



**Serbian Project SAVE –
Social Protection Assessment for Values and Effectiveness**

*Cost-effectiveness and cost-efficiency of the social welfare system,
specifically deinstitutionalization (DI) of welfare services in Serbia*

**EUROPEAN PROTECTION SYSTEMS IN THE
AREAS OF CHILDCARE AND LONG-TERM CARE:
GOOD PRACTICES AND LESSONS LEARNED**

Stefania Ilinca, Kai Leichsenring, Eszter Zólyomi and Ricardo Rodrigues

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1. Introduction

Deinstitutionalization has become the hallmark strategy of social and care services for individuals with limited autonomy across European countries. Once associated with the under-sizing of the residential care sector, deinstitutionalization is now an umbrella term for the process of development of a wide spectrum of community-based services with the goal of substituting and gradually eliminating the need for care provision in institutional settings. The European Expert Group on the Transition from Institutional to Community-based Care (European Expert Group on the Transition from Institutional to Community-based Care, 2012) defines deinstitutionalization as “a process which includes:

- The development of high quality, individualized services based in the community, including those aimed at preventing institutionalization, and the transfer of resources from long-stay residential institutions to the new services in order to ensure long-term sustainability;
- The planned closure of long-stay residential institutions where children, people with disabilities and older people live, segregated from society, with inadequate standards of care and support, and where enjoyment of their human rights is often denied;
- Making mainstream services such as education and training, employment, housing, health and transport fully accessible and available to all children and adults with support needs.”

The definition signals a complete departure from the traditional model of care for dependent individuals, which in most European countries was dominated by large institutions believed to be the most effective approach to care. The isolation of non-self-sufficient persons within institutions clearly reflected the stigma associated with mental and physical disability and dependency and was often justified on the economic grounds that economies of scale could be obtained by accommodating a large number of individuals within one facility.

The move towards deinstitutionalization is based on two core arguments. The first refers to the protection of fundamental human rights as they are recognized by the EU Charter of Fundamental Rights: respect for human dignity, the right not to be subjected to degrading treatment, the right to liberty and security, the right to education, the right to work, the right to health, equality and non-discrimination. Life-long isolation within segregated institutions is considered to deny residents many of these rights, whereas an independent life within the community would promote them. The second argument refers to effectiveness. An increasing body of research is pointing towards better outcomes from community-based care solutions with respect to institutional care; these include better quality of life, higher life satisfaction, and better outcomes for both users and their families (European Commission, 2009) all at comparable costs.

Over the past decades many countries across Europe have developed strategies to support community-based services in an attempt to replace traditional models of care. The number of places in residential facilities has been reduced and many institutions closed, but the trend is uneven and progress is slow. Approximately 1.2 million people still live in residential institutions in Europe – over a quarter of them suffering from intellectual disabilities and 150,000 are children (Mansell, Knapp, Beadle-Brown & Beecham, 2007).

The process of shifting service provision away from residential institutions took place at different speeds and with diverse results in European countries. The permanence of large disparities in

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contextual, cultural and legislative backgrounds means that the path towards deinstitutionalization is a complex, country-specific process. Nonetheless, a lot can be learned from the experiences of countries where deinstitutionalization is well under way and from examples of strategies and models that proved to be effective. Previous experiences have shown that the shift towards community care must be accompanied by a cultural change: beneficiaries must take a central role in the care process and be included in decision-making processes, together with their families and informal care providers. In addition, the focus of care should fall on preventing the development of the need for institutional care and developing parallel care solutions, a process which often involves high degrees of coordination between many different actors. Finally, successful community-based care hinges on the availability of appropriately trained care professionals and the implementation of quality control mechanisms emphasizing user satisfaction.

Common Basic Principles for deinstitutionalization

1. Respecting users' rights and involving them in decision-making
2. Prevention of institutionalization
3. Creation of community-based services
4. Closure of institutions
5. Restriction on investment in institutions
6. Development of human resources
7. Efficient use of resources
8. Control of quality
9. Holistic approach
10. Continuous awareness-raising

Source: Report of the Ad Hoc Expert Group on transition from institutional to community-based care, European Commission, 2009

In the following, we attempt to offer some insight into the complexities and challenges of deinstitutionalization by tracking the general progress of the process in Europe and in some selected countries.

This report is organized as follows. Section 2 outlines the key features of deinstitutionalization in Serbia, identifying the main weaknesses and challenges to be addressed by future policy. Section 3 provides an overview of childcare policies in Europe and the progress of deinstitutionalization in the field. Examples of best practices from two European countries are included: Italy and Hungary. Section 4 focuses on long-term care systems. After a short overview of European care regimes we turn to four case studies: Sweden (representing the Universal-Nordic type), Austria (exemplifying the Standard care mix type), Italy (model country for the Family based care regime) and the Czech Republic (representing the Transition care type). Each case study includes an overview of the long-term care system, a section focusing on barriers and drivers for deinstitutionalization and selected best practices. A short overview of the Serbian long-term care system is also included. We conclude in Section 5.

2. Overview of the deinstitutionalization process in Serbia

The direction of social policy in Serbia was set by the 2005 document on Social Welfare Development Strategy, which indicated a new direction towards deinstitutionalization of social services towards the municipalities and local communities and away from residential care. The Social Welfare Development Strategy, further confirmed in 2011 in a new general Social Welfare Law, aimed to improve the supply and quality of services in all forms of residential placement of beneficiaries. As regards children, for instance, it envisaged a decrease of the number of placements in residential institutions and the development of new services and service departments which would support the life of children with disabilities or without parental care in the community (Redzic, 2011). Similarly, mentally or physically disabled individuals and persons with reduced autonomy were to be cared for, to the largest extent possible, within the community and in their homes.

This Social Welfare Law of 2011 introduced, among other measures, the following key provisions (Redzic, 2011):

- A ban on institutionalization of children aged zero to three;
- Introduction of group homes and small residential units as new forms of placement;
- Introduction of special purpose transfers for community-based services for communities where residential institutions will be transformed;
- Financing of supported housing services for persons with disabilities from the national level.

However, the Social Welfare Law was not followed by by-laws specifying the concrete modalities of implementation of the law. But the trend towards deinstitutionalization is clearly visible. For instance, as regards children and youth with disability, the number placed in residential institutions decreased by 37% between 2000 and 2011. Despite this progress, the deinstitutionalization process in the last decade in Serbia has been severely unbalanced, with a strong focus on the improvement of childcare to the detriment of other beneficiary groups, mainly the elderly and disabled/dependent adults. Whereas the huge gaps in service provision for the elderly are increasingly filled by private providers and the efforts of families and informal carers, alternative support services for the physically and the mentally disabled are lacking. For this latter beneficiary group deinstitutionalization and increases in service capacity are of the utmost relevance. Moreover, much of the progress in the area of childcare can be traced back to strong international donor support (UNICEF, EU, IMF and numerous donor foundations from developed countries), both in priority setting, strategy building, human resources support and development, and most importantly funding. Other areas of social protection have failed to attract such international attention and support. As a result, innovative projects and progress have remained small-scale and isolated.

Foreign donors and monitors have played a key role in kindling and pushing reform initiatives. Their efforts contributed to raising awareness of the living conditions of the beneficiaries in residential care institutions and have brought the problem in the attention of the public and policy-makers. While the necessity to deinstitutionalize social care services for mentally ill adults is apparent, an appropriate strategy to create service alternatives is less evident. Care in the family is very rarely a sustainable solution (due to the necessity of continued professional support and the lack of day care facilities), which in turn means that community-based care services must take the form of supported living arrangements. However, capacity limitations loom large: despite being central to the

Overview of the deinstitutionalization process in Serbia

deinstitutionalization strategy for this beneficiary group, supported living arrangements are currently being offered only in 3% of Serbian municipalities (CLDS, 2013).

Further complicating matters, local authorities are rarely supportive of deinstitutionalization projects because they result in a direct shift of financial responsibilities from the central to the local level as dependent adults are transitioned from state institutions into community-based service alternatives. The necessary funding can put a strain on local budgets even in fairly well-off municipalities, leading local decision-makers to prefer the strategy of relying on Central Government funded residential institutions for dependent adults. It is difficult to imagine that the deinstitutionalization process would register significant and uniform progress in Serbia, unless more stable, earmarked transfers from the Central Government to the local level will be put in place, or the systems of incentives re-aligned to be conducive to the creation of community services.

Further gaps in the legislation render difficult the transition of beneficiaries into supported living arrangements. As per current Serbian legislation, if beneficiaries can obtain gainful employment they lose the right to benefit from some state-provided services. This situation severely limits their ability to transition into a more independent living situation. To complicate the situation, the local labour markets do not have the capacity to provide stable employment opportunities for people with intellectual or physical disabilities, leaving the beneficiaries completely dependent on state financial support even when transitioned to community-based care.

Finally, the quality of local human resources remains an important barrier for deinstitutionalization. More specifically, it is necessary to improve management competences in the key human resources at the local and regional level. Many local leaders in social service organizations are recommended by their high professional competences but such skills must be paired with well-developed strategic and managerial aptitudes. Such abilities have now become essential for the transformation of the system and training and HR upgrading efforts should become a key priority for policy makers. The acquisition of new competencies is also necessary at the level of the Centres for Social Work. As the deinstitutionalization process will advance, the personnel here will be expected to provide new types of services to beneficiaries, for many of which they have received no formal training or education. Interviewed experts have identified a series of key capabilities which are currently lacking and insufficient and which should be built into training programmes: case management capabilities and needs assessment, client focus and ability to customize services to needs, strategy development and long-term planning.

Key features and weaknesses of the deinstitutionalization process in Serbia

- The 2005 Social Welfare Development Strategy, further confirmed in 2011 by a general framework law (Social Welfare Law) on deinstitutionalization has not been fully followed by by-laws specifying the concrete modalities of implementation.
- Initiatives promoting deinstitutionalization are funded through the so-called 'Konkurs system', a type of restricted competitive tendering on a yearly basis. The lack of commitment for medium to long-term financing impedes long-term planning at the municipal level.
- The trend in deinstitutionalization for children is the functional replacement of residential placement by foster family placement. However, support strategies to prevent children from being taken away from their biological families are only starting to be developed.
- On the whole the Serbian foster care system for children has been working well over the past decade and the financial compensation given to foster families appears adequate.
- The development of community-based services for intellectually disabled and mentally ill adults lags far behind the progress made in the area of childcare. Despite being central to the deinstitutionalization strategy for this beneficiary group, supported living arrangements are currently being offered only in 3% of Serbian municipalities.
- The chronic lack of continuity in funding is one of the main barriers to progress in deinstitutionalization and a generalized problem in the social welfare system in Serbia. Most innovative and modernizing projects rely on international donor support and other unstable sources of financing.
- Human resources development at the local level is essential for continuing the deinstitutionalization process. Training programmes for local personnel should help them acquire the necessary managerial and professional competences.
- It is unlikely that the deinstitutionalization process would register significant and uniform progress, unless more stable, earmarked transfers from the Central Government to the local level will be put in place and the systems of incentives re-aligned to be conducive to the creation of community services.

3. Child protection systems in Europe

Key facts on European child protection systems

- Childcare and protection policies in most European countries are converging towards a model that combines elements of family support and child protection.
- A common direction of development can be observed over the last decades: it is characterized by a shift from institutional care to foster care and community-based services.
- Historical conditions, cultural norms, economic and political factors had an enormous influence on the way child care and welfare services developed; they continue to have a crucial role in how child protection is organized today in each country.
- The impetus to change emerged at very different times across Europe with Southern and Eastern European countries having to make up for lost time.

The most commonly known typology of child protection systems was developed by Gilbert (1997) which differentiates countries according to two basic orientations: ‘child protection’ where the priority is to protect the child from harm through the use of legalistic and coercive measures, and ‘Family service/support’ where priority is given to cooperation with and support to the family and the child. Liberal welfare systems such as the US or the UK would typically belong to the first group, the Nordics to the second while countries like Germany or the Netherlands would be somewhere between the two. Since the mid-1990s, however, a convergence towards a third ‘child development’ approach could be observed; it incorporates many features of the two other orientations, but places the individual child in the centre (Table 1) (Gilbert et al., 2011).

Table 1 A typology of child protection systems

| | <i>I. Child protection</i> | <i>II. Family service</i> | <i>III. Child development</i> |
|---|---|--|---|
| <i>Problem frame</i> | Deviant behaviour and dysfunctional parenting | Social/psychological stress and family issues | Child’s developmental needs and unequal outcomes for children |
| <i>Aim of intervention</i> | Protection/harm reduction | Prevention/social bonding | Harm reduction and overall child well-being |
| <i>Mode of intervention</i> | Legalistic/investigative | Therapeutic/needs assessment | Best interests determination and early intervention |
| <i>State-parent relationship</i> | Adversarial/coercive | Partnership with, and offer of help to, families | State supports parental responsibility, independent relationship with the child |
| <i>Balance of rights</i> | Children’s & parents’ rights enforced through legal means | Parents’ rights to family life mediated by professional social workers | Children’s rights paramount but parent’s role supported |
| <i>Child protection-family support relationship</i> | Child protection services separate from family support services | Embedded in broader family support programmes | Located in broader welfare services for all children-in-need |

Source: adapted from Gilbert (1997) and Gilbert et al. (2011).

Child protection systems in Europe

Despite this converging trend, the ways in which child protection systems are organized and services delivered remains much influenced by the historical, cultural and institutional conditions and the specific context in which they developed (del Valle and Bravo, 2013a). Thus, while countries may have similar orientations towards child protection (see Table 2) there are still noticeable differences in how policies and specific interventions are implemented.

Table 2 Main characteristics of the child protection system in Sweden and Germany

| Sweden |
|--|
| <ul style="list-style-type: none"> • Child welfare service is part of general social services • Universalistic with specialised services for those most at risk • Preventive services in the family characterised by a therapeutic, family-sensitive approach • Placement outside the home can take place on a voluntary basis • Low use of out-of-home care with short-term placement • Increased use of foster care, but with less reliance on kinship care • Well-developed after-care services offering support for the transition from care to adulthood • Adoption is used in very rare cases and is not possible without the consent of birth parents |
| Germany |
| <ul style="list-style-type: none"> • Child welfare services provided through youth care services consisting of three modalities: (1) community-based services (incl. ambulant care); (2) day care and treatment; (3) alternative services (residential care and foster care) • Focus on preventive, early intervention services for families • Professionalization of the foster care sector • Personalised approach to service provision using the social pedagogical approach • Adoption is of secondary importance |

There are considerable variations as regards the organization of child protection systems and the operation of related support services, in line with the administrative approaches of European countries. With the exception of a few countries, such as Ireland for instance, child protection systems are built upon a regional or local decentralized model (FRA, 2014). In Austria, Germany, Spain and the UK, responsibilities are assigned to regional-provincial authorities, federal states, autonomous communities or other delineated regions, but municipal authorities still bear primary responsibility for child protection (FRA, 2014). In Hungary, Italy, Poland and Romania, regional and local authorities share responsibilities whereas in Sweden and, since 1 January 2015, also in the Netherlands, local authorities carry full responsibility with a relatively high level of autonomy.

In most countries, outsourcing of care services to private organizations is generally allowed by law, but only in the UK, Ireland, Germany and the Netherlands, private-commercial institutions play an important role in running a large share of alternative care (FRA, 2014). Although in Sweden local authorities are typically the ones to implement child protection policy and act as service providers, there has been during the last decade a notable shift from general welfare services financed by taxes to increasing marketization in sectors of the welfare system including the area of child protection (Backe-Hensen, 2013).

Finally, limited information is available on child protection expenditures. In the overall majority of countries, there are various budget items covering different expenditures falling under the scope of different ministries (e.g. education, health, justice etc.) meaning that expenditures connected to child protection are often not visible (FRA, 2014).

3.1 Deinstitutionalization in childcare

Child welfare and child protection provisions in Europe were generally based on institutionalization until the 20th century when, with the appearance of national legislation on the protection of children, protection measures spread. In Sweden, the first law that regulated foster care was passed in 1902 and was based on the earlier child protection legislation in Norway from 1896 (Hessle and Vinnerljung, 2000). In the UK, foster care or 'boarding-out', as it was more commonly known, had long been an option, but had no legal foundation until 1926 when the first law on foster care came into force (Keating, 2013). Despite these first steps towards family foster care, in most European countries institutional care remained the dominant form of child protection provision until around the 1960s.

The move towards deinstitutionalization was prompted by several factors associated with economic, political, cultural, administrative and legal changes. Perhaps most crucial among them was a growing concern among professionals and social scientist about the ill effects of prolonged stay in large care institutions on children's development. A number of early studies from the 1940s and 1950s that analyzed the impact of institutionalization on young children found long-term scarring effects on their emotional, social and cognitive development (Castle et al., 1999; Dozier et al., 2012). Increased awareness of the importance of family involvement was another important factor in driving forward agendas for change. In the Nordic countries and in the Netherlands, this development was underlined by a strong commitment to the family support model, giving priority to family reunification and rehabilitation of birth parents (Backe-Hansen et al, 2013; Harder et al, 2013). In the UK, de-institutionalization had initially a strong child protection component with a focus on coercive measures, which was partly a response to the child abuse scandals of the 1960s (del Valle et al, 2013a). In the case of Italy and Spain, the development of community-based measures as alternatives to institutionalization began to appear in the 1970s and coincided with major administrative reforms that transferred the responsibilities for health and social services to local authorities (del Valle et al, 2013b). In Eastern European countries, political ideology played a significant part in the development of large-scale institutions after the Second World War as well as in the subsequent deinstitutionalization process that started in the early 1990s (Anghel, Herczog and Dima, 2013). Finally, the modernization of child care and child protection services has been helped enormously by international conventions and guidelines, such as the UN Convention on the Rights of the Child (1989), the UN Convention on the Rights of Persons with Disabilities (2006) and the UN Guidelines on Alternative Care for Children (2009), which provided a normative basis for action.

