuscany to visit Paola. I met the director of the institution. When he perceived that I was so interested in Paola, he suggested that I move to a family-shelter nearby so that I could be closer to her and avoid the journey. I moved in 1990. I spent two years in the family-shelter; in the meantime Paola and I were preparing the documents for our wedding.

A flat had become a basic need because of mine and Paola's desire to get married, but bureaucratic issues got complicated. Our problems in getting married were not only bureaucratic but also practical. Paola's parents were against it, they didn't want her to live with me, they'd rather have her at home with them. But Paola was very confident and she won. We got married in 1995. We made it. We got what we wished for, what we wanted.

Now we live together, we have an assistant. She stays with us all day and sleeps at our place. She deals with shopping and cooking. We get along with her.

Moreover, during the day a guy comes to help her with the housework. Both Paola and I work in the institution's social cooperatives: I am in charge of the wheelchairs and Paola of the local office. During the summer, we go on holiday to the seaside with a group and spend two weeks there. We spend important holidays with Paola's dad. It was a journey in stages, but a very fruitful one.

Jean now has full control over his life as he has the possibility to make his own choices independently. It is possible to say that the most important support came from the people willing to listen to him and who, with him, hoped for this transition from a typical life of a person with disabilities to that of a free man able to determine himself.

#### 3.5.4 Driver 4: Support to families of persons with disabilities

A common element reported as a driver of the DI process is the attitude of families of people with disabilities. Participants from local authorities and institutional and community-based services highlighted that, when the persons with disabilities and their families are involved in the design of their individual DI projects, the projects seem to be more effective. Families also expressed the need to be supported in the autonomy pathway. They ask for more dialogue and involvement. More information on how the process develops would allow families to participate proactively in the process. It is not a linear process and difficulties may occur. They need support in accepting the changes and in overcoming difficulties. They do not want to be merely involved passively in the process of change they are both scared of and long for.

Support provided to families is an important driver also from the point of view of participants with disabilities. They highlighted that information and the support and training of families is crucial to their understanding of their son/daughter and support for him/her in his/her DI process.

#### 3.5.5 Barrier 1: Lack of financial resources

Another common element mentioned by all respondent groups concerns financial resources. It is reported that, in many areas, institutions for people with disabilities receive a lot of financial resources from local public authorities because of traditional agreements and historical criteria for allocating funding. This allocation of funds works against community-based services and DI. Moreover, all participants agree that public financial resources for DI are currently decreasing despite the increasing focus on the issue and the fact that they are now starting to have a better vision and more professional skills for implementing DI.

The wide differences in the implementation of DI measures and initiatives at local level is also related to the discrepancies in the availability of funding in regions and localities. Differences in the contributions people with disabilities are required to make for the community-based services and care services they need can vary significantly from one area of the country to another. This is again related to the lack of financial resources and the high decentralisation of policies in this area.

### 3.5.6 Barrier 2: Short-term planning

Connected to the lack of financial resources is the trend of planning programmes and services in the short-term, year by year. These two elements prevent associations and local stakeholders from designing projects and activities with a long-term perspective. This is a serious problem for the DI process, for instance, in the case of housing projects which are central for independent living and for which a long-term perspective is pivotal.

This barrier is stressed because the Tuscany Region, despite its relatively large financial contribution to the DI process, is currently decreasing the available funds causing the reduction of DI projects, some participants report. This is the reason why autonomous and independent living projects often end due to funding difficulties, leaving people lacking the resources to continue their DI.

## 3.6 Cross-cutting issues

### 3.6.1 Impact of different types and degrees of impairment on the deinstitutionalisation process

#### *Intellectual impairments*

With regard to intellectual impairment, there is no consensus on the impact of different degrees of impairment on the DI process. The conflicting positions emerged among local authorities and staff of institutional and community-based services and concerned psychiatric patients with a diagnosis of intellectual impairment or degenerative disease. According to local authorities, these individuals cannot undergo a DI process while for service providers, DI is possible if well designed.

#### *Psychosocial impairments*

This issue was not tackled extensively during the research. It emerged that the path to autonomy outside the institution is difficult and participants from institutional and community-based services stressed that additional efforts are required to provide adequate support to the individuals involved in the process.

