

Rethinking the Approach to Long-term Care

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This piece takes an overview of the situation regarding long-term care in the European Union (EU) countries and makes the case for a broader approach to addressing how we respond to the challenges involved. I want especially to draw insights from the reforms that have been undertaken, to identify lessons for European countries going forward. Throughout I emphasise that while material and organisation reforms are vital, we have to change the way we as individuals and societies as a whole think about, plan for and manage long-term care.

The term ‘long-term care services’ can be defined as the organisation and delivery of a broad range of services and assistance to people who are limited in their ability to function independently on a daily basis over an extended period of time, due to mental and/or physical disability (Lipszyc et al 2012). For the purposes of this piece long-term care is thought of in relation to the care of frail older people and comprises care at home as well as outside the home. This policy field comprises supports and services for the person requiring care and for the person(s) providing it, although the extent to which countries have both sets of policies is a cross-national variation (Bouget et al 2016). Historically, countries tended to introduce benefits and services for the person needing care first; it was generally only later that benefits for carers (mainly those caring for a family member or friend) were introduced.

What’s the Problem?

Among the problems that have been identified almost elsewhere are rising costs, the inadequacy of the financial support and system of service provision in the light of changing economic, social and demographic conditions.

There are pressing challenges that obtain across countries. Among the most widely debated and researched is population ageing. This is associated not just with demographic change but also an increase in multi-morbidity and, for this and other reasons, an increase in the demand for long-term care. The European Commission has estimated that the number of people needing long-term care will rise by 12 million (from 40 to 52 million) between 2013 and 2060, and the old-age dependency ratio (the ratio of people aged 65 or above relative to those aged 15-64 years) is projected to grow from 27.8% to 50.1% (European Commission 2015). In fact, for the Union as a whole long-term care is the field with fastest-rising projected social expenditure – compared to health and pensions especially. A second contributory factor is change in employment patterns, women’s especially. Female employment continues on an upward course, although again of course there are variations. On average the employment rate for women aged between 20 and 60 years is around 65% in the EU as a whole. According to the EU, women contributed more than two-thirds of the overall change in the labour force in the past 20 years in the EU15 member states (and more than three-quarters if only the prime-age population is considered) (Eurofound 2016: 5). The significance of this change for long-term care could not be underestimated. Women’s movement into the labour market changes the rhythm and organization of family life and means that the supply of carers, especially those who provide care on an informal and/or unpaid basis, is reduced. This is widely spoken of as ‘the care deficit’.

Long-term care is one of the most complex policy fields of all. This is not just because it has at least two main ‘recipients’ – the cared for person and the carer – but also because it is organisationally very complex and is culturally quite sensitive (in terms for example of the

balance to be struck between family responsibilities and desires and state intervention). There is another side to complexity as well which is that our societies seem to be rather frozen in recognising that policy on long-term care is inadequate in most countries and therefore that foresight and strong leadership are necessary.

There are many particular features of long-term care that make it a challenge to organise, to pay for and also to reform. It is labour-intensive for example and therefore costly. It is also spread across sectors – with a mix of providers in all countries criss-crossing public, for profit and NGO providers; one should add here ‘the family’ as another provider. Moreover, it exists in the shadow of the health sector in many countries and so tends to be dwarfed by health-related developments and needs. Another particularity of the care sector is that it relies heavily on informal care which of course reduces the cost but also increases the challenge associated with regulation and supporting those who care informally. The locations of delivery also vary - home care, institutional care and community care as does the type of ‘service/support’ provided (in cash benefits, leaves from employment, in kind benefits or out-of-pocket payments). Systems also vary in terms of how resources are generated (via general taxation, obligatory social security, voluntary private insurance or private payments).

There is also the matter of the workforce and working conditions. In the EU as a whole a high proportion of the services are estimated to be provided within the hidden economy; the sector of personal and household services has one of the highest levels of undeclared work. In addition, the skills set that the care workforce is required to have is increasingly diverse (from ‘traditional’ care-related competences and soft skills to technological expertise related to advances in health technologies), while the attractiveness of the formal care sector to potential workers is undermined by a negative perception and poor working conditions. Unsurprisingly then, there are large variations in terms of access to/eligibility for long-term care. As well as access there are also challenges regarding quality and financial sustainability.