Although the momentum to change emerged at different times across Europe and the processes and the patterns of deinstitutionalization also varied between the countries, there has been a common direction of development over the last decades characterized by:

- A shift from institutional and residential care to family-type placements and community-based care and support services for children and their families; and
- An increased emphasis on prevention and early intervention to avoid new placements.

The closure of large institutions has also been an important part of the deinstitutionalization process especially in Eastern Europe where institutionalization was not only more widespread, but also relatively recent. A number of these countries appear to have successfully managed to close down many of their large institutions, the process, however, is still far from being complete.

Child protection systems in Europe

Transition from residential to foster care

The transition from residential care to family placement is apparent in the statistics, even in the last decade. Table 3 shows the rates of out-of-home care placements (i.e. the number of children taken from their parents' home and placed in care per 1,000 children) by residential and foster care in 10 European countries and England. While almost all countries experienced an increase in out-of-home care placements, the changes in the rates of residential and foster care indicate a decreasing reliance on residential care in favour of foster care. This is most visible in the Netherlands, Hungary and Romania where a clear shift from residential to foster care can be observed. Even in Germany, where residential care tends to be used more frequently, a growing number of children without parental care are placed in foster care.

Table 3 Rates of out-of-home care (OOHC), residential care and foster care (per 1,000 children)

| | | Total OOHC | Residential care | Foster care |
|-------------|-----------|------------|------------------|-------------|
| England | 2001 | 4.2 | 0.8 | 3.4 |
| | 2012 | 5.0 | 0.6 | 4.4 |
| Ireland | 2000 | 3.9 | 0.6 | 3.3 |
| | 2011 | 5.3 | 0.4 | 4.9 |
| Germany | 2000 | 9.8 | 6.1 | 3.7 |
| | 2011 | 12.6 | 7.0 | 5.5 |
| Netherlands | 2000 | 9.1 | 5.8 | 3.3 |
| | 2011 | 10.1 | 4.4 | 5.7 |
| Norway | 2000 | 6.8 | 1.1 | 5.7 |
| | 2010 | 9.2 | 1.3 | 7.9 |
| Sweden | 2000 | 6.9 | 1.7 | 5.2 |
| | 2010 | 8.6 | 2.4 | 6.2 |
| Spain | 2000 | 4.6 | 2.0 | 2.6 |
| | 2011 | 4.3 | 1.7 | 2.6 |
| Italy | 1998/1999 | 2.5 | 1.4 | 1.0 |
| | 2010 | 2.9 | 1.5 | 1.4 |
| Hungary | 2000 | 8.5 | 4.6 | 3.9 |
| | 2011 | 10.2 | 3.9 | 6.3 |
| Poland | 2005 | 10.0 | 2.9 | 7.1 |
| | 2013 | 9.3 | 2.4 | 7.1 |
| Romania | 2000 | 17.2 | 11.2 | 6.0 |
| | 2013 | 16.3 | 6.0 | 10.2 |

Source: Own calculation based on administrative data from UK Department of Education, 2001, 2012 (England); Department of Health and Children, 2000, Health Service Executive, 2011 (Ireland); Harder et al, 2013 (Germany, Netherlands); Backe-Hansen et al, 2013 (Norway, Sweden); del Valle et al, 2013 (Italy, Spain); Central Statistical Office, 2012 (Hungary); Central Statistical Office 2014 (Poland); Anghel et al, 2013 (Romania). Population data: UK Office for National Statistics (population estimates for mid-2001 and mid-2012); Eurostat Database (population on 1 January).

Note: Children aged 0-17.

Caution is needed, however, in interpreting these data for comparative purposes because of differences in administrative definitions and in methods of calculation; in addition, the years represented for each country are not exactly the same. It is also important to bear in mind that the data used for calculating the rates provide a snapshot of the number of children who were in care at a particular point in time and may not capture those who stayed in care only for a brief period.

Child protection systems in Europe

The degree to which foster care is used as an out-of-home-care option varies greatly across countries (Table 4). In England, Ireland and Norway foster care accounts for more than 85% of out-of-home care. In these countries, only a small percentage of children (less than 15%) are placed in residential care. It is notable that in Sweden the percentage of residential care is double that of Norway. This can be explained by the higher number of young unaccompanied asylum seekers that Sweden accepts and which inflates the figures for residential care (Backe-Hansen et al, 2013). Still, foster care is clearly the preferred type of out-of-home placement in Sweden. In 2010, 72% of children taken into care were placed there. In Spain, Hungary and Romania, about 60% of out-of-home care placements are in foster care whereas in Germany, Italy and the Netherlands there is still a relatively large proportion of children being cared for in residential care settings (over 40%). In the case of Italy, there is an equal distribution between residential and foster care placements.

Table 4 Children aged 0-17 years in out-of-home care

| | Out of home care | Residential care | | Foster care | |
|--------------------------|------------------|------------------|------|-------------|------|
| | N | N | % | N | % |
| England ¹ | 57,210 | 6,950 | 12.1 | 50,260 | 87.9 |
| Ireland | 6,007 | 443 | 7.4 | 5,564 | 92.6 |
| Germany | 167,477 | 93,785 | 56.0 | 73,692 | 44.0 |
| Netherlands ² | 35,435 | 15,372 | 43.4 | 20,063 | 56.6 |
| Norway | 10,223 | 1,436 | 14.0 | 8,787 | 86.0 |
| Sweden ³ | 16,600 | 4,700 | 28.3 | 11,900 | 71.7 |
| Italy ⁴ | 29,309 | 14,781 | 50.4 | 14,528 | 49.6 |
| Spain ⁴ | 35,505 | 14,059 | 39.6 | 21,446 | 60.4 |
| Hungary ⁵ | 18,287 | 6,927 | 37.9 | 11,360 | 62.1 |
| Poland ⁴ | 77,072 | 19,252 | 25.0 | 57,820 | 75.0 |
| Romania | 61,640 | 22,899 | 37.1 | 38,741 | 62.9 |

Source: UK Department of Education, 2012 (England), Health Service Executive, 2011 (Ireland), Harder et al, 2013 (Germany, Netherlands), Backe-Hansen et al, 2013 (Norway, Sweden), Central Statistical Office, 2014 (Poland), del Valle et al, 2013 (Italy, Spain), Central Statistical Office, 2012 (Hungary), Anghel et al, 2013 (Romania).

Notes: Data for Norway, Sweden and Italy refers to 2010, for Ireland, Germany, Netherlands, Spain and Hungary to 2011, for England to 2012, and for Romania to 2013.

¹Data refers to children who were in out-of-home care at 31 March.

²The residential care numbers do not include children in inpatient mental health care/child psychiatric provisions and in orthopedagogical residential care centres. The total out-of-home care numbers do not include children who were in residential or foster care for a very short period.

³Data refers to children who were in out-of-home care on the 1st of November.

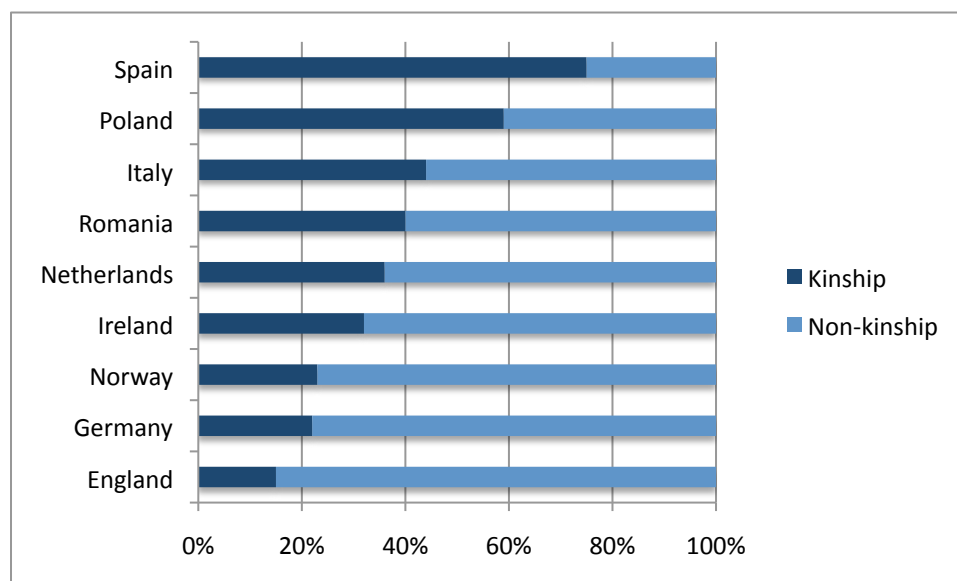
⁴Data refers to children who were in out-of-home care on the 31st of December.

⁵Data on residential care include children living in special care institutions (The number was 315 in 2011).

Further distinguishing foster care by kinship and non-kinship care indicates that a relatively large percentage of children in foster care live with a relative in Poland (59%), Italy (44%), Romania (40%), the Netherlands (36%) and Ireland (32%). In Spain, two-third of foster care was family-related although the figure might be misleading as it includes only those autonomous communities that provide this differentiation (del Valle et al, 2013). In the case of Sweden, no data are available by kinship or non-kinship care, but statistics on network placements show that in 2010 around 21% of children in foster care were placed with a member of the child's own network (this can be a relative, but also an unrelated person close to the child, such as teachers or neighbours) (Backe-Hansen et al, 2013).

Child protection systems in Europe

Figure 1 Foster care placements by kinship and non-kinship care (%)



For sources and Notes See Table 4.

The cases of England and Ireland merit highlighting, because both have implemented an almost exclusive foster care model within a relatively short time, but, unlike in England, kinship care in Ireland has played a significant role in this transformation. The rise of kinship care in Ireland mainly resulted from increased demand on foster care services after the closure of large institutions, which could not be met due to difficulties in recruiting and retaining sufficient numbers of professional carers (Munro and Gilligan, 2013). National minimum fostering allowances paid to both unrelated and kinship foster carers were introduced in 1991, which further formalized kinship care and contributed to its greater role and recognition. In addition, kinship care in Ireland has traditionally been the preferred arrangement when children are not able to stay with their parents and this was also endorsed in the 1991 Child Care Act.

While research is mostly positive regarding the outcomes and experiences of children and young people who are cared for by their extended family (Daly and Gilligan, 2005; Ward et al, 2014), there is also evidence indicating the need for more extensive support for kinship carers. A review of international literature by MacMillan et al (2009) found that kinship carers, despite being more vulnerable (e.g. on average tend to be older, lower educated, report more parenting problems), receive less caseworker support and fewer non-child related welfare services than non-kinship foster parents. In addition, adequate training and parental support is not always forthcoming. While all EU member states have legal provisions in place to ensure the quality of care for children and to facilitate access to training and post-placement support for foster parents, in most cases these do not apply to kinship carers (FRA, 2014).

The following examples from the Netherlands and England illustrate training programmes that also target kinship carers:

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- ⇒ *STAP in the Netherlands*: all foster parents are required to complete a preparation programme called STAP, which is based on the US MAPP (Model Approach to Partnership in Parenting) model (Strijker and Knorth, 2007). Candidates have to attend at least four meetings to be considered for the role of foster parent. Kinship foster parents are invited to participate at the meetings, but it is not obligatory for them. The next step is an evaluation based on a five-criteria assessment for good foster parenting. This is then followed by home visits and creating a family profile. Taking part in the assessment and the family profile is mandatory also for kinship carers. In addition, professional support is available for all foster parents through a 24-hour support line (Laklija, 2011).
- ⇒ *KEEP in England*: training and support has been available for both professional and kinship foster parents in the KEEP (Keeping Foster and Kinship Carers Supported) programme since 2009 (National Implementation Service, 2015). KEEP is designed for foster parents looking after children aged between 5 and 12. It works as a prevention programme with the aim to increase the parenting skills of carers, decrease the number of placement disruptions and to improve child outcomes. The programme is funded by the UK Department for Education and is organized and delivered through local authority partnerships.

Community-based services and support for children and families

Community-based services and support for children and the families are aimed at preventing the separation of children from their parents and thus to avoid the need for alternative care (i.e. residential or foster care). Such services can be provided in the area of health, education, living conditions, and can include a wide spectrum of support measures, such as parenting courses, financial assistance and day care. Examples of development in family support include the Sure Start programme in Hungary, which is implemented in the most disadvantaged micro-regions of the country, targeting high-risk and marginalized families, and the Troubled Families programme in the UK. Three recently implemented government programmes on preventive parental support are the Swedish National Strategy for Developing Parental Support, the German Early Support initiative and the Preventive Measures Package programme in Denmark:

- ⇒ *National Strategy for Developing Parental Support in Sweden*: adopted in 2009, the strategy aimed to enhance and develop universal support for parents throughout the child's entire upbringing (i.e. until the aged of 17) (EPIC, 2014). To achieve this objective, a total of about EUR 15 million was allocated by the government in funds to local authorities and research institutes and an additional EUR 232,000 was assigned for the dissemination of best practices and knowledge gained from the implemented parental support projects. Altogether, 19 municipalities received stimulus funds and 50 more have indirectly benefited through collaboration. The strategy specifically highlighted that the values of the programmes should be based on the UN convention on the Rights of the Child, and in line with gender equality principles.
- ⇒ *"Early Support" ("Frühe Hilfen") in Germany*: this federal parental support programme was implemented as part of the 2012 Federal Child Protection Act to promote the expansion of multi-professional early assistance networks especially in the areas of child and youth welfare and health. The initiative also aimed to ensure that mothers and fathers in vulnerable situations receive greater assistance from family midwives. A total of EUR 177 million has been made available for the Early Support programme until 2015.

- ⇒ *"Preventive Measures Package" in Denmark*: launched in 2011, it covers a wide range of initiatives that ensure early support for disadvantaged children and young people, including those with disabilities. The focus is on prevention combined with strengthening parental skills, building strategic partnerships between municipalities and voluntary organizations, and the use of sports and leisure activities for children. The Government has allocated DKK 70 million per year to the programme for the period 2014-2017.

3.2 Good practice examples in Hungary

Sure Start¹

- The Sure Start programme aims to prevent developmental delay, promote mutual learning and support as well as integration of deprived, mostly Roma, children and their parents into the community.
- It provides a chance, at the earliest possible age (0-5), for children living in poverty and/or who do not have access to quality services.
- Working closely with the local community, enhancing and facilitating cooperation of local actors, especially, various service providers.

Sure Start was developed with the objective that early education and support should be available for all children and their families in order to reduce health and social inequalities in the most deprived micro-regions in the country. All of the 36 sub-regions where the program has been implemented suffer from inadequate child-welfare services, which are often over-burdened, under-resourced and are not able to provide the necessary support. In particular, there are very limited day care opportunities for children under 3 and many of them start kindergarten later than the compulsory starting age.

The most important aims of Sure Start are therefore, to provide early education opportunities to children, to encourage their cognitive development and improved emotional wellbeing and to reduce regional poverty, deprivation and ethnic inequalities. By achieving this, Sure Start aims to improve life perspectives, future opportunities and outcomes. The programme has a holistic and comprehensive approach, based on the child's developmental needs and rights, involves parents as partners and helps them discover and use their own resources and capabilities.

Services and support are delivered on the premises of Sure Start Children Houses, where mothers or other caregivers and their children are offered planned activities delivered by trained staff. While everyone from the local community can use the services, there is a special focus on children from poorer, deprived and minority, mostly Roma, families. The programme mainly addresses the child's complex needs through play and discovery. Sessions are organized around activities that aim to promote physical development, communication and emotional stimulation, independency, attention, memory, major motor skills and sense of direction. The active involvement of parents is a key point

¹ More information is available at:
<http://gyerekesely.eu/wp/>

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to understand and contribute to the optimal development of their children. Parents are encouraged to play and interact with the children and reflect on their needs. In addition, parenting classes are available as well as self-help groups and personal consultations. Parents can also use the washing facilities or seek work with provided assistance and use the IT services.

The location of Sure Start houses is decided based on their proximity to the intervention's target groups in order to make it as accessible as possible. Reaching the most isolated groups has been shown to be often difficult and the involvement of Roma and non-Roma families in the same activity may also be problematic. Since most of the service users are from the Roma population, Sure Start managers often employ Roma staff members, as well. Sure Start works very closely with the local municipalities and local health and child welfare services, kindergartens and other institutions in the local community.

By 2014, 115 Sure Start Children's Houses operated in Hungary. Of these, 49 receive funding from the local municipality and 66 are financed through EU framework projects (i.e. TÁMOP).

Early Intervention Centre²

- The initiative focuses on early intervention and provides a complete approach to care for young children with delayed or impaired development and their families.
- Services and support are delivered by an interdisciplinary team of professionals.

The Early Intervention Centre (EIC) provides a combination of services for children with delayed or impaired development aged between 0-6 years. Services are delivered by a group of specialists focusing on the development of the child as well as the needs and circumstances of the family. The main goal of their activities is to ensure the health and well-being of the child, to enhance families' abilities in caring for their children and to minimize developmental delays.

The Centre provides a complete approach to care with several different experts, including paediatricians, special teachers, physiotherapists, psychologists, social workers and integration specialists, working together in an interdisciplinary team built around the child. In the first step, a diagnostic assessment of the child is carried out where a group of highly qualified professionals review the medical history and recent problems, and then examines the child using the latest methods. After evaluating the assessment results, special therapies that best suit the needs of the child are selected. Specialists do this by working with parents as partners, also taking care of their needs. While some of the therapies completely involve the parents, others require them to only attend and observe. In 2003, 2 day care groups offering specialized help for children with autism and severe and multiple disabilities were added to the Centre's services.

Support for the parents in the form of parent groups, counselling or Individual psychotherapy is also available together with assistance with legal matters or guidance in educational matters such as integration in children's communities (nurseries or kindergartens). The Centre, which was established in 1992 in Budapest, operates as a foundation. Its activities are financed from public subsidies and private donations.

