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Deinstitutionalisation promotes higher quality of life for users and system sustainability

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From care in homes to care at home: European experiences with (de)institutionalisation in long-term care

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I. Introduction: the move away from institutions

Deinstitutionalisation, which is defined as the development of communitybased services as an alternative for care provision in institutional settings, has become the hallmark strategy of social and care services for individuals with limited autonomy across European countries. Two core arguments underpin the effort to deinstitutionalise care: prioritising users' quality of life and increasing the sustainability of care systems. The first argument is grounded in the belief that the protection of fundamental human rights¹ must lay at the core of all care systems: institutions segregated from the community deny residents many of their basic rights, whereas an independent life within the community would promote them. The second argument grows from an increasing body of evidence that communitybased care solutions can achieve better outcomes for users and their families at lower or comparable costs with respect to institutional care (European Commission, 2009). Furthermore, community-based care better maps the preferences of Europeans, the majority of which express a strong preference for ageing in place, irrespective of their nationality and cultural background (European Commission, 2007).

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. However, differences in needs, approaches and commitment levels have led to diverse results and pace of progress. Approximately 1.2 million people still live in residential institutions in Europe (Mansell et al., 2007). In addition, the permanence of large disparities in contextual, cultural and legislative backgrounds renders the path towards deinstitutionalisation a complex, country-specific process.

I The EU Charter of Fundamental Rights recognizes that each individual has a right to not be subjected to degrading treatment, to liberty and security, to education, work, health, equality and non-discrimination.

High variability of European experience in the process of deinstitutionalisation

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Although countries have diverged markedly on their paths to deinstitutionalisation, much can be learned from their experiences and from examples of strategies and models which proved to be effective. This Policy Brief presents a typology of long-term care regimes and proposes four case studies to exemplify: Austria (Standard care mix), Sweden (Universal-Nordic), Italy (Family-based) and the Czech Republic (Transition). In each case we track the complexities and challenges of deinstitutionalisation with a view on synthesizing the dos and don'ts in the context of longterm care for older people. In conclusion we discuss the importance of balancing the development of alternative types of care to maintain or reach low institutionalisation rates. It is argued that these can only be stabilised through a well-balanced mix of formal care services in the community and targeted support of informal care and by improving coordination between different care settings.

2. European long-term care regimes

European states have taken a wide variety of approaches to the implementation of care services, rendering comparisons and opportunities for learning difficult. In order to bridge this divide, Nies and colleagues (Nies et al., 2013) proposed a typology that reduces the complexity of longterm care systems to four so-called 'ideal types'. It considers three key dimensions for the classification of European long-term care regimes (see Table 1): the demand for care (e.g. population in need or at risk of longterm care and the role of poverty-driven factors), provision of informal care (e.g. share of individuals providing care to a relative and of multigeneration households) 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 I: A typology of European long-term care regimes		Demand for care	Provision of informal care	Provision of formal care	Countries
	Standard care mix	High	Medium/low	Medium	Germany, Austria , France, United Kingdom
	Universal- Nordic	Medium	Low	High	Sweden , Denmark, Netherlands
	Family- based	High	High	Low	Spain, Italy , Portugal, Ireland, Greece
Source: adapted from Lamura (2007) and Nies et al. (2013).	Transition	Medium	High	Medium/low	Latvia, Poland, Hungary, Romania, Slovakia, Czech Republic

The four care regimes typology is particularly well suited to our analysis because it considers three key factors that determine the balance between residential and community-based care solutions. The underlying need for care in the population can act as an important trigger for the over-development of residential care solutions. Conversely, strong informal care networks can compensate for high care demand and keep the pressure to institutionalise users low. Finally, the provision of formal services is a proxy for the size and involvement of the professional care sector. The balance between formal and informal care provision is key in determining the extent and speed of the deinstitutionalisation process.

While some countries try to reduce institutionalisation rates, others struggle to maintain them at current levels

A significant change of mind-sets among professionals is needed In order to cover as large a spectrum as possible, we selected a model country from each category. The four case studies represent both situations where the reduction of relatively high levels of institutionalisation for the older population has been explicitly addressed by public policy (Austria, Sweden) and situations where the rates of institutionalisation are relatively low and current policy is challenged to contain future growth (Italy, Czech Republic).

