

3rd NEWSLETTER



The SPRINT project aims to *give meaning to the concept of social investment as applied to long-term care provision.*



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SPRINT is a three-year research project seeking to elucidate how long-term care (LTC) can be located within the concept of social investment. It conducts research with a view to define the “social” character and impact of LTC schemes and to propose a set of tools, guidelines and policy recommendations that will support successful implementation of investment in LTC.



Save the date!

SPRINT project Final Conference

**Social investment in long-term care: opportunities, challenges,
applications**

Thursday 7 June 2018, European Parliament, Brussels



How to measure the use and need for long-term care

Administrative and survey data

How can one know how much Long-Term Care is needed and how much is actually used? The obvious answer is to ask those entrusted with administering long-term care; i.e. use 'administrative data'.

If one does that, as Eurostat's ESSPROS system, you can arrive at detailed and apparently complete data - for some countries. In others, the harvest is embarrassingly full of gaps, while disparities over Europe are extremely wide. Expenditure appears high and the information detailed where public long-term care systems are well-developed and low, where care is primarily a family matter. Any picture based on administrative data shows marked North-South and West-East gradients.

Are these gradients real or do they simply reflect differences in the data? Administrative data is a byproduct of policy. Where responsibility is devolved, statistics will tend to be low. In-country comparisons, administrative data will reflect definitions - of need, availability, types of care - specific to each country.

The alternative is **survey information**. Sample surveys are population-based, with a known relation to the true population. In contrast, specialty LTC surveys may focus on a sub-population without a clear idea of the whole. A general-purpose survey can explore links between LTC and other domains - health, finances etc. Asking the same question everywhere deals with comparability 'by design'. Finally, in dealing with older people, we must not exclude individuals too unwell to reply.

The study of long-term care can use the **Survey of Health Ageing and Retirement in Europe** (SHARE), (www.share-project.org), a panel survey of people over 50. SHARE was launched in 2004, produces data every two years and is closely modelled to surveys in the US and England (HRS and ELSA). The seventh wave of SHARE (collected in 2017) covers all members of the EU plus Switzerland

SHARE has four characteristics which make it especially suitable for LTC:

A. The data are interdisciplinary. Questions probe issues relating to Health, Psychology, Sociology, Economics, and Finance.

B. The data are comparable. Europe can be treated as a kind of 'research laboratory', or as a depository of good practice.

C. The data have a panel structure. Individuals are followed over time, so that the impact of key events, such as retirement or a disability, are monitored.

D. SHARE is designed for an older population. Emphasis is placed on older and infirm respondents, such as proxy interviews for those unable to answer.

Platon Tinios

Assistant Professor

Piraeus University



The social right to long-term care for EU-citizen

The aging of population is a major problem for all member states. First, old-pension systems were affected but more recently long-term care has become the real challenge. More and more people need long-term care in old age. However, providing affordable long-term care is not only an issue for the older generation but

also for younger people and even for children. Progress in medicine allows more people to survive severe accidents, live with diseases that were fatal some years ago or inborn deficiencies that had would have killed new-born children just after birth.

The majority of the EU-Member States provide to their citizens a legal entitlement to long-term care services. This entitlement is laid down in various acts. Most Member States distinguish between help for disabled persons, in general persons under pensionable age and elderly people that have become frail and helpless due to the advanced age. There is a certain relationship between retirement age and entitlement to long-term care benefits although both situations do not necessarily correlate with each other.

The legal regulations among the Member States are very much dispersed and comprise among others social security laws, health law, and laws on social assistance. In some Member States the legal provisions do not even apply to the whole territory or do not cover all citizens in need for long-term care. Indeed, in all Member States, the legal entitlement to long-term care services is not a citizen's right but an entitlement of a vulnerable person in a specific situation of life to certain benefits. Member States define autonomously the legal requirements for belonging to the group of vulnerable persons or being in a specific situation that implies the need for care. Member States stipulate the type and extent of benefits in order to cover the need and the costs for long-term care and they also decide which institutions may operate on the growing and lucrative "market" for long-term care and how benefits are financed.