² More information is available at: <http://www.koraifejleszto.hu/index.php?ln=en&p=text&id=1&m=1>

3.3 Good practice example in Italy

P.I.P.P.I.³

- Using a holistic and integrated approach, the programme offers a diverse set of activities that are carried out with the help of multidisciplinary teams.
- Key strengths of P.I.P.P.I. include its strong focus on the child and the family, and the attention at the local level that supports the development of new coordinating procedures and systems.

P.I.P.P.I., which stands for Program of Intervention for Prevention of Institutionalization, is a research-training intervention targeting vulnerable families. Its primary goal is to prevent the out of home care placement of children through parenting support with its activities focusing on improving parenting skills, promoting involvement in the children's life and strengthening social networks (Daly, 2014). To achieve this, the programme applies an inclusive, holistic approach that encourages the involvement of all relevant adults in the child's life (e.g. parents, other family relatives, teachers, social workers).

The programme consists of four main types of activities:

- Home care intervention provides support in building parenting capacities and parent-child relationships in terms of education, care, emotional, cognitive and behavioural development etc. This is carried out by home-care workers who visit families in their homes on a bi-weekly basis.
- Parent groups, organized once a week, involve group activities where parents can share experiences with each other.
- Family helpers are volunteers who provide families with emotional and practical support, such as problem solving in daily life or learning to use social resources.
- Cooperation between schools, families and social services refers to involving the schools attended by the children in the programme. Teachers are invited to be full members of the multidisciplinary team working with the family.

An integrated needs-assessment and the construction of a care plan are central to the programme. The assessment is carried out using a web-based tool (RPMonline), which was adopted from a similar tool developed in the UK. All members of the child's network are invited to participate and based on results from the assessment, a care plan is devised outlining the actions to be followed by each family.

The evidence from the first phase of the implementation is encouraging. Follow-up assessment with the families who participated in the programme shows an improvement in all evaluated functional areas. In 60% of cases the outcome was successful, and partially successful in a further 19.5%, in terms of keeping children out of care. For all families in the trial group the outcomes were better than for families who did not participate in P.I.P.P.I..

³ More information is available at:
<http://www.minori.it/il-programma-pippi>

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P.I.P.P.I. was implemented in four overlapping stages (Milani et al, 2014). The first implementation phase started in 2011 and involved 206 practitioners (from the Child Protection System, the Local Health Authority, the School, the Cooperation sector) in 10 Italian cities (Bari, Bologna, Florence, Genoa, Milan, Naples, Palermo, Reggio Calabria, Turin, Venice) and with an outreach of 100 children. The selection of cities was based on their ability to secure funding from the National Fund for Children (285/1997). At the end of the first phase it was decided to extend it to a second phase. The Venice region proposed the programme to be implemented at a regional level, and P.I.P.P.I. was extended from the municipal to the district level. In the fourth phase, there was a further extension to 50 districts in 18 regions, reaching more than 500 children. P.I.P.P.I. has since been up-scaled to a national programme, moving from an initial investment of € 500,000 to € 3 million today.

4. Long-term care systems

Key facts on European long-term care systems

- Shifting the balance of long-term care from institutions to care provided at home and in the community has been a key policy trend in the past decades in Europe. As a result, in most countries, only a minority of older people currently receives care in institutions.
- Countries have diverged markedly on the paths to achieve this policy, ranging from an approach based on developing home care services while transforming institutions – and sometimes even banning further construction – to the establishment of cash benefits.
- These policies have also been strongly influenced by parallel policy processes such as implementation of user choice or concerns over the fiscal sustainability of long-term care.
- Despite this trend, policies at the national level were also shaped by their different starting points: for example, low development of long-term care services in general in Southern Europe, or the inheritance of a more medicalized model in Eastern Europe.

The United Nations Convention on the Rights of Persons with Disabilities enshrines in its article 19 the “equal right of all persons with disabilities to live in the community, with choices equal to others”, which includes choosing their place of residency. Similarly, the European Charter of the Rights and Responsibilities of Older People in Need of Long-term Care and Assistance includes under its article 2 the “right to choose a place to live that is adapted to your needs, whether in your own home or in formal care settings”. Both documents provide the political underpinning of a process of transformation of long-term care that has focused on the deinstitutionalization of older people, i.e. on allowing them to be cared for in their own homes and communities. This shift towards ‘*ageing in place*’ (OECD, 2005) has taken place in tandem with calls from the disability rights movement for greater empowerment and independent living (www.independentliving.org); as well as with increased concerns about the fiscal sustainability of long-term care systems based mainly on institutional care. Furthermore, ageing in place seems to correspond to the widespread opinion of the majority of people in Europe (European Commission, 2007).

Although moving away from institutionalization and enhancing availability of home and community care has been a general policy trend (Huber, Rodrigues, Hoffmann, Gasior & Marin, 2009), countries in Europe have followed different paths. In keeping with the service-based Nordic model of long-term care, countries such as Denmark or Sweden have developed a two-thronged approach based on the development of services in the community and adaptation of institutions into adapted-housing or individual services dwellings⁴ (terminology varies between countries). This adaptation process has sought to de-medicalize the care provided and the infrastructure providing institutional care and turn most institutions into home-like environments. Table 5 provides an overview of some of the measures implemented by the Nordic countries.

⁴ The latter refer to houses adapted to the needs of older people where care is available around the clock.

Table 5 Examples of policy measures towards deinstitutionalization in Nordic countries

| Countries | Policy measures |
|------------------|---|
| Denmark | Since 1998, institutions have been transformed into individual dwellings, where care services are provided free and beneficiaries only pay for rent and personal services. Care support and services have been made identical irrespective of where it is provided (institutions or at home). |
| Finland | Combination of increased supply of home-care, with adaptation of existing institutions and ban imposed on the establishment of new ones. |
| Sweden | Increase in supported housing arrangements, the most common being group accommodation located in ordinary housing areas with interconnected flats with social support granted according to needs. Development of personal assistants employed directly by the municipalities, providing help with activities of daily living. |

Source: Adapted from (Shima & Rodrigues, 2009).

A number of other countries sought to establish cash-for-care benefits as part of their strategy to keep people in the community. These cash-for-care benefits have also sought to accomplish other goals, such as cost-containment, support for informal care, user choice and competition and support for informal care (Da Roit & Le Bihan, 2010). The characteristics of cash-for-care benefits vary substantially across countries (see Table 6). In some cases (e.g. England) these benefits cannot be used to pay for institutional care altogether. In most cases these cash-for-care benefits allow for the hiring of personal assistants (in some cases also close relatives) that can also be instrumental in maintaining older people in their homes.

Table 6 Characteristics of selected cash for care benefits

| Country | Benefit | Formal attachment of informal carer |
|-----------------|--|--|
| Austria | Cash Allowance for Care (Pflegegeld) | No need to account for use of allowance. |
| Germany | Cash Allowance for Care (Pflegegeld) | No need to account for use of allowance |
| UK (England) | Direct payments | Carers employed directly by those in need of care must comply with UK employment law. Need to keep record of all expenses, which must be made through a specially created bank account where direct payments are made. Close relatives and co-residing relatives cannot be paid except in exceptional circumstances. |
| The Netherlands | Personal budgets (Persoons Gebonden Budget - PGB) | Need to present proof of expenses. Carers employed by beneficiary have a signed contract. Only a limited amount may be used without accounting for expenses. |
| France | Personal Attendance Allowance (Allocation Personnalisée d'Autonomie – APA) | Employment of carer directly or through agency, or transfer of payment to informal carer (not spouse) which is regarded as taxable income. Municipality monitors the implementation of the care package. Spouses cannot benefit from it. |

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| | | |
|--------------------------|---|---|
| Italy | Attendance allowance (Indennità di accompagnamento) | No need to account for use of allowance No proof of expenses is required. |
| Belgium | Attendance allowance (L'Allocation pour l'aide aux Personnes Âgées – APA) | Can be used to pay for informal care. Individuals need not to account for their expenses. |
| Sweden | Attendance allowance (Anhørig bidrag) | May be used to pay for informal care. Not taxable if used within the household. |
| Belgium (Flemish region) | Flemish Care Insurance (Zorgverzekering) | Possibility to transfer money to informal carer. |
| Luxembourg | Attendance allowance or nursing allowance | Part of in-kind benefit may be received in cash and used to pay for informal care, but only up to 10,5 hours a week, maximum. |
| Poland | Attendance allowance | May be used to pay for informal care. |

Source: Adapted from Huber et al, 2009: Table 5.3.

The information depicted in Table 7 provides an overview of the evolution of the balance between institutional and home care provision (including cash-for-care benefits where relevant) between the middle of the 1990s and today across Europe.

The figures show that only a small share of older users of long-term care is presently cared for in institutions. The unweighted average share of older people in institutions for the most recent date across the countries in Table 7 is only 3.4%. Furthermore, the share of older people that are cared for in institutions has either remained stable or even decreased across several countries.

Behind the general trend for deinstitutionalization stand different national trajectories (Rodrigues & Hoffmann, 2011). Denmark has introduced a legislative ban on the construction of new care homes (Lewinter, 1994). In England, the development of home care was triggered by changes in public financing of long-term care in the wake of the introduction of quasi-markets in the early 1990s (Glendinning, 2012). Furthermore, England, as well as Sweden, sought to target home care services to older people with complex care needs in order to maintain them in their homes (Rodrigues & Hoffmann, 2011). Although the Nordic countries have taken important steps in an effort to deinstitutionalize older people, it is important to emphasize that the conversion of many care homes in these countries did not always fundamentally change the nature of care provided (Lewinter, 2004). Nonetheless, it seems undeniable that the move towards adapted or sheltered housing in these countries was accompanied by a slow transformation of institutional care, which in turn came to resemble more care provided in a home-like environment.

In Southern European countries there was actually an increase in the number of users of institutional care as public policies sought to address unmet needs in long-term care (Leichsenring, 2004). A similar trend was observed in Germany, where there was an increase of 182,000 residents in institutional care during this period, spurred by the introduction of the Long-term Care Insurance which paid higher benefit amounts to people in institutional care than for home care, for comparable levels of need (Rothgang, 2010).

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Table 7 Changes in the share of 65+ cared for at home and in institutions (mid 1990s to most recent date)

| Country | Mid 1990s | | Year | Most recent date | |
|--------------------------|---------------|------------------|---------|------------------|------------------|
| | Home care (%) | Institutions (%) | | Home care (%) | Institutions (%) |
| Austria | 13.2 | 2.8 | 2008/06 | 18.2 | 3.3 |
| Belgium | | | 2004/10 | 5.9 | 5.0 |
| Bulgaria | -- | -- | 2008/07 | 3.0 | 0.9 |
| Czech Republic | 8.0 | 3.4 | 2009 | 11.2 | 2.3 |
| Denmark | 20.0 | 4.1 | 2009/10 | 13.0 | 4.6 |
| Estonia | 1.5 | 1.2 | 2009 | 6.0 | 1.8 |
| Finland | 15.6 | 5.1 | 2009 | 7.2 | 4.8 |
| France | 2.5 | 2.4 | 2007 | 5.0 | 6.2 |
| Germany | 7.3 | 3.3 | 2009 | 7.6 | 3.8 |
| Hungary | 2.0 | 1.8 | 2009 | 7.0 | 3.0 |
| Ireland | 5.6 | 4.4 | 2010/08 | 10.4 | 3.9 |
| Italy | 1.8 | 2.2 | 2009/06 | 3.6 | 2.0 |
| Latvia | 0.3 | 1.4 | 2007 | 1.9 | 1.4 |
| Lithuania | 0.8 | 0.7 | 2010 | 2.1 | 1.0 |
| Luxembourg | -- | -- | 2010 | 7.4 | 5.3 |
| The Netherlands | -- | -- | 2006/09 | 21.4 | 6.7 |
| Poland | -- | 0.5 | 2008/09 | 2.0 | 0.9 |
| Portugal | -- | -- | 2007 | 3.9 | 3.4 |
| Serbia | | | 2010 | 1.3 | 0.7 |
| Slovak Republic | -- | 1.9 | 2008 | 3.5 | 3.2 |
| Slovenia | 8.5 | 4.0 | 2009/11 | 6.9 | 4.9 |
| Spain | 1.1 | 2.8 | 2010 | 5.3 | 1.6 |
| Sweden | 12.0 | 8.4 | 2008 | 9.4 | 5.8 |
| United Kingdom (England) | 14.2 | 3.9 | 2008/04 | 12.5 | 5.0 |

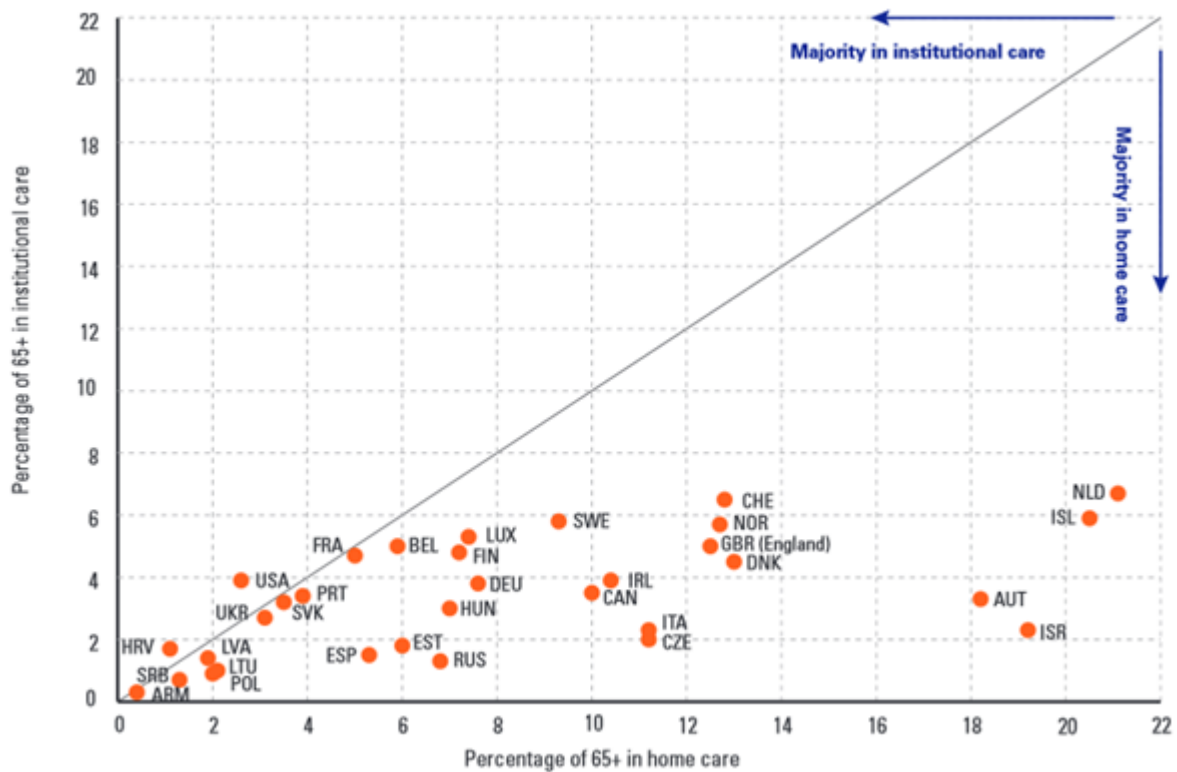
Source: Rodrigues et al, 2012: Figure 7.3 and Huber et al (2009): Table 5.1.

Notes: Belgium, Austria, Poland for 60+. France for 60+ for home care. Czech Republic, Hungary, Latvia, Portugal, Slovak Republic, Slovenia (mid 1990s) and Spain may include younger than 65+. Italy only home care services and not cash benefits.

In Eastern Europe, institutional care still accounts for almost half of older people receiving long-term care (Figure 1). In part this reflects the ‘inheritance’ of decades of a medicalized model of care, which emphasized inpatient care and that saw many hospitals being converted into large nursing homes in the 1990s (Zoidze, Gotsadze, & Cameron, 2007). The reliance on institutional care in these countries has also been linked to reductions in other social benefits for older people (e.g. housing, fuel, transportation) (Tobis, 2000), as well as to housing deprivation among older people, which remains comparatively high in Eastern European countries (Lelkes & Zolyomi, 2009).

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Figure 2 People aged 65 and older receiving care benefits (cash or in-kind) in different care settings – 2009 or most recent year



Source: Rodrigues et al, 2012: Figure 7.3.— Notes: Belgium and Austria for 60+. France for 60+ for home care.

As mentioned before, budgetary constraints were also a driver for the re-focusing of care in home care. With population ageing, there were concerns that a growing share of people with activity limitations would translate into higher demand for institutional care. However, available data on age-standardised institutional care use (i.e. age-adjusted rates of older people in institutional care) do not seem to reflect this concern (Rodrigues & Schmidt, 2010). The policy conclusion to draw from this is that higher use of institutional care is not necessarily an outcome of demographic ageing.

4.1 Four welfare regimes

Long term care has been defined by the WHO as: “The system of activities undertaken by informal care givers (family, friends and/or neighbours) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity”. While this definition embodies the core aspirations of the system, to which all European states subscribe, it is hiding a wide variety in the approach to its practical implementation. This high variability and the lack of satisfactory data and information have frustrated comparisons between different long-term care systems and have limited opportunities for learning and best-practice transfer between European countries. In order to close this gap, a series of simplifying classifications have been proposed over the years, reducing the complexity of long-term care systems to so called “ideal types”.

We note the typology proposed by Lamura (Lamura, 2007), further refined by Nies and colleagues (Nies, Leichsenring & Mak, 2013), which considers three key dimensions for the classification of European welfare regimes: the demand for care (e.g. population in need or at risk and the role of poverty driven factors), provision of informal care (e.g. share of multi-generation households and family care) and provision of formal care services (e.g. public expenditure on long-term care, share of older people receiving formal care services at home or in institutions). Table 8 below summarizes the characteristics of the four types of care regimes and offers some insight into the role of government in different national long-term care systems.