3. Drivers and barriers to deinstitutionalisation

While few systematic studies exist to date, some core principles for successful deinstitutionalisation can be defined (Table 2). The primary driver of deinstitutionalisation is the development of community-based alternatives, in the form of flexible services and support that can be provided in the user's home. However, it is important to emphasise that setting up community-based care is not a sufficient condition for deinstitutionalisation. Paradoxically, it may even reinforce the *status quo* if the same practices used in institutional settings are merely transferred into the community (Mansell et al., 2007). It is therefore crucial to accompany the shift towards community care by a cultural change on the provider side: beneficiaries must be afforded choice and control over their care, together with family carers. A failure to change mind-sets and approaches in the formal care setting is a formidable barrier to successful deinstitutionalisation.

In addition, whatever alternative to institutional care is offered to users, it must ensure comparable standards and outcomes of care. Successful community-based care hinges on the availability of appropriate support services for informal carers and the implementation of quality control mechanisms with an emphasis on user satisfaction. Finally, the focus of care should fall on preventing the need for institutional care, by develop-

the family, in the community and in institutional settings is key to success

ing alternative solutions and opportunities for early intervention that **Coordination between care in** can delay or altogether avoid the development of intense care needs. This process relies on the achievement of high degrees of coordination between many different actors and the establishment of strong governance structures.

> The case studies below are used to exemplify and develop these principles. When relevant, information on salient good practice examples is also included in text boxes. Further information on these good practices can be found in the report: Ilinca, Leichsenring, Zólyomi and Rodrigues (2015) European protection systems in the areas of childcare and long-term care: Good practices and lessons learned, available at:

http://www.euro.centre.org/data/1449059839_59841.pdf

		Common Basic Principles for deinstitutionalisation		
Table 2:	I	Respecting users' rights and involving them in decision-making		
Ten principles of deinstitutionalisation Source: Report of the Ad Hoc Expert Group on transition from institutional to community-based care, European Commission, 2009	2	Prevention of institutionalisation		
	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		

3.1 Austria

With 18.3% of the population aged 65 or over in 2014² and a predicted rising trend in the ageing process over the next decades, Austria faces the challenge of rapidly increasing demand for long-term care. The Austrian long-term care system relies on a combination of cash and in-kind benefits to users, built around a comprehensive system of long-term care allowances (OECD, 2005). This so-called Pflegegeld is funded through general taxation by the federal government with the aim to improve possibilities for independent living in case of care need. It is not means-tested or earmarked, i.e. it can be used to partially cover the costs of in-kind ser-

All population structure data, unless mentioned otherwise, is extracted from the Eurostat database.

Long-term care allowances are shaping the Austrian system of long-term care

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vices or to supplement the family budget as an indirect acknowledgement of family care. In 2013 there were approximately 450,000 beneficiaries of this scheme that contributes to more than 50% of the total public expenditures on long-term care – amounting to 1.4% of GDP (Eurostat).

The Austrian experience emphasises that the use of cash benefits is a key driver for long-term care development and deinstitutionalisation, but insufficient in isolation. Between the mid-1990s and 2008, Austria saw the percentage of its older population cared for in institutions rise (currently 4%), albeit much slower than the increase registered in home care use. Additional endeavours must be established alongside cash benefit schemes in order to successfully downsize the residential care sector. In Austria, the promotion of family care and the introduction of measures to support carers have encouraged community-based care, while the slow progress towards care integration remains an important barrier towards this goal.

In Austria, family care for older people with long-term care needs has long been provided almost exclusively by women and unremunerated. More recently, rising labour-market participation of women and growing mobility have put this traditional model of care under considerable pressure. In 2005, approximately 400,000 family caregivers - often burdened by their professional, personal and care tasks – needed respite, support and social security. Some provisions targeting these issues have been introduced over the past two decades: social insurance contributions for carers, enhanced care counselling, care leaves for employed carers, extensions of day care and other support facilities. They have been supplemented by payments of social security contributions for carers, but this support remains only a minor incentive for family carers. In 2014, an additional measure was introduced to facilitate care leaves for employees who care for a family member that is entitled to the long-term care allowance. For up to six months the carer is entitled to the equivalent of the unemployment benefit (55% of previous wage). Still, as care episodes are often extending beyond this period, about 15% of family carers are reducing or completely abandoning employment, and are often confronted with high barriers to re-enter the labour market. Despite these limitations, support to family carers has allowed numerous older people to remain in their homes, in no small part because the care provided by families can be supplemented with community-based formal care services: 37% of Austrians consider professional care at home affordable, placing the country considerably above the European average of 31% (European Commission, 2007).