Organising and Re-organising Long-term Care Provision

Even though the sector is challenged, it is being reformed.

The reforms can be divided into two main types. The first are focused on the general organisation of service provision and supports in the care sector. Here the core aims of long-term care policy innovation have been to expand the range and diversity of care arrangements available for people in need of care and their families; to complement or replace traditional service forms with new ones; and/or to change the organisational and contractual framework within which care is delivered in order to make it less costly (Ranci and Pavolini 2015). Cost and efficiency have been prominent. Towards the end of a more cost-efficient set of services the following general directions of change have predominated across countries (Ranci and Pavolini 2013):

- Some privatisation of care provision and development of markets in the sector;
- Imposition of stricter eligibility criteria and reassessment of individual entitlements; a propensity to introduce and increase financial support for informal and/or family-based care arrangements;
- De-regulation of care work to make it cheaper and more flexible; ‘active ageing’ programmes pursuing the enablement of older people with care needs within a social investment strategy;
- Promotion of technological innovation in the fields of domotica and robotics;
- Increasing use of migrant labour.

The second major set of reforms relate to supporting informal carers. There are some interesting developments here. However it must be said that a recent EU-wide report which looked at the supports for carers concluded that policy for the support of caring for children is generally more developed in the EU as compared with policies for the support of long-term care (Bouget et al 2016). That said, it concludes that the majority of the member states could be said to have developed and mature support schemes for carers in place. The continental European and Nordic countries take primary place here. The general history in these countries is based on a ‘first generation’ of support schemes, implemented roughly before the 1990s. These ‘got in early’ as it were and recognised dependency of old people as a new social risk and tailored new types of social policies to support care for dependent persons. The second, younger generation of support schemes for carers was launched only around the millennium or after, and therefore had to address this risk in a very different socio-economic context. There is in the EU though a sizeable number of countries with underdeveloped support schemes for carers. These countries include especially the Mediterranean nations and some of the Eastern European countries. In these countries not just is institutional care under-developed but there may be a cultural resistance to using the care on offer. In general this and other research suggests that countries need a wide range of measures in place and that the circumstances of carers is better in countries which have developed various part-time work arrangements and flexible working time as compared with those that have not.

It should be said that one of the general conclusions of research on the reforms being undertaken in the sector is that countries are not converging and that the reform process involves very fine balances for decision makers, not least because the public have very strong opinions about the appropriate course of action. It is this – and the need to address public opinion and individuals’ courses of actions regarding long-term care - that I want to turn to in the last part of this paper. My main point is that policy needs to give greater attention to the private sphere and especially to thinking more systemically.

Thinking More Systemically

A first and overarching step is to change the way we conceive of the ‘system of care’ and to understand sustainability from a more social – as against just economic – perspective. That is a daunting task given that most of the attention to sustainability has been framed as financial sustainability with the challenges understood either from a cost/financing perspective or a demographic angle. My point is not that this is unimportant or unhelpful – it is – but rather that social sustainability is a vital part of the situation and that social and financial sustainability are intimately linked. I suggest along with Costa-Font et al (2015: 5) that we take a systemic approach that goes beyond formal provision and recognise that the definition of the ‘system of long-term care’ needs to include not just formal institutions and services but also the role of the family and other personal sets of relationships and resources.

This will also involve taking a broader view of ‘care resources’. When we do so, we see that while the bulk of spending is public the bulk of the resources for long-term care (viewed more broadly than spending) is private. For example, family-provided long-term care is an ‘informal economic sector’ estimated to range between 50 and 90% of the overall cost of formal long-term care provision in EU countries (Bouget et al 2017). The pressures described earlier that are pressuring informal care provision and leading to a care deficit are not being sufficiently recognised by policy makers. Let us take the EU as an example. The European Pillar of Social Rights, launched in April 2017 as a solemn declaration of intent, lists access to affordable and