Table 8 A typology of European long-term care regimes

| | <i>Demand for care</i> | <i>Provision of informal care</i> | <i>Provision of formal care</i> | <i>Countries</i> |
|---------------------------------|-------------------------------|--|--|---|
| <i>Standard-care mix</i> | Medium/ high | Medium/low | Medium | Germany, Austria, France, United Kingdom |
| <i>Universal-Nordic</i> | Medium | Low | High | Sweden, Denmark, Netherlands |
| <i>Family based</i> | High | High | Low | Spain, Italy, Portugal, Ireland, Greece |
| <i>Transition</i> | Low | High | Medium/low | Hungary, Czech Republic, Poland, Romania, Slovakia, Latvia, Estonia |

Source: adapted from Lamura et al. (2007) and Nies et al. (2013).

Kraus et al. (2011) distinguish between four clusters, which, however, include a very different mix of countries (see Table 9 below). The diverse grouping reflects the increased complexity of the analysis and the different dimensions emphasized in the classification: access to care and entitlement, availability of cash benefits, choice of provider, quality assurance, coordination/integration of care, cost sharing, public expenditure as share of GDP and financing model. The analysis reveals that while the degree of patient-friendliness and financial generosity (average spending as a share of GDP is 1.6% in Western Europe, compared with 0.3% in Eastern states) tend to be higher in Western European long-term care systems, in terms of organizational depths there is no clear distinction between Western and Eastern European countries. Interestingly, the clustering exercise confirms only to a partial extent previous typologies based on macro-regional and geographical groupings: neither Baltic nor Eastern European countries form clusters by themselves, while Mediterranean

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countries are still grouped together and Scandinavian and Continental systems are placed in neighbouring clusters.

Table 9 A new typology of European long-term care regimes

| | <i>Nature of system</i> | <i>Characteristics</i> | <i>Countries</i> |
|------------------|---|--|---|
| <i>Cluster 1</i> | Informal care oriented, low private financing | Low spending, low private, high informal care use and support, modest cash benefits | Czech Republic, Germany, Slovakia, Belgium |
| <i>Cluster 2</i> | Generous, accessible and formalized | High spending, low private, low informal care use but high support, modest cash benefits | Denmark, Sweden, the Netherlands |
| <i>Cluster 3</i> | Informal care oriented, high private financing | Medium spending, high private, high informal care use and support, high cash benefits | Austria, United Kingdom, Finland, France, Spain |
| <i>Cluster 4</i> | High private financing, informal care seems a necessity | Low spending, high private, high informal care use but low support, medium cash benefits | Hungary, Italy |

Source: Kraus et al. (2011).

While such typologies are extremely useful in identifying differences and commonalities between care regimes and form the basis for most international comparisons, it is important to keep in mind that long-term care systems are constantly diverging from these types as they are ever changing under social and economic pressures, which vary between European countries. At the same time, while contextual specificities persist, all European care regimes are currently undergoing a process of convergence towards higher degrees of commodification and an increasing relevance of market-driven provision (Williams, 2012).

The case studies chosen for this report – Austria, Italy, Sweden and the Czech Republic – span all categories, irrespective of which typology is employed and are intended as a snapshot of developments in long-term care and deinstitutionalization across care regimes in Europe.

4.2 Austria

Key facts on the Austrian long-term care system

- Although deinstitutionalization has never been mentioned explicitly, Austrian multi-level long-term care policies have always been inspired by the goal to support people in need of care as long as possible in their own homes.
- The Austrian long-term care system, while relying on a combination of cash and in kind benefits, is built around a comprehensive system of long-term care allowances (*Pflegegeld*). The allowance is not earmarked, i.e. it can be used to partially cover the costs of in-kind services (e.g. institutional or home care) or simply to supplement the family budget as an indirect acknowledgement of family care.
- Responsibilities for social assistance, including long-term care services and facilities, are devolved to the regions, while the Federal Government has strengthened its responsibilities for financing the long-term care-allowance scheme and the so-called 'Care Fund' through general taxation.
- Over the past decades support for family carers has considerably improved (social insurance contributions for carers, enhanced care counseling, care leave for employed carers, extension of day-care, etc.) but cash-benefits are insufficient to compensate caregivers.
- The high degree of fragmentation between health and social care, insufficiently addressed by recent reforms, hinders collaboration between different care providers and remains a major barrier to an effective shift of care towards the community setting.

4.2.1 Overview of the long-term care system

With about 1.5 million people over 65 years of age (18.2 percent of the population) Austria has a relatively aged population even for EU standards and the ageing process is not likely to slow significantly in the next decades. As the health status of older people is an important determinant in shaping the demand for long-term care, the projected rising number of people above the age of 80 will contribute to rising demand, even if the proportion of older people with a rising healthy life expectancy will increase. A specific challenge for the development of long-term care in Austria consists in the fact that demographic ageing takes place particularly in rural areas, with respective problems concerning accessibility and the organization of support structures in alpine regions.

Although this scenario has been reported repeatedly over the past decades, long-term care policies have for a long time remained in the shadow. Indeed, it was the disability movement that triggered the political debate about comprehensive care allowances during the 1980s, when various organizations of people with disabilities yielded concerns about inconsistencies in treatment of different groups and gaps in coverage. This debate, however, eventually resulted in the introduction of a comprehensive system of long-term care allowances in 1993. This reform responded to the hitherto fragmented system of allowances that had existed to cover need for long-term care under various schemes and with different responsibilities across the social security system.

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The new system of a comprehensive long-term care allowance (*Pflegegeld*) replaced and unified the existing schemes (Evers, Pruckner, & Leichsenring, 1994; OECD, 2005). As a first step towards standardization, however, a state treaty and nine more or less corresponding provincial Long-Term Care Allowance Acts had to be adopted, as the nine provinces are responsible for long-term care by constitutional law. Thus, funding for the long-term care allowance (from general taxes) became a responsibility of the federal state while the provincial governments remained responsible for services in kind. This situation was slightly amended in 2010, when another reform step centralized all responsibilities for benefits in cash at the national level, while the provincial governments continue to be responsible for long-term care facilities and services. Since the implementation of the Long-term Care Allowance Act (*BPGG*) in 1994, all citizens in need of care, irrespective of age, are eligible for the same amounts of attendance allowances that are granted without means-testing, but according to a needs assessment in seven levels reaching from €154.2 to €1,655.8 per month (see Table 10).

The allowance has been conceived as a 'flat-rate contribution to compensate for expenditures caused by care needs in order to facilitate the necessary help and support for people with long-term care needs, and to improve their opportunities for independent living according to their needs' (*BPGG*, §1; own translation). This rationale did not interfere neither with social insurance based health legislation nor with social assistance related regulations for social services and long-term care facilities. Indeed, if – according to medical rationales – a person cannot be cured anymore and is in need of long-term care, it is up to the individual to cater for respective care, rather than the health insurance. If the person in need of long-term care moves to a care home, for instance, s/he has to use his/her income and the long-term care allowance granted upon application. If these amounts (and potential assets) do not cover all costs – which is most likely with fees for a place in a nursing home amounting to up to €6,000 – provincial welfare offices will step in according to the social assistance rationale, i.e. only if the individual pension, care allowance and assets do not cover all expenditure, social assistance may provide funding. However, the long-term care allowance as such is not earmarked so that it may also be used to purchase subsidized home care services, to compensate a family carer or to increase the general household budget. Indeed, about 80 percent of beneficiaries are cared for mainly by spouses and daughters, but also by sons and/or other family members without ever using professional support by home care services.

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Table 10 The Austrian Long-term Care Allowance (2014)

| <i>Level</i> | <i>Care needs per month</i> | <i>Amount in €/month (1)</i> | <i>No. of beneficiaries</i> | <i>Beneficiaries in %</i> |
|--------------------------------------|---|------------------------------|-----------------------------|---------------------------|
| I | > 65 hours | € 154.20 | 98,989 | 22.5% |
| II | > 95 hours | € 284.30 | 131,843 | 29.9% |
| III | > 120 hours | € 442.90 | 76,410 | 17.3% |
| IV | > 160 hours | € 664.30 | 62,534 | 14.2% |
| V | > 180 hours of heavy care | € 902.30 | 43,752 | 9.9% |
| VI | > 180 hours of constant attendance | € 1,260.00 | 18,183 | 4.1% |
| VII | > 180 hours of care in combination with complete immobility | € 1,655.80 | 9,186 | 2.1% |
| Total number of beneficiaries | | | 440,896 | 100.0% |

Source: Statistik Austria (www.statistik.at). Notes: (1) values as paid by 1/1/2014.

The care allowance can be used by individuals to cover the costs of formal (in-kind) care services, subject to availability. Two main types of long-term care services form the core of the Austrian system: institutional care and home-based services. Institutional care (including residential care, care in nursing homes, day care, short-term care, transitional care and senior citizens residences) is generally provided by local or regional authorities, but religious organizations and more recently NGOs are also relevant care providers. The provision of home-based services is strongly dominated by NGOs (most important of which are Caritas, Hilfswerk, Red Cross and Volkshilfe) and includes domiciliary care, home nursing care, home-help, 24-hour care, meals on wheels, mobile therapeutic services and transport services (Riedel & Kraus, 2010).

Given these key features, the Austrian long-term care allowance cannot easily be labelled as this scheme is neither part of the social insurance system nor an explicit element of social assistance schemes. Still, with yearly expenditures of about € 2.47 billion for about 447,000 beneficiaries (2013), of which 60 percent are over 80 years of age, it has become an important budget line. Together with net expenditures of about 2 billion € by provincial governments to subsidize care homes and long-term care services, the sector of long-term care is currently accounting for about 1.4 percent of GDP and for about 5.6 percent of total social security and health care expenditures (Eurostat). Whilst these expenditure levels are only slightly above the average of Western European welfare states, they are still relatively low compared to Sweden or the Netherlands. Due to the constantly rising demand⁵ and general cuts in public spending, current policies tend to restrict access conditions, e.g. by increasing the thresholds for eligibility in lower levels of care needs.

These restrictive tendencies are likely to neglect the fact that strengthening the purchasing power of people with long-term care by means of cash benefits and subsidized services has triggered a number of economic and societal advances that must not be underestimated. First, since the mid-1990s, though from a very low level, the supply of long-term care services and facilities has steadily increased, e.g. the number of hours provided in home care doubled to now about 17 million hours of

⁵ The number of beneficiaries has constantly increased from about 316,000 beneficiaries in 1995 to 451,000 at the end of 2013 (all administrative bodies; BMASK, 2014).

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care per year (BMASK, 2013; own calculations). These services are almost exclusively provided by private non-profit organizations, while residential facilities are managed by public (50 percent), private non-profit (25 percent) and commercial (25 percent) provider organizations. Secondly, the sector has contributed to a steady growth in employment, thus mainly contributing to a rising share of women in the labour market. Thirdly, considering the social return on investment of, for instance, home care where each euro invested is likely to foster monetary values of between €2.5 and €3.7 (Schober, Schober, Peric, & Pervan, 2012), the positive impact of developing long-term care services and facilities should not be neglected.

However, the use of cash benefits as a key driver for long-term care development also entails a number of caveats that call for additional endeavours to avoid undesirable consequences (Österle & Bauer, 2011). These include the support of family carers, the regulation of 'grey' markets in care, and the further development of an integrated long-term care system.

4.2.2 Drivers and barriers to deinstitutionalization: Encouraging family care and integrated care

Concerted policy measures aimed at deinstitutionalization and the promotion of community-based care in the Austrian system have, unfortunately, been limited. We note the cases of family care and the introduction of measures to support carers as positive steps towards encouraging long-term care in the community, while the slow progress towards care integration remains an important barrier towards this goal.

As for many other countries, the general goal in long-term care is to keep people in need as long as possible at home. While this type of (family) care has for a long time and almost exclusively been provided by women and free of charge, societal changes, in particular the rising labour-market participation of women and growing mobility, but also mounting longevity even with disabilities, have put this model under huge pressure. This pressure continues to be sustained by a large number of family carers – in Austria these account for at least 400,000 people – who would need respite, support and social security (Pochobradsky et al., 2005). Although a number of provisions have been introduced over the past two decades (e.g. social insurance contributions for carers, enhanced care counselling, care leave for employed carers, extension of day-care and other support facilities), cash benefits that cover only a small part of care-related incremental costs are only a minor incentive for family carers who are predominantly driven by family ethics in terms of duty, love and devotion. In 2014, an additional measure was introduced to facilitate care leaves for employees who care for a family member who is entitled to the long-term care allowance. During up to six months the carer is entitled to the equivalent of the unemployment benefit (55% of previous wage). Still, as care episodes are in many cases extending beyond this period, about 15% of family carers are reducing or completely abandoning employment, and as 'older workers' they are often confronted with high barriers to re-enter the labour market. In sum, the measures in place do not suffice to support a better balance between employment and care, and to provide respite to overburdened family carers. Despite these limitations, 37% of Austrians consider that professional care at home is available at an affordable cost, placing the country considerably above the European average – 31% (Special Eurobarometer 67.3, European Commission, 2007).

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Organizing and financing long-term care at the interfaces between formal and informal care, and between health and social care is a complex task that most welfare states have only started to address by means of still fragmented and often uncoordinated measures implemented in a reactive way, rather than through pro-active strategies responding to demographic ageing and the predictably rising demand (Leichsenring, Billings & Nies, 2013).

The legal and organizational framework of health and social services in Austria is still characterized by the fact that health and social services are strictly divided concerning legislation, competencies and financing. Whereas health care and its financing are subject to the logic of social health insurance (Ministry of Health, self-governing management of sickness funds), social care and long-term care are in the competence of the provincial governments – once more, with different departments for health and social affairs – and the Ministry of Social Affairs and Consumer Protection. A large variety of regional laws lead to differing regulations in social care between the Austrian provinces. For example, residential care homes as well as education for staff in these homes are part of the social services and thus legislated by the provinces, while hospitals and the education of nurses are subject to basic regulation by federal laws. Decentralization thus is an inherent issue to the Austrian division of competences based on the principle of subsidiarity, but not always linked with positive experiences when it comes to reforms and coordinated action.

In practice this leads to very restricted cooperation between hospitals responsible for the acute treatment of a patient and providers of necessary follow-up treatments and long-term care services (rehabilitation, home care, residential care). Functioning links and satisfactory forms of cooperation are often based on informal arrangements between institutions or on personal relationships, e.g. between a general practitioner and the director of a nursing home, between hospital staff and the provider of home care. The involved actors in this field – federal government, regions, health and social service organizations, municipalities, health insurances – have been aware of this dilemma for quite a long time and a number of efforts have been made to improve the situation by means of different model projects of integrated or at least coordinated health and social care. One lesson to be learned from these projects aimed at improving health and social care is that social service providers have learned to work together and keep the logic of competition in the background. In the meantime, many hospitals have nurses trained as discharge managers but the medical specialization still influences the organization and quality of discharge.

In the future, additional efforts will have to be undertaken to systematically improve the interplay between health and long-term care systems. Unfortunately, health care reforms and reforms in the long-term care sector are still largely discussed at separate tables. While an intermediate solution has been established for funding long-term care services and facilities by installing a 'long-term care fund' at the federal level, major reforms have been postponed. While strategic goals of health reform include a number of issues concerning coordination and comprehensiveness, related measures remain confined to the existing health care system. And while reforms in the education of social care workers have started to include health competencies, the latest reforms in the education system for nurses are likely to marginalize these efforts to better adapt to the long-term care needs of people living at home and in different residential care settings. Further improvements in the long-term care system are thus expected to be realized in small steps only. This includes the expansion of ICT applications to better organize and support the various stakeholders involved, quality development and measures to recruit and retain the workforce that is necessary to maintain and improve care services for people in need of long-term care.

4.2.3 Good practice examples in Austria

Integrated Care for Older People in Ludesch (IAP an der Lutz) – Vorarlberg region

- The municipality of Ludesch promotes ageing-in-place through an integrated care network consisting of: local doctors, the nurses' association, the local church group and community representatives (NGOs, patient families, local volunteer groups)
- The model includes: case management, home care services, outpatient and inpatient care in the Social Centre, short-term care, senior housing and promotes social and community activities

The Regional Government of Vorarlberg has started already during the 1990s to support and develop integrated care for older people in municipalities to promote ageing in place, community care rather than residential care, and to facilitate local solidarity by satisfying the needs of all stakeholders involved. Ludesch is a municipality where this model has been developed in a particularly efficient way, including case management and networking between several partner organizations. Driven by the goal to allow dependent elderly to remain in their familiar surroundings and to avoid for as long as possible their permanent institutionalization, the Ludesch municipality has made great strides in assisting the families of dependent persons to the extent necessary that they can perform the care tasks themselves.

The project started as a collaboration between the local doctor, the nurses' association, the local church group and some community representatives, and was initially dedicated to providing home care services. As the partnership took roots additional services were included in the mix: first the meals on wheels service and later case management. Finally, in 1993 a local Social Centre for community seniors was opened with the help of the municipality. Financing for the development of the necessary infrastructure was partly provided by the regional government, but operational costs for both inpatient and outpatient services are covered from federal funding, according to national reimbursement rules. The municipality of Ludesch contributes to personnel costs for community-based services, but their contribution remains limited.

The IAP has managed to establish:

- Case management for all geriatric patients after an adverse health event or at risk of institutionalization. The case management team includes doctors (GP or specialist), nurses and representatives of the social centre, who plan together the necessary care services and the future course of treatment. The team helps organize the care tasks of the family and, when necessary, provides the required training to family members.
- Outpatient home care, consisting of meals on wheels services and the "Mobile Forum" (MoHi), which provides cleaning and domestic help services. Depending on their mental and physical health, older individuals can decide which of the available services are necessary and which tasks they can carry out themselves (or with help from informal carers).
- The Social Centre has a capacity of 9 beds, 4-5 of which are used for outpatient care or short-term care, while the remaining are intended for inpatient services. The centre also includes a

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large public area that is accessible free of charge to everyone. It is specifically designed to accommodate the needs of the elderly and of individuals with reduced mobility and is often used for community events such as senior dances, card games, social get-togethers.