This point of view was shared by participants at the local level, where this kind of disability was prevalent. Service providers and families did not impose limits on the possibilities these patients might have; they only stress that in this case a more gradual approach is required.

#### *Sensory impairments*

There is a consensus among participants from local authorities and institutional and community-based services that the DI process for this form of impairment is not only possible but in many cases already achieved. For instance, blind people, deaf people or people with visual and hearing impairments do not end up anymore in institutions since they have many opportunities to be included in the society with adequate support. There are still issues in many places across the country concerning the accessibility of public spaces and this is commonly acknowledged.

### *Physical impairments*

Participants from all respondent groups consider DI for physical impairments something that is possible to achieve even when the impairments are severe. In this respect, people with minor or medium degrees of disability are easier to involve in the DI process and in independent living experiences. According to participants, persons with severe disabilities can participate in the DI process with specific and tailored precautions and devices. For example, home automation devices can be an efficient tool to support persons with severe disabilities who want to experiment independent living, providing them with remote 24-hour assistance in emergencies and a comfortable environment tailored on their needs.

The real issues here are, on the one hand, the availability of funding (as highlighted by participants from both local authorities and service providers) and, on the other hand, the need for a cultural change. To promote cultural change concerning the whole society, from families of people with disabilities to policymakers and the whole population in general, awareness raising activities should be fostered and implemented.

#### 3.6.2 Impact of age on the deinstitutionalisation process

Concerning the deinstitutionalisation of older people, a consensus can be identified among the participants in the research that this process needs to be implemented carefully and gradually for people who spent most of their lives in institutions. Another issue that emerged among participants from local authorities and community-based services and institutions is the condition of people affected by degenerative diseases. In this case, ageing implies a continuous deterioration of their condition and therefore a hardly reversible process of institutionalisation.

In the case study locality, local public services focus their attention on older persons with severe intellectual and mental impairments who still live in institutions. The attention is mainly focused on severe intellectual disabilities, as they often concern persons who have remained in institutions because they lost their families and/or persons who are viewed as unsuitable for assisted living in an apartment because of their disability. These persons can benefit from a wide range of recovery activities provided in the locality, such as the daily centre which allows them to go back to the institution only to spend the night. Some of the activities are organised by the institution itself, such as the "Ortiz" which is an organic farming project offering different kinds of workshops.

## 4. MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION

### 4.1. Commitment to deinstitutionalisation

All participants agreed that public authorities at the national, regional and local levels are primarily responsible for promoting and implementing DI, as they design and implement policies. However, among associations, NGOs, social cooperatives, people with disabilities and their families, and professionals there is a widespread expectation of greater involvement of other stakeholders to help achieve positive results. Where existing institutions play a positive role in DI, as in the case study locality, where the large institution cooperates with local authorities, local social cooperatives and families of people with disabilities to implement individualised DI paths, networking is commonly acknowledged by participants as pivotal to the process as well as to the elaboration and implementation of a DI culture.

Participants also suggest the need to increase awareness raising campaigns and networking activities where the DI process is implemented. One national level stakeholder declares:

*"We need many, many promotion and awareness and campaigns. [...] We also need to organise public demonstrations [...] and use the media to be on the front lines [...] to make people understand [...] that good practices exist. These simply need to be [brought to the awareness] of public officials that can then apply them."* (National official)

Awareness raising is needed because a cultural change towards the perception of people with disabilities as capable of autonomy is far from being achieved in full in Italy. Great progress has been made since the 1970s when school integration for children with disabilities was first established and the DI process for neuropsychiatric patients was implemented. These measures kicked off an irreversible cultural change so that now large institutions which only provide residential care without implementing any kind of project or activity aimed at fostering autonomy and social inclusion no longer enjoy a generalised consensus among professionals (social and medical professionals) and policymakers.

However, there is still resistance to the effective social inclusion of people with disabilities in the population, especially among the older generations who have not experienced any personal contacts during their schooling with people with disabilities. As a result, stigma – especially concerning labour market integration – is still an issue. Employers are sceptical about employing people with disabilities. This is the reason why the promotion of social inclusion is pivotal in this field. It can be achieved by fostering not only school inclusion but also labour market inclusion and all the other activities and projects that might ease the contact and the inclusion of people with disabilities into the local community.