High decentralisation in the Austrian system hinders coordinated action

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Notwithstanding these improvements, fragmentation at the interfaces between formal and informal care, and health and social care, remains the main barrier to deinstitutionalisation in Austria. The legal and organisational framework is still characterised by a strict division of competences and financing.³ A large variety of regional regulations affects the organisation and practices of residential care homes and professional education standards. Decentralisation, an inherent effect of the Austrian division of competences based on the principle of subsidiarity, is often a hindrance to coordinated action. In practice, cooperation between acute care and providers of follow-up treatments and long-term care services is limited. Despite the growing awareness of the need to integrate care and a series of efforts implemented to improve the situation, coordinated health and social care projects have not moved past the model phase.

Good Practice example:

Ageing in good company (Salzburg region)

Initiative of the regional government to encourage local projects promoting active ageing in the community, by establishing local care networks which can help improve the coordination between outpatient, inpatient and community services.

3.2 Sweden

With 19.4% of Swedes aged over 65 (2014), the country ranks among the oldest in Europe and has one of the highest public expenditure ratios on long-term care – 3.6% of GDP in 2010 (OECD, 2012). While financial sustainability has become a pressing issue, the benefits of sustained investment accrue to older Swedish citizens, who rank first in the world for social and economic wellbeing (HelpAge International, 2013). Recognised for its comprehensive social programmes, Sweden has a well-established, universal,⁴ public long-term care system. At the core of the system lays the devolution of responsibilities for social and primary health care provision for older people to the municipal level. The financial responsibility for long-term care is shared between national, regional and local governments, but approximately 85% of costs (2010) are covered through local and regional taxes.

Whereas health care and its financing are subject to the logic of social health insurance, social care and long-term care are competences of the regional governments – each with different departments for health and social affairs – and the Ministry of Social Affairs and Consumer Protection.

⁴ Eligibility criteria and the range of available services are established at the municipal level and vary between localities.

After 1990, Sweden registered a marked reduction of capacity in residential care facilities

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After 1990, Sweden made great progress towards deinstitutionalisation by constantly expanding and strengthening the provision of home-based services. In fact, the institutionalisation rate for people above the age of 80 dropped from 24% to 15% between 1993 and 2008; between 2000 and 2008, the number of beds in residential facilities decreased by approximately 20,000 units, while the number of home care recipients increased by 20,000 individuals. The downsizing of the institutional sector in Sweden has been facilitated mainly by the realignment of incentives for providers across the health-social care divide. However, only recently efforts have been taken to further invest in measures to support informal care networks and family care.

The fragmentation between the health and social care systems was addressed, among other measures implemented through the so-called Ädel reform in 1992, by instituting a reimbursement scheme for delayed hospital discharges and mandating the use of joint care plans. Primarily targeting patients with long-term care needs who were 'blocking beds' in hospitals without needing acute treatment, the reform made local authorities accountable for the costs of patients whose hospital treatment was completed but who could not be discharged due to the lack of necessary long-term care arrangements in the community. Concurrently, the joint care plan model stressed cooperation between health and social care professionals, facilitating patients' transitions to the appropriate level of care. These provisions have been powerful incentives for municipalities to provide appropriate home care services in order to avoid the higher costs of hospitalisation or residential care. At the same time, they promoted a culture of collaboration between care professionals, ensuring care appropriateness and more seamless transitions for users between different levels of care.

Family carers greatly contribute to the system but receive insufficient support

In contrast, one of the main barriers to deinstitutionalisation in Sweden has been the under-development of support services for informal caregivers. In 2010, Swedish families covered an estimated 70% of long-term care needs, but received little support and recognition from the welfare state. Amendments to the Social Services Act in 1998 and 2009 increasingly recognised the necessity to provide support for family care,⁵ but they are weak instruments of enforcement, with the main decision-making powers concentrated at the local level. A case in point is the care allowance, a cash benefit awarded to care recipients and intended for the remuneration of family care. Its availability, however, is limited to those municipalities that voluntarily subscribe to the scheme, leading to restricted take-up

⁵ The current legislative framework defines the responsibility of local authorities towards caregivers as a compulsory requirement.

(Fukushima et al., 2010). Similarly, Swedish carers are entitled to support and counselling services, but as no national standards exist, municipalities determine the type and extent of provided services (Johansson et al., 2011). Even relief and respite care, the most common type of support for carers, are offered free of charge only in half of Swedish municipalities, while the others charge a fee. Such geographical differences lead to situations where caregivers receive insufficient support, leading to overburdening of family carers.