- Senior housing, designed to respond to the specific needs of the elderly while allowing them to maintain full independence.
- Short-term care is intended for older individuals who are generally cared for in the family. However, in the case of rare events like holidays, construction or repair work, etc. the family carers might be in need of relief from their care duties. In such situations, the IAP can take over all care duties and house the dependent older person in the Social Centre for up to 6 weeks.

The model has shown that traditional social planning must take into account that social innovations and the definition of clear goals may overhaul mainstream scenarios. For instance, while the regional plan for the nine municipalities coordinated by the social and long-term care centre situated in Ludesch had stipulated that 51 places in care homes would be needed by 2015, today there is hardly any need for about 30 places in residential care (19 long-term, 7 short-term and 4 day-care), although the proportion of residents above the age of 75 has risen consistently. An evaluation study carried out in Ludesch concluded that the average total per patient costs of day care, outpatient care and home care services provided is 30 to 50% lower than the corresponding costs per patient in a nursing home. Due to the success of integrated care for the elderly, since 2006, neighbouring municipalities have started to apply the same model for long-term care. As the Ludesch Social Centre will become the main hub in this network, plans currently exist for increasing its capacity.

‘Ageing in good company’ – Salzburg region

- Ageing in good company is an initiative of the regional government to support and encourage local initiatives promoting active and healthy ageing in the community, with the goal of establishing local care networks which can help improve the coordination between outpatient, inpatient and community services
- The model includes: case management, educational activities, promotion of social interaction and trainings for volunteers and caregivers

Within the social community development the regional government of Salzburg has initiated the project ‘Ageing in good company’ to support local initiatives that wish to become active in the field of healthy and active ageing.⁶ These initiatives are created by local working groups consisting of representatives of associations for older people, mayors, social care associations and volunteers that set up their own agendas and objectives intervening in different domains for independent and autonomous living of older people (Moser, 2013). The overarching goal is to establish local care networks which can help improve the coordination between outpatient, inpatient and community services allowing older individuals to remain active and be cared for in their homes.

⁶ see http://www.gemeindeentwicklung.at/fileadmin/PDFs/GE_Folder.pdf

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Older individuals can benefit from a series of services, which are managed and offered in the community or the home by the local network rather than in a nursing home; among them: recreational activities and outpatient therapy services (occupational therapy, physiotherapy, logotherapy, foot care, etc.), social and physical activities and volunteering.

These initiatives have achieved to establish and to set up:

- A case manager in the communities as contact person for caring relatives;
- Trainings and workshops for older people in relation to security and mobility in daily life (transport, traffic, secure living environment, remaining active in old age, etc.) and monthly presentations and workshops on relevant health-related topics (correct nutrition, understanding of diseases, recognizing symptoms, disease self-management, etc.);
- The “barrier-free community” project aims to improve access for people with reduced mobility, by identifying and gradually eliminating barriers to access in the local community. In addition, information with respect to the location of such barriers is regularly being updated on the project website, allowing individuals with reduced mobility to easily identify accessible routes.
- Extending the scope of the “barrier-free community” project, the “barrier-free economy” aims to improve access for seniors and individuals with mobility limitations to local businesses and public places, promoting the installation of accessible entrance/exit, automatic door opener, sufficient lighting, product arrangements and labelling adapted to seniors’ needs.
- Activities promoting social interaction and inter-generational support, including educational and cultural activities such as computer and internet courses offered by young volunteers (generally in their teens) to older persons and the organization of theatre plays by seniors for young children. Local groups have also organized experimental events, like “Science at the inn” – offering seniors an intellectual challenge and an opportunity to learn about interesting scientific results and discoveries in a familiar and relaxing atmosphere.
- The MiA project, offered in cooperation with Caritas, trains volunteers for supporting and accompanying caring relatives in their daily life, offering trainings for carers, support and counselling. In addition to improving access to information and providing constant support, the MiA project has managed to create a strong social network of caring relatives and organizes monthly meetings in an informal atmosphere. Such meetings offer carers an opportunity for relaxing social interaction and a platform for the exchange of experiences, accumulated knowledge and solutions to common challenges. Starting in 2012, the pilot project ‘Gut umsorgt vor Ort’ (‘well cared-for in place’) has been jointly implemented with a nursing school to provide technical support and guidance for caring relatives.

4.3 Sweden

Key facts on the Swedish long-term care system

- Sweden has a well-established, universal, public long-term care system, with responsibilities for long-term care decentralized at the municipal level
- Eligibility criteria and the range of available services are established at the municipal level and vary between localities. Access to services is granted on the basis of a needs assessment process and is not conditioned by income (no means-testing) or any other uniform set of standards
- In 2010, long-term care spending in Sweden absorbed 3.6% of GDP, ranking second highest in the world. Recent projections indicate a 1.1 to 1.5 percentage points increase by 2060
- During the 1990s and the 2000s, Sweden made great strides in shifting the provision of long-term care from the institutional setting to the community, constantly expanding and strengthening the provision of home-based services. More recently, the deinstitutionalization process came to a near stop as it is being increasingly questioned in the policy arena
- Despite increasing recognition, support to informal and family caregivers remains limited

4.3.1 Overview of the long-term care system

In 2011, 19% of the Swedish population was accounted for by older persons (aged over 65) ranking among the oldest populations in Europe and surpassing the OECD average by four percentage points (de la Maisonneuve & Martins, 2013). According to recent population projections Sweden will converge towards the OECD average by 2050, when a predicted 24% of the Swedish population will be aged 65 and over and circa 10% of the population will be 80 years or older. Sweden used to have the oldest population in the world, but has since been surpassed as the rate of ageing here has been far less dramatic than in other European and Asian countries over the past decade. Nonetheless, as its population continues to age Sweden will have to face an increasing burden from its provision of long-term care services. This is a particularly worrisome trend in the Swedish case, as spending on long-term care in 2010 reached an impressive 3.6% of GDP, ranking second only to the Netherlands and far outstripping the levels of spending in other OECD countries (OECD, 2012). While its financial sustainability is called into question with increasing urgency, Sweden consistently outperforms all other OECD countries in its treatment of the elderly: a recent UN-supported report has ranked Sweden first in the world for the social and economic wellbeing of its older citizens (HelpAge International, 2013).

Recognized for its comprehensive social programmes Sweden has a well-established, universal, public long-term care system. The first social services for the elderly were introduced as early as the 1950s and were provided to all Swedes as part of their citizenship rights. The 1982 Social Service Act and the 1983 Health and Medical Services Act extended and further regulated the supply of services and remain today the backbone of the legislative framework in the area of long-term care. On the backdrop of economic recession and increased demand for services by the 1990s, the tax-funded, centrally managed Swedish social care system had become financially unsustainable. The necessary

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revision came in the form of the Ädel Reform, passed in 1992, and devolved the responsibility for social care and primary health care for the elderly to the municipal level. While the financial responsibility for long-term care is still shared between national, regional and local governments, after the reform individual municipalities became responsible for the provision of all relevant services. The bulk of long-term care costs, i.e. approximately 85% in 2010, is covered through local and regional taxes. General government grants finance an additional 10% of the costs, and only the remaining 5 to 6% are covered from user fees (Socialstyrelsen, 2009). User fees, while common, remain moderate and the level of the co-payment is capped and commensurate with income (Colombo, Llena-Nozal, Mercier & Tjadens, 2011).

The Ädel Reform resulted in the simplification and integration of the delivery system and quickly led to an expansion in the housing capacity for dependent elderly and the development of home care services (OECD 2005). While long-term care provision is still dominated by public providers, private providers have been a part of the market ever since the 1990s. Their market share increased slowly in the institutional care setting – from 5% in 1993 to 14% in 2006 – and had a comparable development in the home care services setting: from only 3% in the beginning of the 1990s to 11% in 2006 (Socialstyrelsen, 2009). However, private provision remains highly concentrated geographically (mainly in metropolitan and densely populated areas) operating in 15% of all Swedish municipalities.

All Swedish residents have a legal right to social and care services and can claim them from the municipality they reside in (single-entry system). However, as care provision is not nationally regulated the service level, eligibility criteria and range of services are established at the local level and can vary markedly between regions and localities. Access to services is granted on the basis of a needs assessment process and is not conditioned by income (no means-testing) or any other uniform set of standards. There is no national regulation defining the process of needs assessment and no guidance with respect to the instruments and tools to be used has been formulated – in practice, a wide range of assessment instruments are used, e.g. ADL taxonomy, EQ-5D, RAI instrument, the Functional Independence Method. While the process remains to a large extent discretionary, it is carried out by trained evaluators or the general practitioner and includes a visit to the care recipient's home, interviews with the care recipient and his family carers and consultations with other professionals.

Once admitted to care, the recipient is assigned to the most appropriate care level, from a range of available services which includes: home care (i.e. help in regular housing), institutional care in residential facilities, day care, home nursing care, meals services, personal safety alarms, home adaptation and others. Home care remains the main service provided for the elderly by the municipality and refers to help with daily activities (e.g. shopping, cooking, cleaning and laundry) and personal care (e.g. bathing, toileting, getting dressed). Institutional care (generally termed special housing services) is provided in nursing homes, residential care facilities such as old age homes, service houses, group homes. In addition, short-term care can also be provided in a semi-institutional setting complementing more intensive and permanent forms of residential care, by providing a setting for rehabilitation and transitional services (Fukushima, Adami & Palme, 2010).

In 2007, the total costs for long-term care services for older people in Sweden amounted to 83.5 billion SEK, in decline by 1.6% as compared to 2003. Out of the total costs approximately 60% are accounted for by institutional care, while home care services absorbed 32% of total budgets. Interestingly, the pattern of growth differs between the two main types of care, with a reduction of

six percentage point with respect to 2003 for institutional care services and a corresponding increase of 6 percentage points for home care (the equivalent of 5.2 billion SEK more in 2007 which corresponds to a 2% increase). The most recent OECD projections paint a more worrisome picture. After a 0.7% increase in public long-term care spending as percentage of GDP between 2006 and 2010, the next decades will bring a more contained but constant growth. By 2060, long term care costs in Sweden will absorb an additional 1.1% of GDP in the cost containment scenario and as much as 1.6% in the cost pressure scenario (de la Maisonnette & Martins, 2013). While the increase places Sweden considerably below the 2.1% OECD average, it is important to keep in mind that the reference point for the projected increase in the case of Sweden was an already very high rate of 3.6% of GDP.

4.3.2 Drivers and barriers to deinstitutionalization: Increased focus on home care services and limited support to informal care

After the overhaul of the Ädel reform (1992), decentralizing the responsibility for long-term care services at the municipal level, a strong economic recession in the first half of the 1990 sent the system in crisis. In order to contain costs, the capacity of health care facilities was significantly reduced – 47% of county hospital and 75% of geriatric bed capacity were closed between 1992 and 2008 (Socialstyrelsen, 2009) – leading to a downward shift (towards primary and long-term care at the municipal level) of a substantial part of the caring burden. As a means to cope with the increased demand for services, social service providers redefined eligibility rules as to become more restrictive, allowing access to care only to patients with increasing degrees of dependency: between 1993 and 2008 the service coverage rate of the population aged 80 and above decreased from an estimated 23% to approximately 20% for home care services. Not surprisingly, while the coverage rate has been contracting, the intensity of provided services has shown a contrasting trend: in 2008, approximately 20% of all home care recipients were eligible for 50 hours of care or more per month.

During the same period, technical advances and improved service organization had rendered home care and home nursing care a less costly alternative to institutional care, becoming a more attractive option for many Swedish municipalities. The increasing pressure to contain costs as much as a general reorientation of policy towards promoting ageing-in-place, helped trigger the massive deinstitutionalization of the system. The Social Services Act, enacted in 2001 to complement the existing legislative framework, states the main goal of the system is to offer people with functional impairments the possibility to continue living in their homes. What is more, municipalities should ensure that older individuals or those with long-term care needs remain socially active and are engaged in society, are able to influence their own lives and enjoy security and independence in later life.

Between 1993 and 2008, the coverage rate of institutional care services for the older old (80+) had plummeted from 24% to roughly 15%.⁷ This reduction of 9 percentage points is threefold that registered for home-based services (Socialstyrelsen, 2009). In 2008, the number of older people in institutional care was 95,600, out of which approximately 80 percent were 80 years or above and 70 percent of the care recipients were women. A similar trend was registered for younger seniors in the

⁷ The proportion of institutionalized persons in Sweden was at its highest in 1975, when an estimated 30% of the very old population lived in a residential care setting (Fukushima et al., 2010).

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beginning of the 2000s: less than 100,000 recipients of institutional care in 2006, a decline of almost 12% with respect to 2001 (Fukushima et al., 2010). This time, however, the decrease in institutional care capacity has been paired with a corresponding increase in the demand for home care services, indicating a major shift in the main locus of care in the Swedish system. Between 2000 and 2008, the number of beds in residential long-term care facilities in Sweden had decreased by approximately 20,000 units. During the same time frame, the number of home care recipients has shown a mirror increase (20,000 individuals), a strong indication of a successful shift from institutional to less intensive care settings.

Table 11 Beneficiaries of long-term care services in Sweden

| <i>Year</i> | <i>2001</i> | <i>2002</i> | <i>2003</i> | <i>2004</i> | <i>2005</i> | <i>2006</i> |
|------------------------------|-------------|-------------|-------------|-------------|-------------|-------------|
| <i>Population aged 80+</i> | 464,211 | 469,526 | 475,938 | 482,337 | 487,163 | 490,254 |
| <i>% aged 80+ receiving:</i> | | | | | | |
| <i>Institutional care</i> | 0.20 | 0.19 | 0.18 | 0.17 | 0.17 | 0.16 |
| <i>Home care</i> | 0.23 | 0.23 | 0.24 | 0.25 | 0.25 | 0.26 |
| <i>Home nursing care</i> | 0.023 | 0.019 | 0.019 | 0.018 | 0.019 | 0.017 |

Source: Fukushima et al. 2010

Despite the changes in relative importance between institutional and home-based care, in 2007 almost two thirds of the long-term care budget were absorbed by residential care services (50 billion SEK), while home care services accounted for 32 billion SEK. Approximately 70% of the total costs for home-based services for the elderly correspond to home-help services. The costs for short-term (semi-institutional) care account for an additional 17% while the remainder (13% of total home care costs) covers adult day care, home nursing care and other home-based services. Between 2003 and 2007, semi-institutional care was the fastest increasing category of costs (up by 20%) closely followed by home-help services, the cost of which has increased by 13% over the same period.

The long-term care system in Sweden has been long hailed as a pioneer of genuine deinstitutionalization, successfully replacing care giving in large institutions by support services in the community. The transition from an institutional-centric system to a more community care based one has not only helped to reduce care costs but has also allowed older Swedes to remain independent and maintain a regular lifestyle for much longer. Deinstitutionalization in Sweden has been made possible by improvements in home care services rendering this less intensive and cheaper type of care preferable for local authorities. However, other reasons contributed to the rapid deinstitutionalization progress. The relative improvements in the general health status of the elderly population lead to a decrease in the demand for intensive care; in addition, older Swedes have become more independent (sometimes with the help of assistive technologies) and can continue living in the community for much longer periods, reducing the need of care even further. More recently, increasing concern has been expressed by experts and policy-makers with regard to the replacement of institutional care by home-based alternatives. After decades of deinstitutionalization, the residential care system in Sweden has started to show signs of under-sizing: the average waiting time for institutional care was 57 days in 2008, ranging between 10 and 170 days depending on the municipality (Socialstyrelsen, 2009). The quality and appropriateness of care services in the community for certain recipient groups have also been called into question and are under increasing criticism. In 2006, Swedish policy-makers had converged on the consensus that the pace of deinstitutionalization should be significantly slowed if not altogether halted.

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One of the main barriers to deinstitutionalization in the Swedish long-term care system has been a general overreliance on formal care services and the consequential under-development of the strategies to support informal caregivers and family carers. As the main pillar of the system has been the development of state provided home or institutional care, informal caregivers have received less recognition. Nonetheless, family caregivers have always been major providers of care in Sweden, with a more and more central role in care provision as population ageing accelerated and access to formal services was being restricted by increasingly more stringent eligibility criteria. One of the few studies on the breadth of informal care giving in Sweden estimated that, in 1994, 60% of the care provided to older individuals (75 years or older) in the community was shouldered by family and informal caregivers. The share increased during the 1990s to reach an estimated 70% by 2000 (Sundström, Johansson & Hassing, 2002).

Soon after the Ädel reform, it became apparent that despite increased reliance on family caregivers the Swedish system was providing insufficient support to improve their situation. In 1998, the Social Services Act was amended to include a provision recommending that social service providers offer the necessary support and relief for informal caregivers (i.e. spouses, family members, friends, and neighbours). The initiative was supported by a 300 million SEK appropriation intended to finance local projects supporting relatives who care for an older person over the next three years (Fukushima et al., 2010). A further amendment to the same law came a decade later, in 2009, changing the responsibility of local authorities towards caregivers from a recommendation that municipalities “should provide support and relief” to a compulsory requirement – municipalities are “obliged to provide support to persons caring for next of kin with chronic illnesses, elderly people or people with functional disabilities”. While the legislative framework is adapting to the ongoing policy debate and informal care in Sweden is receiving more recognition than ever before, the new amendments represent only a weak instrument for enforcing support for carers (Johansson, Long & Parker, 2011). Given the nature of the Social Services Act and the lack of specificity in the national legislative framework (i.e. the new amendment does not specify what type of support, in what degree and to what quality standards), municipalities continue to retain strong autonomy over the organization of social care services and will be sole deciders with respect to the implementation of the law. Ultimately, the extent to which the new legislation will impact on the situation of family carers in Sweden will depend on how various local stakeholders will agree to apply it in practice.