Participants agree that more effort should be put into labour market integration strategies as labour is the first and most important step towards full social inclusion. Effective integration, especially in the labour market, still remains an

issue because existing tools have either been scaled down (the preference assigned to social cooperatives of people with disabilities in calls for tender was recently eliminated) or do not offer proper incentives to local employers to hire people with disabilities or disincentives for not hiring them (firms prefer to pay the fine rather than employ people with disabilities). Labour market integration is an important step on the path to autonomy and these difficulties may hinder the DI process at the individual level. Promoting labour market integration requires a cultural change to overcome stigma about the capacities of people with disabilities, especially people with intellectual disabilities.

Another crucial strategic measure concerns specific training for the professionals active in the implementation of the DI process. According to employees of both institutional and community-based services, professional training should promote the paradigm shift towards autonomy that DI implies. This view is also shared by policymakers at the national and regional levels. Professionals who are not used to the DI paradigm should get used to it to guarantee better assistance for people with disabilities undergoing the DI process.

Funding is another very important issue. Most of the funding for the “disability” area allotted at national level is destined for institutions. The overall amount of resources for the DI process should be increased and distributed according to criteria rewarding institutions that are actually committed to DI, participants suggest. There are institutions effectively committed to DI, such as in the case study locality, where the largest existing institution is actively involved in DI. Other organisations in the case study locality manage institutions but show resistance to the DI process and therefore did not develop any kind of project or activity in this respect:

*“There are five facilities and four organisations; out of these organisations, two contributed to the creation of DI processes, implementing assistance paths ranging from intense assistance minimal assistance, such as the apartment with mere supervision.” (Employee of an institutional service)*

There is consensus across respondent groups on the need to allocate more funding to community-based services at the national, regional and local levels and to discourage the development of new institutions. Considering the general fiscal difficulties in Italy, interesting experiences of joint funding between the public, private and third sectors can be taken into account. Social cooperatives have developed ‘self-managed economies’: they are developing an autonomous project design approach, using not only social bodies’ calls for tender but also proposing innovative projects to local authorities, partially financed by social private stakeholders, by the services and by families. This approach seems to be very successful and might represent a potential solution to the enduring lack of funds.

#### 4.2. Availability of guidance to support the deinstitutionalisation process

The role of the Observatory is crucial in respect to the DI process. It is very active in providing guidance at national level on DI and independent living to the authorities involved in the process at the national, regional and local levels, as the National Plan and Guidelines for Independent Living projects approved in 2017

show. To better achieve this aim, the Observatory also promotes the exchange of good practices at the national level in the area of DI.

The more informal contacts favoured by associations in the field and the direct exchange of information among professionals, associations and other stakeholders also provide a good support. According to service providers, a lot can be done through local presence and proposing activities directly involving persons with disabilities. As a proper culture of DI is not widespread among service providers, training and re-training should be promoted at the national and local levels to provide them with the tools to actively implement the DI process and support it at individual levels.

*“It cannot be taken for granted that all staff share the concept of deinstitutionalising the person [who is going through the process]. On the contrary, in my experience, they tend not to let that person become too autonomous.”* (Employee of a community-based service)

#### 4.3. Active cooperation between the people involved in the deinstitutionalisation process

According to employees of institutional and community-based services, a change in the distribution of competences among the different level of governance, and more coordination among the private and public stakeholders involved in the DI process is needed to effectively implement DI in Italy.

The complex distribution of responsibility for structuring the offer of community-based services and promoting effective DI between national, regional and local levels and across different departments is an important obstacle that hinders the homogeneous progress of the DI process across Italy. Participants felt that it should be reformed to create a clearer distribution of competences.

These reasons are why the former and the latest National Plan lack enforcement, participants suggested. These documents are designed according to the law transposing the CRPD into national legislation and so promote the implementation of the principle of DI, the more recent one with a more courageous attitude than the previous one. However, they are not always properly put into practice, due to governance issues: local authorities, regions and central government have different roles and responsibilities and the process cannot easily be governed from the central level (see chapter 1). It is not by chance that the most interesting and advanced examples of DI are in localities characterised by effective and integrated governance of social and healthcare policies. Participants suggest an important and practical step would be to operationalise DI in minimum standards of the healthcare system, as happens for most of the social and healthcare services ruled by Italian legislation.