3.3 Italy

Italy is the country with the oldest population in Europe, reaching 21.4% in 2014 and projected to increase to 33% by mid-century. Public expenditure on long-term care is currently (2011) estimated at 1.7% of GDP due to a widespread cash benefit scheme, which may be interpreted as an indirect acknowledgement of the significant contribution of households to care provision. Responsibilities for funding and provision of community care, residential care and cash benefits are divided between municipalities, regional authorities, the National Health System (NHS) and the National Institute of Social Security (NISS), constituting a high degree of fragmentation and ample geographical disparities.

Italy has not been confronted with the challenges of deinstitutionalisation, because the institutional care sector has traditionally been undersized with respect to needs. The current rate of institutionalisation of approximately 2% is more than two times lower than the European average. This has been possible only due to the vast contribution of households underpinned by strong cultural and family values. In contrast to the case of Sweden, support to families (in the form of generous cash benefits) has been the main instrument for containing institutionalisation rates in Italy. However, due to increasing difficulties in conciliating care and paid work, the gap between the supply and demand for care is widening, raising the challenge of maintaining the current low rates of institutionalisation by strengthening the provision of community-based services.

The relatively generous cashThe namebenefit scheme is the mainisteredpillar of the Italian long-termable sicare systemfrom t

The national cash benefit scheme (*indennità di accompagnamento*), administered by the NISS and financed through general taxation, has been available since 1980 to individuals of all ages with care needs, independently from their financial situation and carrying no utilisation restrictions. It represents the main pillar of the long-term care system in Italy, with the highest number of beneficiaries (coverage rate of 12.5% in 2010)⁶ and

Despite having the oldest population in Europe, Italy's formal care system remains under-developed

⁶ Coverage rates varied between 8.4% and 19.5% of the population aged 65 and above, depending on the region. They are higher in regions where formal services are under-developed (South and Centre) and lower in the North where levels of institutional and home care provision are considerably higher.

Migrant carers complement family care, as a result of the low availability of formal care and support services

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absorbing the highest amount of public resources (Istituto Nazionale di Statistica, 2014). Local authorities also provide other forms of cash benefits for households with a person in need of care (family allowances or 'assegni di cura'). These target exclusively individuals with high degrees of dependency, are means-tested and often awarded as an alternative to public formal care services. In addition to cash benefits, some regions also offer relief services for carers, including access to day care centres, shortterm care and self-help groups.

The over-reliance on informal care in the Italian long-term care system has produced considerable labour-market distortions particularly among women, as well as physical and psychological problems for caregivers. In order to relieve the burden of informal carers without resorting to institutionalisation, community-based care services must be developed. Under Italian law, personal social services, including domestic and personal care tasks provided in the recipient's home, are planned and provided by municipalities, while home health services fall under the responsibility of the NHS. In 2012, the coverage of home-based services for older people in Italy was 4% (the European average was over 7%) with large geographical differences in quality and quantity of provided services - mainly along the North-South divide. During the same year, home-based care absorbed only 18% of the long-term care budget, attesting to its secondary role in the system. Underinvestment in home care has led to a situation where the demand far outstrips public provision, and many households must bear the financial burden of growing care needs, although less than one in three Italian families (27%) can afford to pay for professional care in the home (European Commission, 2007). As a result, a large and growing number of Italian households rely on migrant live-in carers to complement or replace family care (Da Roit et al., 2013). Hence, concerns are growing that the unsustainable burden placed on families might spill into increased institutionalisation rates over the next decades.

Good Practice example: Family Nurse (Varese region)

Pilot project building around the care management of frail individuals in the community by assigning a trained health professional to plan and oversee their care pathways and to provide health education and support for informal and family carers.

3.4 The Czech Republic

With 17.4% of the population aged 65 and above, the Czech Republic ranks below the European average, but is one of the countries with the highest proportion of older people in Eastern Europe. Despite marked increases in life expectancy, these gains are not paralleled by better health in old age: almost half of the life expectancy gained will be spent in poor health. Current (2010) public expenditure amounts to 0.8% of GDP, a figure that is likely to rise due to demographic ageing alone. Responsibilities for service provision are currently fragmented between the health care system, the social care system and local authorities and only few steps have been made in recent reforms to increase coordination and integration. Support for people with long-term care needs consists mainly of cash benefits, supplemented by services in kind. These, however, are chronically undersized with respect to needs and the patchy geographical coverage raises serious concerns with respect to equity in access.

Similarly to the case of Italy, institutionalisation rates in the Czech Republic remain very low: in 2011 residential care covered only 2% of the older population. This trend is partly explained by the general underfunding of formal care, both in the institutional care sector (available mainly in urban areas) and in home care. In addition, institutionalisation rates are contained due to the significant involvement of families in the provision of care: the Czech Republic is one of the EU countries with the highest reliance on informal care provision, with an estimated 80% of care needs covered within the family (Sowa, 2010). While the support of carers has improved after recent reforms (cash benefits) the underdevelopment of community-based services remains a barrier to ensuring that most older people will be able to receive necessary care in their homes.