Currently, informal caregivers are directly targeted by three types of support services, provided by municipalities as part of the formal long-term care system. The first refers to the “attendance allowance”, introduced as early as the 1940s for family carers of disabled individuals and later extended to cover the dependent elderly. The allowance is a cash benefit, not subject to taxation, awarded to the care recipient and intended for the remuneration of family members providing care. The monthly value of the allowance varies between 1000 and 3000 SEK and its availability is geographically limited (i.e. not available nationwide). As a result, take-up has remained limited; the total number of recipients was 5,200 in 2006, on a slight increase from 4,600 in 2000 (Fukushima et al., 2010). The second and most common type of support is respite care. In order to offer temporary relief to the caregiver, institutional care, day care, or home respite care are made available, with the help of home care services personnel or support from NGOs and voluntary organizations. Approximately half of Swedish municipalities offer relief services free of charge, while the others charge a small fee. Finally, informal carers can access counselling services. Carers can receive one-to-one support and individual counselling sessions, but more commonly the service is offered by group

counselling sessions and through the organization of support groups and support centres. As is the case for all care services, no national guidelines or standards for counselling support to caregivers exist, and municipalities determine the type and extent of provided services (Johansson et al., 2011).

4.3.3 Good practice example in Sweden

Reimbursement for delayed hospital discharges and joint care plans

- In order to incentivize patient treatment in less intensive care settings, the Ädel reform introduced a reimbursement and joint care plan model, placing the economic responsibility for inappropriately hospitalized elderly on municipalities (also responsible for care services).
- If the discharge of an elderly person is delayed because the appropriate long-term care arrangements are not in place, the municipalities must reimburse the county councils (health care financiers) for the costs of the unnecessary inpatient stay.

The 1992 Ädel reform marked the overhaul of the long-term care system by redesigning the division of responsibilities for elderly care between municipal, county and national actors. One of the problems the reform addressed was hospital over-crowding, acutely intensified by inappropriate care cases. Because significant numbers of patients, often elderly and dependent, were 'blocking the beds' in acute care without necessitating acute treatment, waiting times for hospitalizations had increased to reach months of delay. In order to solve this problem the municipalities were given the responsibility for managing nursing homes for frail and disabled individuals, who had both health care and social care needs. At the same time, municipalities also shouldered the economic responsibility for bed-blockers in hospitals, through a system of cost reimbursement, complemented by a joint care plan. The reimbursement model (implemented in 1992) obliged local authorities to pay for the cost of care of patients whose hospital treatment was completed but who had not been discharged because the necessary long-term care arrangements (e.g. a nursing home place) were not in place. The joint care plan model, introduced in 2006, stressed co-operation between county councils and municipalities, facilitating patients' transitions to the appropriate level of care.

Following the reform, the typical path of a geriatric patient from the health to the long-term care system included the following stages:

- When a patient has completed his acute treatment, representatives from the relevant hospital unit and the municipality's needs assessment unit meet with the patient and, if applicable, an informal carer, to plan rehabilitation and future care together, according to the patient's needs. Once the joint care plan has been defined, the hospital announces to the municipality the imminent referral of the patient.
- Once the referral is registered it is up to the municipalities to provide the needed care. It is at this point in the process that the reimbursement policy takes effect. If the municipality received a referral but is not able to provide a bed or home care services, the discharge of the patient will be delayed but the municipality has to reimburse the county for the hospitalization costs for each extra day the patient spends in the acute care setting.

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The joint care plan model and especially the reimbursement system have been powerful incentives to provide home care and care at the municipalities' nursing homes and led to a significant reduction in the pressure on the health care system. According to evaluations carried out by the Swedish National Board of Health and Welfare, between 1992 and 1999 there was a 60% decrease in the number of "bed blockers" within a cross-sectional sample on a random day (from almost 2,500 patients to just above 1,000 patients). After 1999 the trend stabilized and the number of "bed blockers" has remained relatively stable.

4.4 Italy

Key facts on the Italian long-term care system

- The Italian long-term care system includes three main kinds of formal assistance: community care, residential care and (relatively generous) cash benefits, financed and provided by municipalities, regional authorities, the National Health System and the National Institute of Social Security. This leads to a high degree of fragmentation and wide geographical disparities
- The institutional care sector is undersized with respect to estimated population needs with a rate of institutionalization for individuals aged 65 and above (approximately 2%) more than two times lower than the European average.
- The availability of formal services and the coverage rate of the cash benefit scheme varies markedly between regions, with an extremely pronounced North – South gap.
- Families are the largest care group provided for in Italy, with one in two dependent older individuals receiving no formal care services (other than cash benefits). The overreliance on informal care provision has helped maintain public expenditure relatively low, but has put increasing pressure on an estimated 3.35 million Italians who provide care to an older person.

4.4.1 Overview of the long-term care system

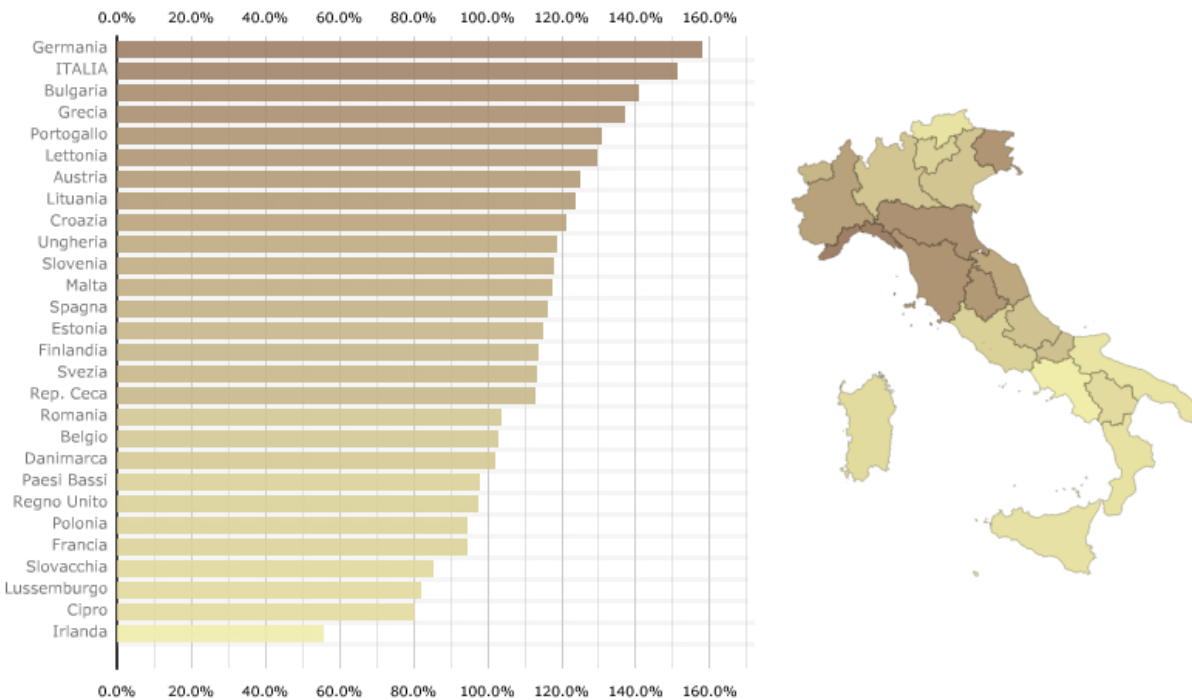
Italy is currently the country with the highest percentage of older individuals in Europe (20.8% of the population was aged 65 and above in 2012), and is second only to Japan in the OECD area (Eurostat; OECD, 2014). The most recent data released by the Italian Institute for Statistics place the share of the older population at 21.4% in 2014 (iStat – Noitalia), confirming a continuous ageing trend in the Italian population verified over the past decades (18.7% in 2002 and 15.3% in 1991). Figure 2, plotting the ageing index in 2014 (the number of persons 65 years old or over as a percentage of the population under age 15) across European countries and Italian regions, illustrates both the severity and the unequal geographical distribution of the phenomenon. The increase in the proportion of the elderly population in Italy is a direct result of the gains in life expectancy, combined with a significant decline in fertility rates: between the 1991 and the 2001 censuses the Italian population as a whole grew by only 0.4%, to be compared with a growth rate of approximately 20% in the older population groups. By 2050, the 65 and older are projected to represent 33% of the Italian population, far outstripping the EU average of 28.9% and the OECD average placed at 26.7% (World Bank, 2015).

The impact of this profound and accelerated ageing has been felt in all aspects of economic life but is expected to particularly strain the health and social care systems; by 2050 one in three Italians will be aged 65 or older and one in 7 individuals will be aged 80 or above, generating an enormous burden of care. Estimated at 1.7% of GDP in 2011, the public expenditure on long-term care in Italy was comparable to the OECD average. Nonetheless, in the future, the demand for long-term care and the associated costs are expected to significantly increase: by 2050, long-term care expenditure is projected to reach 3.9% of GDP if a shift towards institutional care will take place. Even in the more optimistic scenario, of increased utilization of lower intensity care in the community setting,

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expenditure will almost double to reach 3.3% (de la Maisonneuve & Martins, 2013). While these figures place Italy only slightly above the OECD average, it is important to remember that a significant share of long-term care expenditure is funded directly by Italian households and does not contribute to these statistics.

Figure 3 Ageing index in 2014 (by country and Italian region)



Source: Istat noi-Italia, 2015; available at: noi-italia.istat.it

The Italian long-term care system for older persons includes three main kinds of formal assistance: community care, residential care and cash benefits. It is often described as a collection of “many long-term care systems”; the metaphor reflects the very high fragmentation of responsibilities between different levels of government and different institutional actors. Responsibilities for funding and system management are shared between local (municipalities) and regional authorities who enjoy a high degree of autonomy in decision-making and organization. As a result, institutional frameworks basing long-term care delivery vary widely between geographical settings and exhibit particularities in almost every Italian region (Tediosi & Gabrielle, 2010). Further complicating matters, the provision of services is split between the National Health System (SSN) and the social care system whose development over the years followed a very different track. When the Italian SSN was born in 1978, embodying principles of universal access to care and providing free or low-cost health care to all residents, a national system of social protection was entirely lacking. Only two decades later, through Law 328 in 2000, the framework for the financial basis and the development of universal and homogeneously regulated social services was developed. Although integration between the two systems has been a constant concern and always present on the policy agenda, in the absence of a common national framework and more radical reform efforts, progress has remained limited.

The provision of long-term care services is carried out by three principal actors: the municipalities, local health units (ASLs – 144 in 2011, part of the National Health System), nursing and the National Institute of Social Security (responsible for the cash benefits programme). However the central

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government, the regional and the provincial authorities all play a role in the funding and the planning of long-term care services. The municipalities plan and provide personal social services, including domestic and personal care tasks provided in the recipient's home; they retain some responsibility for the management of institutional social care but these services are planned in coordination with the local health unit. The National Health System, through the local health unit retains the responsibility to plan and provide home health services (also called integrated domiciliary care) as well as other medicalized services in the residential care setting (including nursing care, therapeutic care and rehabilitation). Public provision is supplemented by private providers who can offer both institutional and home-care services (subject to accreditation).

Access to care services is granted to all "persons in need" but no nationally accepted legal definition of the term exists. In practice, eligibility is decided on the basis of an initial needs assessment, which falls under the responsibility of the local ASL. No standard criteria or assessment guidelines exist in Italy, but most ASLs delegate needs assessments to multidisciplinary teams in geriatric evaluation units. The standard multidisciplinary team includes doctors, nurses, social workers and less commonly, administrative employees. The goal of the assessment is to classify the individual into the appropriate need category, set out the care plan and choose the most suitable care setting. Need categories are region-specific (exceptionally, some variations persist even at the provincial level) as are the instruments used for the assessment. Nonetheless, the tools used for evaluation generally reflect validated international standards (Tediosi & Gabrielle, 2010).

As the range and depth of services varies widely at the regional and even at the municipal level, the sustained levels of expenditure at the local level are also very variable. Severe limitations in data availability make estimation difficult but a survey carried out by the National Institute of Statistics concluded that, in 2005, the average expenditure per capita on long-term care services reached 177 Euro and displayed a high degree of variability: from 34 Euro per capita in the Calabria region to over 250 Euro per capita in the Friuli Venezia Giulia region (Tediosi & Gabrielle, 2010). Such geographic differences are indicative of the gaps in service quality and quantity (mainly along the North-South dimension) but also of a chronic underfunding of social services in Italy. The coverage of Italian institutional care was estimated at 2% of the older population in 2010 to be compared to a Western European average of approximately 5%; and only 4% received home nursing-care services (European average of circa 7%). A further indication of capacity gaps across Italian regions, in 2009, an estimated 246 beds per 10,000 older people were available in the North-East of Italy but only 76 per 10,000 in the Central regions and as few as 16.8 per 10,000 in Southern Italy (Mangano, Montemurro, Mancini & Torre, 2012). What is more, the under-provision of institutional care in long-term care facilities is often associated with a shift towards a more intensive care setting, determining the over-hospitalization of older people with long-term care needs and raising concerns with respect to the appropriateness of the treatment they receive (Colombo et al., 2011).

Care services to older people (over 65 years) accounted for two thirds of the total public expenditure on long-term care in 2012. Service provision from ASLs covered 47% of the total compared with only 9% of total expenditure for services administered by municipalities. Despite a relatively low share of elderly individuals receiving care in institutions, more than 30% of the expenditure on long-term care for individuals aged 65 and above in 2012 was absorbed by services provided in institutions, while home-based services accounted for approximately 18% (Ministero Dell'Economia e delle Finanze, 2013).

4.4.2 Drivers and barriers to deinstitutionalization: informal and private home care provision

The third important component of the Italian long-term care system is the national cash benefit scheme, administered by the National Institute of Social Security and financed through general taxation by the central Italian Government. The attendance allowance (*indennità di accompagnamento*) was introduced in 1980 and is targeted at all disabled and dependent individuals of all ages and independently from their financial situation (not means-tested). It is a universalistic instrument (not linked to the payment of social security contributions) and can be freely used by the recipient – the amount can be considered as a supplement to the beneficiary's monthly income as there is no requirement to use it for purchasing long-term care services. In order to qualify for this flat-rate attendance allowance, an individual must be assessed as fully disabled and dependent (unable to carry out the activities of daily living and being in need of continuous assistance). As described above, the assessment of needs is subject to different regional standards, generating considerable differences in the number of beneficiaries between regions. In 2009 the monthly value of the attendance allowance was set at 472 Euro but is subject to yearly indexing; presently (i.e. for 2015) the monthly benefit is 508 Euro.

The attendance allowance can be considered the main pillar of the long-term care system in Italy, as it has the highest number of beneficiaries and absorbs the highest amount of resources of all long-term care measures. In 2010, over 1.5 million individuals aged 65 and above were eligible to the attendance allowance, the equivalent of a coverage rate of 12.5% of the older population (values ranged from 8.4% to 19.5% depending on the region) (Istituto Nazionale di Statistica, 2014). As a rule, the cash benefit scheme has a higher number of recipients in regions where the formal services are underdeveloped (i.e. Southern and Central regions) and a lower coverage in Northern regions (under the national average) where levels of accessibility to institutional and home care services are considerably higher. In this respect, the attendance allowance cannot be seen as more than supplementary to other long-term care services but rather as a substitute to the utilization of formal care.

In addition to the attendance allowance, local authorities (both regions and municipalities) provide other forms of cash benefits for the households of dependent individuals. These are means-tested care benefits (so-called family allowances or "*assegni di cura*") targeting individuals with high degrees of dependency, and generally carry no utilization restrictions. The nature of the cash benefits and the amount granted varies across Italian regions: in 2009, the monthly amount ranged from 200 Euro in Veneto to 515 Euro in Bolzano. The take-up of family allowances is equally variable but the share of over 65 years old recipients never surpassed 3% and can be as low as 0.2% in some regions (Di Santo & Ceruzzi, 2009). Family allowances are often awarded as an alternative to public formal care services and are intended as a means to finance the purchasing of private assistance or to compensate informal carers.

As the share of Italian elderly who access formal long-term care services has been estimated at approximately 50% in 2004, one in two older Italian individuals who are dependent on continuous long-term care receive no public support other than a monthly cash benefit (ESN, 2008). As a result, they are reliant on the care provided informally, in the community, most often by close relatives,

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who are generally women, married, unemployed or employed part-time in a position with low earning potential (Mauri & Pozzi, 2007). An estimated 3.5 million Italians provide care to a dependent elderly individual – generally a close relative (Quattrini et al., 2006) – and as much as 16.2% of the population aged 50 and above reported being an informal carer in 2007, the highest rate registered in any OECD country (Colombo et al., 2011). Because the care provided is often quite extensive – 37,3% of carers evaluated the elderly people they attend to as severely dependent (Quattrini et al., 2006) – care obligations have a profound impact on both the professional and personal life of carers.

The family has traditionally been the locus of care for dependent individuals in Italy and the main support network for the elderly; families and sometimes more extended social circles are by far the largest provider of elderly care in Italy, while institutional care is generally limited to those individuals who have no immediate family in their area of residence or who suffer from severe health problems. The strong cultural underpinning and family values in Southern Europe (50% of Italians consider the care of an older parent should be taken on by their children and 70% consider children should financially support elder parent when necessary) can explain to some extent the under-development of formal care services (Special Eurobarometer, European Commission, 2007). Nursing homes are seen as a viable care alternative for elder parents only by 7% of Italian respondents (EU average stood at 10%), because the standards of institutional care are perceived as insufficient by a majority of respondents (53% compared to a 45% EU average). Finally, as professional care in the home is only affordable for 27% of the Italian families with members in need of care, the result is a generalized overreliance on informal carers: 75% of respondents to the Special Eurobarometer (2007) consider dependent people in Italy have to rely too much on their relatives.

The accelerated demographic ageing experienced in Italy over the past decades has led to an increased burden of care for a growing number of families and, as life expectancy continues to rise, for longer periods of time. As care tasks often conflict with other professional and personal obligations in modern family nuclei, an ever-larger gap has been opening between the supply and demand of care. In response, many Italian families resort to hiring private assistants ('badanti'), whose services they must pay for entirely out-of-pocket. The majority of paid private carers are migrants from East Europe, the Philippines or other parts of the world; they tend to care for individuals with high to severe dependency levels and often provide 24-hours support.