The majority of national-level participants directly referred to the complexity of the Italian governance system for social and health policies as hindering the implementation of policies related to DI. More specifically, as regards the national health system, competence is shared by the national government and the regions and coordination takes place by means of LEAs, which are the minimum standards

expected to be uniformly implemented by regions. Social assistance is completely up to regions, even if the state has the right to define the LEPs. Both the LEA and the LEP work as a tool to reduce differences across regions in services and provisions, with the LEA being more effective.

National-level stakeholders agree that a possible way to ensure the implementation of DI and proper development of community-based services would be the implementation of LEAs. This seems to be a viable solution to make the process more homogeneous across the country, even if it implies that the process would result in stronger control for health authorities with the risk of reducing the flexibility of the system and the autonomy of local authorities.

Another effective action to favour the implementation of the DI process would be the direct involvement of people with disabilities and their families in the design of individual processes of DI. But family involvement requires that information and active support are provided to them. In this respect, professionals and educators are key actors, as they can provide assistance in the DI process and make persons with disabilities feel involved in this transition.

Local networking is also one of the main drivers of the DI process. It allows better implementation of a multidimensional approach and contributes to overcoming the local community's resistance and social stigma. Local networking is facilitated by active citizenship and participation. Good practices such as the creation of local agreements with the participation of the different stakeholders in the field, should be promoted.

#### **PERSONAL STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?**

##### **Romeo**

My name is Romeo, I'm 56 years old and my story begins many years ago, at the moment I was born. I was the son of a single mother who left me with my grandparents because she wasn't able to take care of me. I spent my early childhood with my family – my grandparents and three young and single uncles – in the countryside in Tuscany.

I went to school up to secondary school after I had failed four times in primary school. A difficult period began. I started drinking, did occasional jobs, started working as a *pizzaiolo*. I continued this activity for a long time. It is a confused period, made of drinking, messy days and I often slept in the street because I was too drunk. At home, relationships got tense: my uncle drank too and sometimes beat me.

"I thought I was another person and sometimes when I drank I slept out during the night. It was a life that could not continue for a long time [...] in that period I didn't work much. I started working when I was 20."

During this period, I got in contact with a 'lady of the province', who maybe was a social assistant who pointed me to the local *Mental Health Centre (CSM)* where I met Dr. Romano who sent me to the family shelter created by the institution.

I kept on working, so during the day I was out of the centre. I felt at ease in a tidy environment made of rules and scheduled times, which was reassuring for me. My problem with alcohol continued though.

I owe a lot to the institution because [...] it helped me also giving up drinking. I used to drink, yes, I used to drink.”

When I turned 25, I achieved the secondary school certificate, attending evening classes. When the family shelter was closed because of administrative problems, I was moved to the institution. I consider it to be a positive experience too. The institution had some more rules, a more rigid time organisation compared to the family shelter.

I lived in the institution from 1990 to 2003. My addiction problems continued even during the institution period; my health worsened too. I succeeded in giving up drinking when I was 34. On 15 May 1995 I gave up drinking forever. In July of the same year, I met my present partner in the institution. I applied for social housing and I received a flat where I gradually moved. Moving to an apartment was a big change for me. I bought the furniture with my partner and together we decorated the flat.

I had a life ... having a house feels like I won the lottery.

My routine has changed: I invite friends over or I'm invited by them. I decide my life routine together with my partner: "the house is a completely different thing".

My current condition is independent living. I live with my partner, we take care of each other, and I'm satisfied and happy because I succeeded in changing my life. I don't live in a protected apartment with an assistant: the responsibility is entirely on me and my partner, including expenses and everything else. I was hired by the social cooperative linked to the institution and I'm working again as a pizza delivery man. I'm only assisted in money management: some money is directly credited to my bank account and some is given to me weekly in cash by the administrative office of the institution so I can meet my daily expenses. I'm supported by the institution's psychiatrist.

Now I'm waiting for social benefits so I can do what I like, such as looking for mushrooms or going for a drive in my car.