Long-term care is a specific social risk that is not defined as such by law. Of course, in most Member States there are regulations for assessment procedures that fix the need for care. But they are not legally "neutral" in the sense that they define long-term care on an abstract level, e.g. like retirement age. The assessment is always seen in relation to the benefits to be granted. As a rule, Member

States try to rely on the assessment procedure on objective legal parameters. Most of them use a scale of points taking into account different aspects of capabilities in the activities of daily life (ADL). But here the experts' discussions begin to drift apart since some try to measure the capabilities that the person involved is missing whereas another legal approach is to look at the capabilities left to manage the activities of daily life. The law reflects the respective approach since it is the legal basis for granting benefits. Despite the look for objectiveness, the assessment has always a subjective component, too. On the one hand, the person involved may perform better because at the assessment day he or she was in a good state. On the other hand, the personal impressions of the assessment persons may deviate and result in a different valuation. This is why most national case law on long-term care, if there is any at all, deals with the question of valuation and upgrading in order to receive higher benefits or to get benefits at all.

The provision of long-term care benefits is very much related to financial resources. Long-term care is very costly because there is a big need for manpower. Most needs have to be met with personal aid and support. There is not too much possibility of rationalization of workflow and only a few things can be made by machinery. An example of this relationship between the scope of benefits and the available financial means are people with dementia. In many systems, they are legally excluded from benefits or only entitled to small benefits although they need personal care in form of surveillance all day long. In particular, for these persons, the Member States rely very much on the help and support of family members. But also for other persons in need of care most Member States count on the assistance of family members. Officially, this support of family members is often promoted as a better form of long-term care because the dependent person can stay in the accustomed surrounding. In reality, it is a disguise to save as much money as possible.

Although in none of the Member State exists a legal obligation to

take personal care of a next-of-kin, in the majority of Member States the family remains the basic pillar for the provision of long-term care. This leads to a bundle of legal consequences. Labour law should be amended to guarantee the conciliation of work and family tasks. Only a few Member States have already changed their respective laws to allow a care leave. However, it is rare that the loss of salary is compensated. This is why a majority of family carers, mainly women, make part-time arrangements which end up in most Member States in low pensions in old age. In addition, family members are often overstrained with the provision of long-term care which may result in health problems or –in case of negligence for the dependent person- in punishment under penal law.

Apart from moral aspects in some Member States there is also an indirect legal tool to achieve family care. In several Member States, maintenance law does not only ask for maintenance payments from parents to children but also vice versa. With the exception of the Scandinavian countries which have a universal approach, the other Member States cover only part of the costs for professional care. The remaining costs are due to the dependent person. If the dependant person does not dispose of enough money he or she will get means-tested benefits like social assistance. In some countries, the competent authorities may ask the children for total or partial reimbursement of the prepaid costs. A way out of this cost trap is the engagement of a person from abroad that works for less money, in particular, an immigrant from Eastern Europe. The legal consequences of this model are often an infringement of migration law, e.g. the EU-legislation on the free movement of persons and services, of labor law by poor working conditions or of social security law by payment of insufficient contributions.

Notwithstanding all differences in national laws and legal approaches, there seems to be common sense that long-term care for the frail and elderly people is a legal issue that has to be dealt with in the near future in view of the dramatic demographic change. It is also common sense that the state has to intervene

with legal regulations. The affordability of adequate long-term care for dependent persons is a right that every human being should enjoy leading or concluding its life in dignity, a demand that is stipulated in the constitutional law of some Member States and codified as binding for all Member States in the European Charter of Social Rights. Therefore, in recent years almost all EU-member states have developed a form of social protection for dependent persons. This common sense might be named a European Social Model although a model normally implies a certain uniformity of application. In any case, the desirable extension of social protection for long-term care in this European Social Model faces financial constraints for many Member States. Unfortunately, Member States with financial constraints are at the same time Member States with a less developed social protection for long-term care.