While this phenomenon is not restricted to Italy, the magnitude it has taken in this country renders it one of the main features, and the most noteworthy specificity, of the Italian long-term care system: an estimated 10.1% of older individuals cared for in the home live with a paid home carer (Quattrini et al., 2006). In addition, this is not a new trend in Italy (family helpers were documented as early as the 1980s) but it has significantly accelerated recently. According to INPS data, in 1992 only 20% of registered carers were migrant workers, a proportion that increased steadily over a decade to reach 53% in 2000 and 73% in 2003 (Hooren, 2008). It is important to mention here that such statistics cover only registered carers, disregarding the contribution of undeclared work – a widespread phenomenon as many carers are undocumented migrants. While it is difficult to estimate the true number of paid private carers in Italy, experts agree that documented caregivers are likely to account for less than half of the actual number. In order to reduce the size of the grey market, Italian authorities have introduced yearly quotas of work permits specifically targeting paid carers and have attempted several regularizations of undocumented informal caregivers. The long-term care system has, unfortunately, been less responsive. Though not openly declared, the cash benefits received by

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dependent individuals are often aimed at financing paid private carers. Only few regions in Northern Italy have introduced earmarked benefits, in the form of cash allowances that are linked to the existence of an employment contract between the family or the recipient and the informal caregiver. Such measures should be extended throughout Italy, because, in addition to the support provided to the families of dependent elderly, they motivate undocumented carers to transition into regular employment (Di Santo & Ceruzzi, 2009).

While the enormous contribution of households to long-term care has helped maintain public long-term care expenditure in Italy under control and has decisively contributed to the low institutionalization rate that characterizes the system, the shift of such a large share of the care burden on families comes with serious drawbacks. To begin with, considerable labour market distortions are associated with occupying predominantly female family members with excessive care tasks. In addition, accumulating research evidence is confirming that intense caregiving, even when desired by family carers, associates with a range of physical and psychological problems and impacts on the emotional state of the caregiver. Policies for the support of family caregivers have always been a part of the Italian long-term care system, but they are generally limited to financial support in the form of cash benefits. However, some regions include among their services relief measures targeting informal carers (access to day care centre and temporary care, intended to relieve the family from care duties for a limited period of time) and self-help groups (listening groups, family care associations, social activities groups, etc.).

4.4.3 Good practice examples in Italy

Recognition of non-formal skills – Piemonte Region⁸

- As part of a wider policy on migration, the non-formal skill recognition programme addressed carers whose competences were not formally recognized. The programme includes a formal training component and a skill evaluation component and ends with the awarding of a certificate of attendance and recognition of family support skills.
- A set of complementary policy measures, including incentives to the families and mentoring has contributed to the successful implementation of the programme.

In recognition of the increasing importance of informal care in the Italian long-term care sector, since 2008, the Piemonte region has actively committed to supporting and regularizing the work of informal caregivers through a programme of skill recognition. Much of the care provided to dependent elderly in the home is done by persons who have acquired in time most if not all the necessary skills, despite never having received any structured training and not having any official professional recognition. The skill recognition programme is an attempt to confirm and certify these non-formal competences, with the goal of improving the quality of informal care and promoting the professional development of carers. In addition, the programme is expected to reduce irregular work

⁸ More information is available at:
<http://www.regione.piemonte.it/pariopportunita/cms/index.php/lavoro/assistenti%3Cfamiliari/411%3Cconvegno%3Cpiemonte%3Cass%3Cfam%3C2013>

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in the sector (many carers are unregistered migrants) and improve employment opportunities for skilled carers (the programme includes a financial incentive to families employing certified carers). The programme is managed at the regional level in collaboration with provincial governments and other local stakeholders and is funded as part of the 2010 Migration Policy plan.

Two objectives stand at the core of the programme:

- The creation of appropriate tools for the identification and assessment of non-formal skills – at the end of the experimental phase, in 2010, a set of survey questionnaires was administered to the carers, focusing on self-rated skills and daily care tasks; in light of the results, a specialized commission designed an entry-test for the programme, with the goal to validate the competencies declared by the carers. The tests included a practical evaluation of skills and allowed for the placement of registered carers in the appropriate level of training. If the declared competences were fully verified during the initial test and deemed sufficient, the carer could pass directly to the final examination phase and receive a certificate recognizing his/her skills.
- The provision of services for skills assessment and acquisition and mentoring – after the registration to the programme and the initial assessment (including a language proficiency test), a certified training agency offered a specialized training module on “elements of family support”. The training lasted 30 to 50 hours depending on each individual’s need for support and skills acquisition.

In order to promote participation in the non-formal skills certification programme, 150,000 Euros (in addition to the regular programme budget) were allocated by the Regional Directorate of Social Policy, for the payment of a small economic incentive for participants in training courses. A second complementary measure focused on the labour market placement of participating carers: the region awarded economic incentives to families who enter regular contracts with a caregiver whose skills have been certified (thus facilitating the regularization of grey work).

A programme evaluation in August 2013 established that 22 training courses for the qualification of family assistants (via the recognition of skills acquired in non-formal working) were activated. 617 participants had obtained the certificate of attendance; almost half of which were EU nationals (327 had non-EU citizenships) and 216 families obtained the financial incentive after formally hiring trained carers.

“Family Nurse” Saronno – Varese Province⁹

- The Family Nurse pilot builds around the care and case management of frail individuals in the community, by assigning a trained health professional to plan and oversee the care pathway of dependent individuals in the community.
- The Family Nurse has a central role in the coordination of care: evaluation of necessary interventions, planning of doctor visits, coordination with other health professionals
- Health education and support for informal and family carers are also important parts of the project, building towards independent management of the care recipient and his immediate care network.

In May 2013, Saronno (in the Varese province) was chosen as the site for a pilot project called Family Nurse (it is a paid service). Responding to a recent trend of a reduction in residential care in Italy, the project aims to develop alternative care settings for dependent individuals, with a focus on the management and the personalization of care in the local community. As the project is run by a private company called “Finisterre consortium” (providing care services in many Local Health Districts in the Lombardia Region), it maintains a strong focus on economic sustainability and effectiveness. The core idea is to train long-term care professionals able to respond to the various aspects of chronicity and dependency in the home setting, under the coordination of a local clinic. The Family Nurse is specifically trained for care management tasks and would ideally provide continuous care for dependent individuals in an attempt to delay more intensive care processes and institutionalization.

The Family Nurse is expected to carry out the following activities:

- direct assistance to the patient at home with technical nursing interventions and rehabilitation;
- evaluation of care interventions to be implemented within a patient care plan (the care pathways are usually decided upon in coordination with medical personnel and can change according to the progression of the patient’s health);
- planning of any medical specialist consultations and coordination of activities of other health workers involved in the recipient’s care process;
- health education and information relevant to the care recipient and his primary care network (most often the family but can also include other informal caregivers);
- technical support aimed at making the family carer independent in the management of the person with a chronic disease or other limitations.

The Family Nurse project puts case management and care management of chronic and fragile individuals at the core of its model, within an estimated basin of 1,000 inhabitants per nurse (the population of Saronno is approximately 100,000 inhabitants). The yearly budget for the project was set at 300,000 Euro, to be covered entirely from patient fees. Currently, discussions are under way with the Lombardy region and prominent insurance companies for the coverage of the costs of

⁹ More information at: <http://www.changemakers.com/innovationinaging/entries/family-nurse>

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services to at least a partial extent. It is, however, unlikely that the services can be covered by public funding in light of the overall decrease of resources in the National Health System.

No systematic evaluation of the Family Nurse pilot has been carried out so far, but the initial results after the launch of the programme give cause for optimism. The average weekly number of users who contact the centre requiring nursing services is large enough to make the initiative financially sustainable and to consider replicating this service in other geographical areas. The viability of this care model has been extensively documented in the United Kingdom, where Community Nurse experiments have resulted into improved care and well-being perception of frail and dependent individuals.

4.5 Czech Republic

Key facts on the Czech long-term care system

- Public expenditure on long-term care in the Czech Republic is currently low (by European standards) but projected to increase rapidly over the next decades as a result of population ageing and policy convergence.
- Responsibilities for service provision are fragmented between the health care system, the social care systems and local authorities and few steps have been taken to increase integration.
- Home care services are the main formal service provided to older individuals while institutionalization rates remain very low: in 2011, home based services covered 13.1% of the individuals aged 65, while residential care covered only 2%.
- The overwhelming burden of care still falls on informal caregivers: the Czech Republic is one of the EU countries with the highest reliance on informal care provision but carers receive very limited formal support.
- While the availability of formal care services is improving, major concerns remain with respect to capacity limitations and equality of access across geographic areas.

4.5.1 Overview of the long-term care system

The current level of expenditure for long-term care as a percentage of GDP in Central and Eastern European (CEE) countries remains significantly lower than the European average; in 2010 public expenditure on long-term care in the Czech Republic amounted to 0.8% of GDP, in comparison to a 1.9% average in the EU27 (Lipszyc, Sail & Xavier, 2012). According to recent projections, the level of expenditure on long-term care in European countries will likely double between 2010 and 2060, assuming current population trends continue in the future and long-term care unit costs and coverage converge between EU countries. Nonetheless, such projections do not directly account for convergence in long-term care policies and their generosity. In such a scenario, CEE countries are likely to see a more substantial increase in their long-term care costs as policies adjust to meet Western European standards. In addition to a pressure to improve service standards and coverage, long-term care in the Czech Republic must face the added burden of slow progress in healthy life expectancy. While marked increases in life expectancy have been registered in the past (Bryndová et al., 2009), these gains have been made at the expense of reduced health in old age. In other words, Czech citizens are expected to live longer, but increasingly unhealthier lives. According to the Global Burden of Disease Study 2010, between 1990 and 2010, gains in life expectancy at the age of 50 have been accompanied by an expansion of the number of years lived with poor health, both for men and women in the EU. The gains in life expectancy at this age for both Czech men (+4.8 years) and women (+4.1 years) were quite substantial, but almost half of the life expectancy gained will be spent in poor health.

Similarly to other CEE countries, the Czech legislation does not recognize a long-term care system or a single institutional body in charge of long-term care policies, and places responsibilities for care

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provision under the umbrella of the health care sector on the one hand and of the social services sector on the other. Adding to this fragmentation, different levels of government (local, regional and national) share responsibilities for financing and providing different care services. Building on a legislative framework dating from the 1980s, the incremental and often uncoordinated policy changes made during the 1990s had little if any impact in modernizing the system. No clear responsibilities for the financing of long-term care were provisioned by the law and quality standards and assessments lacked completely. As a result, the development of social services was severely hindered and the availability of services remained geographically concentrated (Barvikova, 2011). The promulgation of Law 108/2006, in force since January 2007, was the first attempt at a system overhaul and brought about considerable changes with respect to care financing from the central budget, the definition of service standards and quality assurance procedures and the redefinition of available services responding to manifest needs in the population. While the systemic changes it mandated encouraged the development of the social care services, Law 108 did little to reduce fragmentation; care services are provided in both the medical and the social sectors, each with its own regulatory frameworks, eligibility criteria and financing mechanisms (Barták & Gavurová, 2014).

The Ministry of Health and health care institutions have long been the main providers of long-term care, whether it refers to inpatient services (i.e. rehabilitation and nursing in geriatric units, long-term care units or general hospital units) or to outpatient services (home nursing care). The Ministry of Labour and Social Affairs is responsible for social services provided in social care facilities. These include residential care in pensioners' homes for older individuals with limited capabilities who require comprehensive care, and services provided in day- and weekly-care centres for individuals with limited autonomy that require constant support with regular activities and tasks. The system of social services also covers a series of in-kind and cash benefits for individuals with long-term care needs. In the first category, personal assistance and community care are provided in the home environment to individuals with different degrees of dependency and are not subject to time limitations. Cash benefits are awarded exclusively to individuals who receive full time care from an informal caregiver (more often than not a family member). Municipalities and regions are responsible for "community planning" of social services and for the availability of residential and community care services. As a result, access to care services largely depends on the regional availability of social facilities and care providers and varies considerably at local level.

Table 12 Characteristics of the care allowance in the Czech Republic

| <i>Level of care need</i> | <i>Beneficiaries up to 18 years of age</i> | <i>Beneficiaries aged 18 or above</i> | <i>Number of beneficiaries 2010</i> | <i>% beneficiaries 2010</i> |
|---------------------------|--|---------------------------------------|-------------------------------------|-----------------------------|
| I – mild | € 115.4 | € 30.8 | 115,926 | 38.02 |
| II – medium | € 230.8 | € 153.9 | 91,305 | 29.95 |
| III – heavy | € 346.1 | € 307.7 | 59,801 | 19.62 |
| IV – complete | € 461.5 | € 461.5 | 37,810 | 12.41 |
| Total | - | - | 304,842 | 100 |

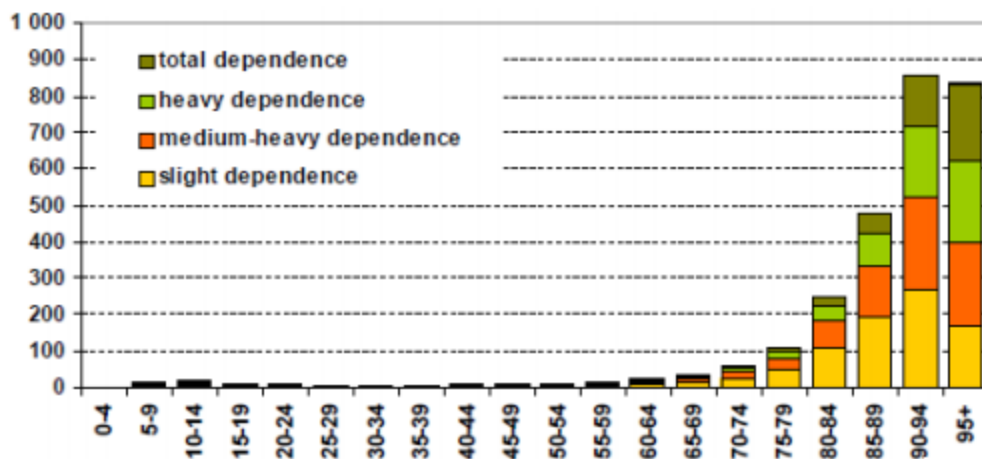
Source: Barvikova & Österle, 2012. Note: values calculated at 1€ = 26CZK.

Following the social services reform in 2007, cash benefits in form of care allowances are awarded to the individual in need of care, rather than to the caregiver, as was previously the case. Eligibility and the level of the allowance are linked directly to the level of care needs that are assessed on the basis of limitations in activities of daily living. The law distinguishes four levels of care needs, from mild (or

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slight) to complete dependency, which together with the recipient's age result in eight categories for the contribution (Table 12). At the time of the social sector reform per capita income in the Czech Republic was approximately EUR 1,000 while the average old age pension was about EUR 400. The allowance can be used to cover the costs of arranging assistance for the dependent in the home, to pay for formal care provided within the social services system or to pay costs incurred by informal caregivers.

Figure 4 Beneficiaries of care allowance by age group and level of care needs (in 2010)



Source: Horecky, 2013

While care allowances are not targeted towards older people, in practice the vast majority of recipients are 65 years of age or older (67% in 2008) while 57% constitute older seniors (75+) (Sowa, 2010). Cash benefits in the Czech Republic are not means-tested and were accessed by over 300,000 individuals in 2010 (Barvikova & Österle, 2012). In 2009, the Ministry of Labour and Social Affairs estimated that a total of EUR 650 million annually are necessary for financing care allowances, while later estimates place the figure at 770 million in 2010 (Holub & Nemec, 2014). Funding for the cash benefits scheme is provided by the state budget and financed through general taxation.

4.5.2 Drivers and barriers to deinstitutionalization: Supporting care in the home and limited availability of services

The long-term care system reform in the Czech Republic has been strongly oriented towards shifting the locus of care from institutional settings to the community, promoting ageing in a home-like environment. As stated in the National Programme of Preparation for Ageing for the years 2008-2012: "Effective provision of health care should be based on an integrated model of health and social care in communities. Health services should improve integration of older persons in their home environment and society and mobilize their potential of independence and self-sufficiency." Recent policies have encouraged the development of accessible social services at the local level, with special emphasis on non-residential services and have introduced incentives and support (care allowance) for families to care for their elderly members. However, low service capacity and care fragmentation have frustrated reform efforts. In practice, the overwhelming burden of care still falls on informal caregivers, who are often close relatives of the older person or members of their immediate social circle. The Czech Republic is one of the EU countries with the highest reliance on informal care

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provision, with virtually every older person depending on informal carers for some form of support before the long-term care reform (96.8% according to the Ageing Report, 2007). No systematic analysis of the informal care sector in the Czech Republic has as yet been undertaken, but the Ministry of Labour and Social Affairs estimated that a total of 80% of older people's care needs are covered within the family, by children or by spouses (Sowa, 2010).

The situation can be partly explained by a strong preference among Czech citizens for family-based care. According to results of a 2007 Eurobarometer survey, 66% of respondents in the Czech Republic indicated that an older father or mother who lives alone and can no longer manage to live without regular help because of her or his physical or mental health condition should receive the necessary help from their children. More than half of them (36%) consider the older person should receive the care they require from a co-residing child. Only 13% of respondents consider nursing homes a desirable alternative for older people. The resulting burden of care is considerable, with OECD estimates placing the share of the Czech population aged 50 and above reporting to be informal carers at 17.7%, one of the highest in Europe and considerably above the OECD average of 15.6%. Nearly 70% of these carers report having daily care obligations, with the remaining 32% providing support to older people in need of LTC on a weekly basis. Such intensive care provision conflicts with competing labour commitments (the majority of caregivers hold full-time employment contracts) leading to under-provision of care with respect to needs. As elsewhere in Europe, women carry a disproportionate amount of the care burden accounting for 63.5% of all informal caregivers (OECD, 2013). Informal care often substitutes entirely formal care provision, but even in cases where the beneficiary has access to formally provided care services, these are very often supplemented by support from informal carers – on average 20 hours of informal care per week are provided to elderly Czechs who also benefit from state agency provided home care (Genet, Boerma, Kroneman, Hutchinson & Saltman, 2013).