good quality long-term care services as one its core principles (European Commission 2017). The Pillar privileges home-care (provided at the home of a person in need of care) and community-based services (range of care services of a non-institutional character) including for persons with disabilities in line with the UN Convention on the Rights of Persons with Disabilities. This important not least in recognising care as a foundation for social rights but the question has to be asked whether this kind of promise to those needing care can really be realised? Most countries have waiting lists for home care services and in many situations also people can only remain in their own homes because of informal care. But this is not recognised – it is more or less assumed that people – women mainly – will continue to provide unpaid care. All the indications are that this may not happen or will be impossible. I certainly believe that it will not happen unless we make much better efforts to recognise, respect and better value informal care and those who provide it.

One first step might be to stop seeing long-term care as a burden. It is striking that whereas we consider caring for children as an ‘investment’ care for older people is generally seen as a burden. Of course this varies to some extent by country and culture. But still, the overwhelming representation of long-term care is as a problem or a negative experience. This is present for example in discourses about societal ageing and related changes in life expectancy which tend to be cast negatively, rather than seen as an achievement and an opportunity. There is much we can do to change this if we direct public policy attention to it. The goal to aim for is to improve the value we place on older people and on care-giving as an activity and set of relationships. The campaigns on positive ageing help but these tend to focus on maintaining healthiness and hence to some extent avoid reference to social care – much of their purpose is to prevent people having to make recourse to care. We should not avoid referencing social care but actively raise its profile and try to raise its value. Different ways we might do this include public education campaigns for people across the age spectrum which highlight the activities involved in caring and the value attaching to them, and to those who both give and receive care. Other possible ways of raising the profile would be to create prizes and awards systems for ‘good care’ and ‘good carers’. These already exist in some countries.

These kind of changes will not be easy because we have for so long assumed that the most people need to do to prepare for old age is to ensure that they have pension entitlements and have paid their care insurance I suggest that we can no longer take either of these for granted and need to be much more proactive about ensuring that people as individuals and we as societies plan for and reward long-term care.

References

- Bouget, D., Spasova, S. and Vanhercke, B. (2016) *Work-life balance Measures for persons of Working Age with Dependent Relatives in Europe, A Study of National Policies 2016*, Brussels: European Commission.
- Bouget, D., Saraceno, C. and Spasova, S. (2017) 'Towards new work-life balance policies for those caring for dependent relatives?' in Vanhercke, B., Sabato, S. and Bouget, D. (eds) (2017) *Social Policy in the European Union State of Play 2017*, Brussels: ETUI.
- Costa-Font, J., Karlsson, M. and Øien, H. (2015) *Informal Care and the Great Recession* (June 30, 2015). CESifo Working Paper Series No. 5427.
- Daly, M. (2012) 'Making policy for care: Experience in Europe and its implications in Asia, *International Journal of Sociology and Social Policy*, 32 (11/12): 623-635.
- European Commission (2015) *The 2015 Ageing Report Economic and Budgetary Projections for the EU 28 Member States (2013-2060)*, European Economy 3/2015, Brussels: European Commission.
- European Commission (2016) *Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability, prepared by the Commission Services (Directorate-General for Economic and Financial Affairs), and the Economic Policy Committee (Ageing Working Group)*, Volumes 1 and 2, Brussels.
- European Commission (2017) *Taking Stock of the 2013 Recommendation on 'Investing in Children: Breaking the Cycle of Disadvantage'*, Commission Staff Working Document, SWD(2017) 258 final. Brussels.
- Eurofound (2016) *The Gender Employment Gap: Challenges and Solutions*, Luxembourg: Publications Office of the European Union.
- Lipszyc, B., Sail, E. and Xavier, A. (2012) *Long-term Care: Need, Use and Expenditure in the EU-27*, Brussels: Economic Papers 469, November 2012.
- Ranci, C. and Pavolini, E. (eds) (2013) *Reforms in Long-term Care Policies in Europe: Investigating Institutional and Social Impacts*, New York: Springer.
- Ranci, C. and Pavolini, E. (2015) 'Not all that glitters is gold: Long-term care reforms in the last two decades in Europe', *Journal of European Social Policy*, 25 (3): 270-285.