Although the Treaty on the European Union does not stipulate competences in the field of social protection and social security, nevertheless there are several regulations that would allow the European Union to develop a legal framework for the provision of long-term care. One legal aspect is social cohesion. Long-term care is a problem that affects all Member States and the same is true for the quality of services. It makes no sense that EU-citizens in one Member State enjoy a relatively good social protection whereas in other Member States the benefits are relatively low or inexistent. This is also a severe obstacle for the free movement of persons within the EU because, as the jurisprudence of the European Court of Justice shows, migrants may lose acquired social protection for long-term care if they move to another Member State. Since most benefits for long-term care are benefits in kind the EU legal instruments on the freedom of services and on competition may also be a tool for the development of protection. In addition, in most Member States private entities also provide care services either as a profit organisation or as a non-profit institution. Social investment could combine these two approaches to achieve an adequate provision of long-term care to the full advantage of dependent persons. However, it is reasonable that the same

principles for social investment in long-term care apply all over the EU. This would also make it easier for institutions to provide trans-frontier care services. Up to now the provision of long-term care is a fully restricted market bound to national regulations only. Moreover, social investment might also be a legal tool to activate people to utilise preventive measures or to undergo rehabilitation arrangements. It may also be a legal incentive for enterprises to develop new technologies to ease or even avoid long-term care. Social investment might make these new technologies affordable so that people in danger of getting dependant can make use of it to retard more expensive measures for long-term care, e.g. residential care.

Prof. Dr. Hans-Joachim Reinhard

FULDA University



Social Investment Criteria in Long-Term Care

Designed to provide a practical development to the definition of social investment in long-term care developed within SPRINT, a set of social investment criteria has been created. Framed by the three dimensions of economic return, social impacts, and risk, they

provide decision makers with information on the relevant outcomes experienced by multiple social actors.

Examining outcomes for institutional and individual actors identifies the effects that policymakers and others interested in social investment should account for when making decisions about long-term care. Broadly, economic returns address employment effects and efficiency improvements, social impacts refer to largely intangible changes experienced by people, and risk concerns both financial and social components.

Many of the outcomes can, of course, be viewed from the perspective of multiple dimensions of impact. Such an interdependent nature of the outcomes highlights the potential tensions between the various social investors and can often be distinguished by macro- and micro-level priorities. For example, care recipients and their families will want to maximise health and wellbeing outcomes, whilst those responsible for financing will have to balance these demands with pressures of sustainable and equitable care provision.

It is important to recognise that different welfare traditions have various levels of formal and informal care, and decisions taken in each country about care provision will likely be different. Nevertheless, the improved levels of information regarding stakeholders and their experiences will increase the transparency of the issues involved. By providing a single typology of outcomes mapped against the various social investors, SPRINT is helping to increase the transparency of issues to be considered to support the allocation of resources.

Policymaking and others interested in social investment need to take account of material outcomes to assist their decision-making. Therefore, having identified what is relevant, SPRINT will also be examining the potential to identify monetised values of the relevant outcomes to help decision-makers to appreciate the significance of changes experienced through long-term care.

What is “social investment” and how can it support improvements to long-term care for older people through new ways of funding and service development? Social investment “involves strengthening people’s current and future capacities” and helping people to ‘prepare’ for life’s risks rather than simply repairing the consequences. The SPRINT project is exploring how this could be applied to the provision of long-term care across Europe.

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CUIDAR DE QUEM CUIDA
Os direitos dos cuidadores em Portugal

6 JANEIRO 10h30
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 **Bloco de Esquerda**

Consultation about Informal Care legislation in Portugal

Dr. Alexandra Lopes, director of the research center of the Sociology Institute of the University of Porto and member of the SPRINT research team was invited to participate in the consultation on new legislation regarding the recognition of informal carers in Portugal and the establishment of relevant support mechanisms for this group of population. Following a petition, presented last year to the Portuguese Parliament, by a group of citizens, acting on behalf of patients and family members of patients with Alzheimer disease, the government has nominated a committee of experts to

study the topic and to produce a report with recommendations on new legislation about informal care. In response to this initiative, members of the Portuguese Parliament organised some public debates, in Lisbon and in Porto, to discuss the topic with both academic experts and the general public.

Consultation sessions took place in January and February 2018 and one of the topics of discussion concerned the identification of the multidimensionality of the implications of being an informal carer. Considering also the research work in the context of the SPRINT Project, Dr. Lopes suggested that any legislative effort must take into account not only the creation of mechanisms of direct support to the carers (e.g. respite care, training, adaptation of living environments), but also mechanisms that minimize the indirect costs of becoming a carer (e.g. carer's allowance, pension entitlements, part-time and flexible hours labour legislation, tax relieves).

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