Carers receive very limited support in the Czech system; they are not granted any direct benefits but can receive pension credits and provision of health insurance. Caregivers can be remunerated from care allowances granted to dependent individuals, which can be used to pay for support from family and other informal carers, such as social care assistants. As of 2012, their contribution to the care system is officially recognized, based on a written contract with the recipient of care and can be remunerated from the care allowance. Any person 18 years or older and in good health can act as a care assistant as no licensure procedures are in place and no formal qualification is required. Furthermore, no restrictions are placed on the number of persons a care assistant can provide services for, raising concern with respect to the quality and sufficiency of provided services. This remains a general concern, which applies equally to family carers, as, while some respite services are available for informal caregivers, support, training and counselling opportunities remain very limited.

Home care services, including personal assistance services and community care in daily activities, (e.g. clothing, shopping, transport, meals on wheels), are the main form of care provision in the community and fall under the responsibility of the social services system. In comparison, home nursing services are a form of outpatient care covering nursing or rehabilitation services provided by or under the supervision of a primary care doctor (Sowa, 2010). Both types of services are generally provided by nurses and volunteers and coordinated by home care agencies. The bulk of provided services relates to home care, provided by 594 contracted home care agencies with 5,500 staff members who served 115,000 clients in 2008 (Genet et al., 2013). During the same year, personal assistance services targeting individuals with limited autonomy as a result of old age, chronic

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diseases, or health problems were provided by 183 services, with 1,800 staff members and covering approximately 7,000 clients. The estimated total expenditure for home care services reached EUR 70 million (out of which 16 million out-of-pocket contributions from clients), while personal assistance services accounted for €15 million (of which client contributions amounted to €3 million) (Genet et al., 2013; Sowa, 2010).

While the availability of services is improving, national experts report that the level of provision is not commensurate with population needs and serious concerns remain with respect to equality of access. In 2007, 2,530 municipalities organized and offered home care services to a total of 98,373 recipients, the number of recipients increased to 128,250 persons; at the same time, the number of municipalities where home care is available also increased (2,696) (Sowa, 2010). Even when available, home care services suffer from a lack of capacity to cover key time frames: it is estimated that only 58% of home care agencies offer around the clock services (including nights and weekends), while 22% operate during weekends but do not offer any services during the night.

An even more worrying limitation in accessibility is caused by the unequal regional distribution of home health care agencies (Sowa, 2010), with older individuals in certain localities being entirely deprived of access to home care. The unequal geographical concentration of service providers and the overall under-sizing of care services are equally relevant for institutional and semi-institutional services. The former are available mainly in urban and densely populated areas and barely cover the rural population and can accumulate waiting times of 4 weeks or more, while the latter are grossly undersized – the number of rejected applicants more than doubled between 1995 and 2003.

4.5.3 Good practice example in the Czech Republic

AREÍON Emergency care¹⁰

- AREÍON is a distress care service helping frail older or disabled people to maintain autonomy and continue living in their homes by allowing them to cope with emergency situations caused by injury, deterioration in their health, endangerment by another person or by social exclusion.
- It links domestic monitoring devices to a 24/7 call centre, where operators with nursing expertise can coach the recipient in the event of an emergency and alert the necessary intervention services.

The AREÍON Emergency care service, arguably the only telemedicine service used in long-term care in the Czech Republic, is part of a comprehensive social service which aims to reduce health and social risks for senior citizens and handicapped people. The main objective of the Emergency care service is to allow handicapped people and seniors of advanced age to live in dignity, in their home environment, by ensuring rapid access to care, in case of necessity. The AREÍON Emergency care service is an alarm system provided by Zivot 90 (a non-profit organization relying on volunteer work) since 1992. It connects a series of user terminal stations (generally including a household station and a mobile device to be worn by the care recipient at all times), pre-installed in the homes of

¹⁰ More information at: <http://eng.zivot90.cz/4-social-services/10-areion-emergency-care>

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dependent individuals with a centralized control room with a 24/7 call centre with nursing expertise, allowing remote monitoring. The user device alarm can be activated by the individuals themselves in the event of an emergency or by a motion sensor detecting lack of activity (if the household device sensor does not record any movement during a pre-set period, it automatically calls the operator). In order to ensure timely interventions AREÍON works in partnership with a range of emergency and local services (e.g. rescue service, police or providers of social and legal services), which are alerted by the Emergency care service operators and respond to a client's need in the shortest time possible.

The AREÍON service targets frail older or disabled persons, who suffer from health or psychosomatic problems, mobility impairments or functional decline associated with old age. All individuals aged 60 or above who live alone or in remote areas (exposing them to social isolation and mental stress) are also eligible for the service. The service is currently provided to approximately 1,300 clients in 34 different Czech towns (spread over 6 different regions), by the central control room in Prague and the regional centres in Hradec Králové, Kutná Hora and Jihlava. However, as the Czech population aged 60 and above numbered over 2.4 million in 2012, the Emergency care service is accessible to only a very small share of its target population.

In 2005, the project won the Markopoulos Prize of the Ministry of Health of the Czech Republic for extraordinary well-functioning projects addressing the needs of seniors and people with disabilities. Further national recognition of the merits of the Emergency care service came in 2006, when it was incorporated in the Social Services Act (Act 108/2006 Coll.) under the care service category. The major benefit of this recognition is that recipients can now cover the monthly service fees (of approximately 10 Euro) by claiming a state subsidy, reducing previous concerns of barriers to access (the monthly fee can prove to be an excessive burden for low-income persons).

4.6 Overview of the long-term care system in Serbia

Key facts on the Serbian long-term care system

- Despite having one of the oldest populations in the world, Serbia has a severely underdeveloped provision of long-term care services, divided between the social protection system and the health care system
- Public expenditure on long-term care is very low: a rough estimate places it at 0.55% of GDP (0.36% absorbed by the cash benefit scheme)
- Residential care, financed and managed by the central Government, is undersized, highly concentrated in urban settings and subject to severe concerns regarding quality of care
- Community-based services, provided under the coordination of local centres for social work, are slowly developing but remain insufficient with respect to population needs and have a limited geographical coverage
- Informal care fills a big part of the remaining service gap, but no data is available on the frequency and type of care provided and to how many beneficiaries. Unfortunately, no policy measures supporting carers currently exist

The population of the Republic of Serbia is currently ranked among the oldest in the world raising a major challenge for the protection of the rights of the elderly and the sustainability of the long-term care system. Representing 17.3% of the population (the equivalent of 1.6 million people) in 2007, the share of individuals aged 65 years and above is projected to constantly increase over the next decades. By 2030 the elderly will represent more than 20% of the total population and as much as 26.6% by 2050, when 7.2% of the population will be aged 80 and over (Mamolo & Scherbov, 2009). The increase in the number and share of elderly people and the increase in additional life years spent in ill health will lead to an inevitable increase in the public expenditures for long-term care, very roughly estimated at 0.55 % of GDP – 0.36% of which for cash benefits (Matkovic, 2012).

Long-term care is currently not a differentiated social protection system in Serbia; rather, competences for long-term care are split between the social welfare and the health care systems (providing preventive, therapeutic and rehabilitative care¹¹). The ties between the two systems tend to be very weak (full organizational and financial separation) and present a substantial obstacle to the creation of a comprehensive long-term care strategy. Unfortunately, recent policy developments have largely ignored the interdependency between different segments of the system and the need for increased integration.

The social welfare system includes two types of entitlements for long-term: access to publicly provided services (both institutional and home-based) and access to benefits (both cash and in-kind) (Arandarenko & Perisic, 2014). However, public support for elderly care relies mainly on the provision of cash allowances and the provision of residential care in public institutions funded by the Central government (public homes for adults and elderly people). This latter form of service provision

¹¹ In Serbia, persons over 65 are exempt from co-payments for medical procedures and devices.

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suffers from severe capacity limitations, currently offering a number of places in social care institutions that barely account for 0.7% of the number of Serbian elderly. Private providers complement public provision, raising care capacity to 1 to 1.1% of the elderly, still a gross underdevelopment of care services with respect to the needs in the population. Among the beneficiaries of institutions, two thirds are women and the average is over 80 years¹². Almost 50% of users are entirely dependent on help and care from personnel and about 70% of the beneficiaries came to the home from single households. Experts estimate the current capacity of public care homes to be approximately 10,000 places, reaching around 13,000 when considering also private providers. Even when accounting for both private and public provision, institutional care only covers less than 1% of the population aged 65 and above.

The territorial distribution of residential care facilities (be they public or private) raises serious equity concerns: public residential institutions are mainly concentrated in urban centres and private providers are almost exclusively operating in the Belgrade area (Arandarenko & Perisic, 2014). Care quality is of concern in both public and private institutions: in the former mainly due to overcrowding, in the latter mainly due to the lack of control of minimum standard enforcement. Only recently several private care homes have been closed because of the low quality of provided services, raising some awareness to this problem.

Similar findings emerge from the *Deprived of rights out of ignorance* report (prepared by Amity and The Autonomous Women's Center with support from SIPRU). The authors conclude that elderly individuals living in public residential institutions in Serbia accept institutionalization as "a necessary evil", but while the living conditions tend to be fairly good they are generally isolated from the local community. Nonetheless, the guarantees of their human rights are insufficient and many of their rights are neglected. This situation, however, seems to stem primarily out of the ignorance of the staff and not from intentional neglect, and persists because the elderly themselves are very poorly informed with respect to their rights. Far worse living conditions are available in privately owned, unregistered nursing homes (i.e. not licensed by the Ministry), and residents there have no guarantees of their human rights. In both public and private homes, staff is insufficiently trained in specific aspects of care of older people, i.e. work with dementia patients or with regard to the human rights of the elderly.

The lack of adequate service capacity is the main issue in the elderly care system, with only secondary importance for deinstitutionalization. It is also clear that, while an increasing reliance on community-based and home-provided services is desirable, full deinstitutionalization is neither plausible nor appropriate – as it may be in childcare. Many residents of elderly care institutions are fully dependent, in need of medicalized care and unlikely to ever leave the institution. Nevertheless, the development of community-based care services for the elderly should become a strategic priority, as they are currently severely undersized with respect to care needs.

Three main types of community-based services are currently provided in Serbia under the coordination of local centres for social work and gerontology centres:

¹² This average value does not account for the fact that many publicly provided homes also accommodate beneficiaries who are considerably younger than 65 years.

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- Home care assistance

Home-based care is provided to elderly dependent individuals when no family or informal carers are available. It covers assistance with household activities, such as cleaning the house, purchasing food and other necessary items, hygiene maintenance and other things. In 2012, home-care services absorbed 1 billion RSD, accounting for 40% of funding for social welfare services within the mandate of local governments and roughly half of all spending on community-based services. The public finances are supplemented by user co-payments, the amount of which varies somewhat at the municipal level. Despite their relative importance in the Serbian social welfare system, home-care services are also severely under-developed: currently, public providers offer services in the home to approx. 10,000 beneficiaries in 155 localities (Arandarenko & Perisic, 2014), which represent little more than 1% of the potential target population. Public services are supplemented by the efforts of NGOs but no data or credible estimations of the number of recipients are available.

- Day care centres

While day-care centres should form the core of community-based services for the elderly, current capacity does not surpass 1,100 places. No precise estimate of how this capacity compares to care needs exists, but experts have characterized it as grossly insufficient. Despite diverging somewhat on the numbers, several experts converged to the conclusion that the availability of day-care services is highly geographically concentrated: the SIPRU mapping of social welfare services identified such services in 7% of the municipalities. Interestingly, the geographic concentration does not necessarily follow the size of the municipality or its relative affluence, e.g. no day-care centre is currently operating in Belgrade.

- Foster care system for adults

The system used to be much more developed during Socialism, when approximately 3,000 dependent adults were placed with foster carers but has since considerably contracted. Currently, the number of adults in foster care arrangements is lower than 300 (Arandarenko & Perisic, 2014).

Highly dependent individuals, who require permanent help and care from another person and who are entitled to receive a public pension, are eligible for cash benefits for assistance and care provided by a caregiver. The monthly allowance reaches almost 140 Euro but less than 80,000 older Serbians applied for it in 2012. The parallel social cash benefit scheme is subject to means-testing and very strict eligibility criteria, leading to an artificially small pool of eligible recipients. In 2012, only 35,000 elderly individuals received social welfare benefits, despite the fact that the risk of poverty in this category, estimated at 20.6% for the same year, far surpasses the national average (Arandarenko & Perisic, 2014). In addition, the value of the cash benefit remains very low: only 78 Euro per month in 2013, representing less than half of the minimal Serbian wage and being below the poverty line.

Informal care fills a big part of the remaining service gap, but no data is available on the frequency and type of care provided and to how many beneficiaries. In the absence of any systematic data collection or research effort the interviewed experts refrained from offering any estimate. They, however, expressed concern with respect to the quality of the care provided and the burden it places on informal carers (be it financial or time and effort). Unfortunately, no policy measures supporting carers exist and it is unclear to what extent they will be adopted in future legislation.

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All in all, since the passing of the 2011 law mandating the development of community-based social services, implementation has been slow and difficult with respect to services for the frail elderly. The main barriers to deinstitutionalization have been the unwillingness of local authorities to accept the inherent financial obligations and the lack of political support. The urgency of the phenomenon of population ageing and its likely impact on social protection systems, is poorly understood by Serbian decision-makers and their commitment to the issue remains low and unstable.

5. Transferability of good practices to the Serbian context

Deinstitutionalization, both as it regards childcare and long-term care services, has long been accepted as a general goal in European social protection systems. However, while the direction of change is remarkably similar the challenges to be overcome are highly diverse, leading to a situation where different countries find themselves at markedly different points in the deinstitutionalization process. These divergences can be traced back to the diverse historical, political, social and economic underpinnings of national social protection systems, creating a veritable microcosm of solutions and frameworks for the provision of care for dependent adults and children. Nonetheless, some commonalities can be identified and from them, valuable lessons can be derived. The lynchpin of success is sustained commitment to the goal. Deinstitutionalization is a gradual process whereby carefully targeted, successive interventions can add up to a system overhaul, rebalancing the core components of the system. The move away from residential institutions crucially hinges on the development of community-based alternatives and programmes and on the continued support to carers and individuals in need. Similarly, deinstitutionalization is facilitated by early, preventive interventions that can help curb the demand for intensive forms of support. Finally, deinstitutionalization is an investment – efficiency gains and cost savings must be preceded by the commitment of sufficient financial resources in stable streams.

With respect to deinstitutionalization in childcare, Serbia has made significant progress in the last decades, successfully shifting the focus of the system from residential to foster family placement. The current performance of the childcare system can be assessed as satisfactory, with carers receiving adequate financial support. Among the areas in which childcare services remain underdeveloped we note the insufficient preventive efforts for maintaining children in their families and the targeting of disadvantaged groups. The PIPPI programme in Italy and the Early Intervention Centre programme in Hungary provide examples of best practice initiatives for the prevention of abandonment and institutionalization which could be adopted in the Serbian context. Such programmes can be adapted to the characteristics of the local setting and established with limited start-up costs, followed by progressive scale-up. The Sure Start programme in Hungary is an example of a comprehensive intervention to prevent developmental delay, promote mutual learning and support the integration of children from deprived and marginalized groups and their parents into the community. By targeting and providing support to the family nucleus, rather than the child alone, all above mentioned programmes help build capacity in the community, empower families and reduce demand for intensive intervention (by preventing situations where the placement of the child would be necessary).

The development of long-term care services for dependent adults, unfortunately, lags behind. At the core of the problem lie the lack of continuity in funding and the misalignment of incentives for care providers. This situation has impeded the development of community-based care programmes and services and has led to a continued over-reliance on residential institutions. An example on how carefully drafted legislation can reshape the system of incentives and promote a shift towards less intensive care settings comes from Sweden, in the form of the Adel reform. While much local specificity must be accounted for, the design of the legislation for reimbursement of delayed hospital discharge can be a model for strengthening the legislative framework for long-term care services in Serbia.

Transferability of good practices to the Serbian context

However, even in the absence of stable and sufficient financial support from the central Government, a host of relatively inexpensive local projects can be relied on to promote deinstitutionalization. From the Austrian experience, we extracted two cases that emphasize the importance of small-scale, community-based initiatives. The Ludesch integrated care project is an example of how care providers, families and other representatives of civil society can work together to build up the necessary services. In the same spirit of promoting the goals of the community and mobilizing its resources, the “Ageing in good company” project is a model for how support from higher levels of Government can be best applied at the local level.

From Italy, a country where families are still the main providers of care, we present two initiatives that recognize the key role of informal care provision in the long-term care system. The first is a local initiative (the Family Nurse) which emphasizes the importance of reshaping care providers’ roles in a way which is conducive to the provision of care in the home: namely, by supporting family carers and building independent care networks. The second is a regional project aiming to recognize and enhance the skills of informal caregivers. The Serbian long-term care system also relies to a large extent on the provision of informal care from family members and local communities to dependent adults and elderly, especially in small localities and remote areas. Promoting initiatives similar to the ones presented in this report could go a long way to improving the quality of informal care in Serbia.

Finally, from the Czech Republic, a representative of the transition care model to which most Eastern European and Balkan countries could be ascribed, we presented the AREION project. This inexpensive telemedicine service, set up and run by a local NGO, provides great support for frail elderly and disabled individuals, allowing them to remain in their homes and live independently. Currently scaled-up to the national level, the AREION initiative can serve as a model for non-profit organizations active in the field of long-term care in Serbia that wish to improve the safety of frail adults and the coordination of scarce care resources, especially in remote and isolated areas.

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