Thanks to the family shelter and the institution, I started a regular life.

#### 4.4. Promoting a change of attitudes of families of persons with disabilities involved in DI

Effective psychological support should be provided to families of individuals undertaking the DI process. This is because, although much has been done to promote a new culture concerning disability, participants note that families are afraid of autonomy and this might become a reason for them to oppose their

relatives' path to autonomy. As one family member of a person with disabilities involved in the transition process stated:

*"Looking back, I remember the great fear: I have to say sometimes I went to check whether everything was alright: Did you iron the clothes? Did you switch off the iron? [...] Make sure you don't answer the door to anybody"*  
(Family member of a person with disabilities)

Discouragement and negative attitudes of families towards DI are still very present. They are often scared by the concept of DI as they think that people with disabilities need protection.

Participants also pointed out that a new positive attitude is emerging among younger families of children with disabilities. They are contributing to the transformation of the cultural approach to disability which is a crucial element of the DI process. This is giving a positive new impulse to the DI process that should be further encouraged by a positive response from policymakers and service providers, participants believe.

More awareness-raising activities should be implemented targeting policymakers (politicians and officials) at the local, regional and national levels, participants believe. The role of these actors is considered pivotal by all participants as they can encourage DI – as the Tuscany Region did by developing guidelines for projects for independent living, for example – or discourage it. Raising their awareness might entail the promotion of more effective organisational tools which are crucial to implementing the DI process.

#### 4.5. Practical organisation of the deinstitutionalisation process

The crucial step to take for the implementation of DI is the clear definition of the governance model for DI within the existing governance structure of services and provisions, participants believe. More integration between the Social and Health systems would allow everyone to access all the services more easily, because thanks to an individually tailored project a person can be supported throughout the whole process. At the same time, more clarity is needed on how funding is allocated, and how much recipients are expected to contribute towards the costs of services and assistance. The effective monitoring and evaluation of DI is not in place. The complexity of the governance system requires that the monitoring/evaluation system be developed at each level of governance.