Following the Social Services reform in 2007, cash benefits in the form of attendance allowances are awarded to beneficiaries on the basis of assessed needs. The level of the allowance is linked to four levels of care needs and its amounts are relatively generous for advanced care levels (surpassing the average old-age pension). With more than 300,000 beneficiaries (a vast majority of which are 65 years or older) the attendance allowance has become the most important pillar of the Czech long-term care system. The allowance is not means-tested and is financed through general taxation by the national government. It can be used to remunerate informal and family caregivers (who also receive entitlements to pension credits and health insurance coverage), while no direct cash benefit is assigned to carers. In its current form the benefit scheme is likely not to be sufficient to incentivize carers to maintain comparable levels of provision in the future, especially for individuals with advanced disability.

The Czech Republic is one of the European countries with the highest reliance on informal care provision, as formal care services remain chronically undersized

Cash benefits alone are not sufficient to maintain the care of older adults in the community However, the allowances ensure that care for older people with intensive care needs can be provided in the community for longer.

Community-based care encompasses two types of services generally provided by nurses and volunteers and coordinated by home care agencies. Home care services (including personal assistance services and community care in daily activities) fall under the responsibility of the social assistance system. Home nursing services cover nursing or rehabilitation and are provided by or under the supervision of a medical doctor. The bulk of provided services relates to home care, but almost a quarter of costs is represented by out-of-pocket contributions from users (Sowa, 2010). While the availability of services is improving, in remote areas service coverage is practically lacking and for many older people out-of-pocket costs remain prohibitive. As a result, unless targeted policies promote the development of community-based care services, standard convergence to EU levels is likely to be associated in the Czech Republic with a considerable increase in institutionalisation rates.

Good Practice example: AREÍON Emergency care

Distress care service (linking a domestic monitoring device to a 24/7 call centre) helps frail older people maintain autonomy and continue living in their homes by allowing them to cope with emergency situations.

institutionalisation in longterm care need to overcome 'silo-thinking'

Conclusion: the lessons of 4. deinstitutionalisation in Europe

Successful strategies to avoid Whether they face the challenge of reversing or all together avoiding high rates of institutionalisation of frail older people, all countries analysed are in effect facing challenges to define and maintain a balance between different long-term care settings. Through this lens, the chosen case studies emphasize a core principle for successful deinstitutionalisation: it must not build on the crude counter-position of residential and community-based formal care services, but rather on a triangular relation between formal care in both institutional and community-based settings and family-based care. Successful strategies to avoid institutionalisation in long-term care need to overcome 'silo-thinking' and to focus on the boundaries between care settings in order to facilitate synergies between different levels of care and (professional) cultures.

A good balance between formal and informal care promotes low institutionalisation rates

Integration between different care settings is paramount for deinstitutionalisation A second core conclusion is therefore that both well-developed community care and support schemes for family caregivers are necessary preconditions but none is, in isolation, sufficient for maintaining institutionalisation rates low. As our analysis points out, each dimension can become both a driver and a barrier to deinstitutionalisation, depending on its interplay with other parts of the system. Italy and the Czech Republic are prime examples of systems where support to family carers has helped avoid over-institutionalisation, but at the cost of passing the burden of care onto individuals and families. The economic and personal consequences for households put these long-term care systems under pressure of becoming unsustainable in view of population trends. Conversely, Swedish deinstitutionalisation and home care development policies have become canons for a shift towards community-based care. Nonetheless, soaring costs and service shortages are forcing Swedish policy-makers to reconsider this approach, to target services on those with the highest care needs, and to reinvest in support for family-based care.

Finally, it is important to recognise that a harmonious balance between different care settings relies on achieving high degrees of coordination between the different stakeholders involved in the process of social *and* health care. In general, responsibilities for long-term care provision across the health and social care spectrum are fragmented between different administrative levels, stakeholders and sectors. Appropriate and timely care for individuals with complex care needs depends on ensuring effective transitions between care levels, cooperation between involved professionals and informal carers, and on fostering continuity in treatment and support. Here, the Austrian experience is a case in point: fragmented efforts to develop home-based care (both in the formal and informal sectors) have not led to the desired overhaul of the system. While care integration remains a goal rather than a reality in European long-term care systems, it is increasingly emerging as the lynch pin of balance and sustainability.

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