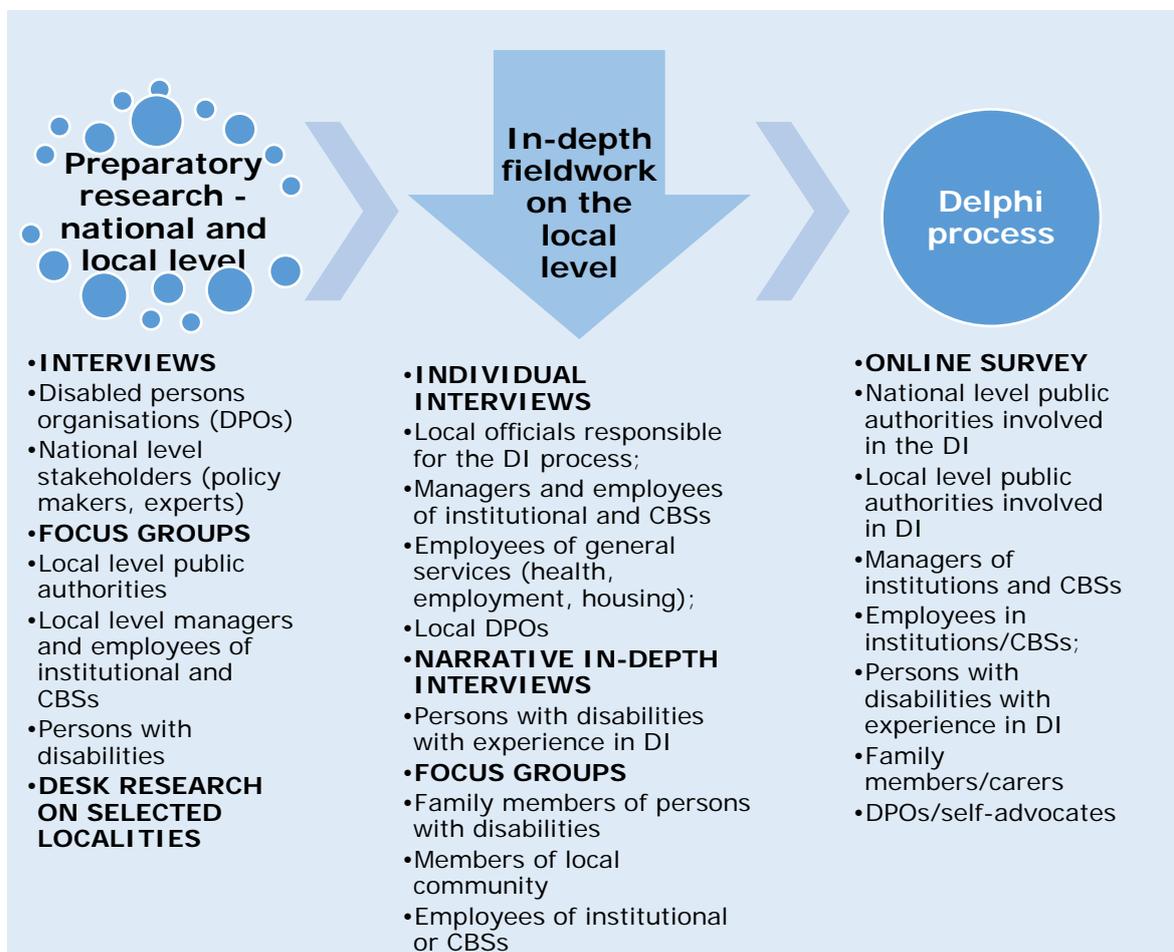
## ANNEX: RESEARCH METHODOLOGY

The fieldwork employed several common qualitative research methods to capture the views of a variety of different stakeholders. These included participatory research methodologies enabling full participation of persons with disabilities:

- Preparatory **semi-structured interviews** with selected national stakeholders to gather contextual information about the status of the national deinstitutionalisation process and to identify key themes to be explored in later interviews.
- **Focus group discussions** to explore differences and commonalities in the experiences and perceptions of groups of participants with similar roles in the deinstitutionalisation process.
- **Face-to-face semi-structured interviews** with individuals involved in the deinstitutionalisation process in the case study locality to gather their views about what works and what does not work regarding policies and practices.
- **Narrative interviews** giving persons with disabilities the opportunity to share their experience of the deinstitutionalisation process and how it affects their lives.

Much more information on the design and methods of the fieldwork research is available in the main report '[From institutions to community living for persons with disabilities: perspectives from the ground](#)'.

**Figure 1: Research methods and target groups**



Source: FRA, 2018

## Inclusion of persons with disabilities

Participatory research principles guided the development of the research design. Particular attention focused on ensuring that persons with disabilities are active participants at all stages of the research.

In preparation for the research, FRA held an international expert meeting with representatives of disabled persons organisations (DPOs) and experts with experience of conducting research with persons with disabilities. This was complemented by a similar process at the national level, where researchers in the fieldwork countries conducted consultations and interviews with national DPOs and experts.

FRA ensured the preparation of easy-read research materials and reasonable accommodation in all activities part of the research.

The names of persons with disabilities telling their personal stories of deinstitutionalisation are pseudonyms.

## Delphi process

To validate the results of the fieldwork research at both the national and local levels, FRA carried out a Delphi survey. Delphi is a participatory group communication process which aims to conduct a detailed examination of a specific issue, bringing together a range of stakeholders in a time-efficient way. The process enabled FRA to assess areas of consensus and disagreement between and across stakeholder groups and countries.<sup>34</sup>

FRA's Delphi survey included almost all those who had participated in the fieldwork. Participants were presented with a summary of the key findings and asked to identify the most important drivers and barriers of the deinstitutionalisation process.

## Peer review meeting

In addition, FRA organised in-country peer review meetings in each of the five fieldwork countries between January and February 2018. These meetings allowed a small number of research participants to reflect on the findings emerging from the research. Discussions at these peer review meetings fed into the revision of the national case study reports and informed the drafting of the main report bringing together the findings from the five countries where the research took place.

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<sup>34</sup> Hsu, Chia-Chien and Sanford, A., Brian (2007), [The Delphi Technique: Making Sense of Consensus](#), Practical Assessment, Research and Evaluation, No. 10/12; Cuhls, K. (2005), [The Delphi Method](#), Fraunhofer Institute for System and Innovation Research ISI.