ROSEnet COST ACTION (CA 15122)

REDUCING OLD-AGE SOCIAL EXCLUSION:
COLLABORATIONS IN RESEARCH & POLICY

Seven Policy Messages on Long-Term Care

Prepared by

the ROSEnet COST Action

Reducing Old-Age Exclusion in Europe

COST Action (CA 15122)

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Policy Message 1

Valuing long-term care and the people in long-term care

The structure and development of long-term care systems should be based on an acceptance of the merits and possibilities of creating valued, effective and sustainable models of provision that will enable everyone to age without fear of deficient care and support, whatever our circumstances in older age.

Why this message? Supporting research evidence

European and international research demonstrates how views of long-term care for older people can be shaped by negative perceptions of population ageing as a problem and of long-term care as a potentially overwhelming financial drain on limited public resources (Walker, 2018). Research studies have illustrated that, in some jurisdictions, older adult long-term care can be a marginalised care and occupational sector, and characterised by a lack of prioritisation, a lack of investment and sustained issues around quality of provision and workforce conditions (Moreno-Colom et al., 2017; Ostaszkiewicz et al., 2016). It has been shown that ageist narratives can be engrained in long-term care policy and practice which clouds public discourse and distracts from innovative ways of thinking about how best to design and implement systems of provision that respect and enable older people's dignity, choice and wellbeing (Ayalon and Tesch-Romer, 2018). It is critical that there is a shift away from such a stigmatized framing that undervalues the significance of the sector, the contribution of the labour force that work within it, and the importance of the people it caters for (Walsh and O'Shea 2010). Furthermore, research has demonstrated that disability/dependency is often a dynamic condition in older age, as it is throughout the life course (Goode and Fitzgerald, 2005). With reablement and rehabilitation strategies, and with enabling environments, people can and do regain capacity lost through stroke, falls, symptoms of chronic conditions. The World Health Organisation's (2015) conceptualisation of long-term care recognises the interplay between loss of intrinsic capacity (physical and mental) and the scope to extend functional ability through enabling environments (attitudes, medication, assistive devices, age friendly transport, social connectedness). A more fluid and flexible system of long-term care would recognise and work with possibilities and human potential for healthy ageing and support older people's right to autonomy and independence wherever they choose to live.

Some considerations for indicator development

1. Assess the capacity of long-term care systems to generate reablement and rehabilitation outcomes;
2. Measure attitudes internal and external to the sector towards long-term care as a societal need and responsibility, a career opportunity and profession, and as a source of high-quality support;
3. Routinely employ multifaceted quality of care and quality of life measures to chart the impact of long-term care provision on people's lives, including explicitly involving older people in developing these measures and in reporting on them from their experience of long term care settings.

Policy Message 2

Models of funding long-term care

Although the last decades have seen the development of private provision of long-term care insurance, given the context of demographic changes and the expected degree of future needs, European countries face a challenge to develop comprehensive social insurance or social support schemes to meet the expected rising costs of long-term care and ensure equitable access to these services.

Why this message? Supporting research evidence

Private insurance has been put forward as one way to finance long-term care. However, it is unlikely that most individuals can accumulate enough savings and assets over a life-time to cover the costs of long-term and institutional care (OECD, 2017). This means that many governments are likely to be faced with an increasing number of older people in need of long-term care but without the financial means to pay for it. A compulsory universal social insurance would address this problem by mutualising and spreading the financial risks of losing autonomy because of a long-term illness or disability (Schut and Van den Berg, 2010). Research on countries that have adopted a social insurance scheme for long-term care, such as the Netherlands or Germany, shows that these schemes are both financially and politically sustainable, and that they can co-exist with private insurance (Nadasht et al., 2018). On top of this governments should secure funding to cover long-term care needs of those who would fail to meet the social insurance criteria and who would thus have to rely on welfare support. Such means-tested schemes operate in most OECD countries, but it is likely that their scale will have to grow in the future. In addition to a compulsory social insurance scheme, it is important to develop the potential of equity release for individuals with medium to high housing assets as a complement (Mayhew et al., 2010). Governments should also plan for expansion of long-term care service provision to meet the expected growing needs, in particular with regard to appropriate training of staff. In countries where retirees collectively hold a relative high level of assets, consider a social insurance scheme for long-term care (i.e. compulsory scheme participation for seniors 60+ who receive a pension). Where dependency needs are high and asset wealth is present, consider the development of reverse mortgages, both in the private sector and supported by the public sector.

Some considerations for indicator development

1. To understand better the financial situation of older people and their ability to cover their potential long-term care needs there is a need to develop comprehensive measures of financial distress and material deprivation (Cavasso and Weber, 2013; Adena et al., 2015).
2. Researchers and policy-makers should consider developing comprehensive, comparable measures of long-term care needs based on international social surveys such as SHARE.
3. Just as with ageing itself, there is likely to be a strongly unequal distribution of long-term care needs by regions and municipalities. It is important to develop regional long-term care needs indicators on the basis of demographic forecasts to provide early warnings to sub-national governments who in the end will be responsible for organisation, provision and potentially also financing of care.

Policy Message 3

Empowerment and decision making

The right of older people living in long-term care institutions to make decisions on their own care should be guaranteed and supported, and facilitated by the staff of care institutions. Residents should also have the right to participate in appropriately designed activities addressed to sustain their selfhood and promote their wellbeing and development.

Why this message? Supporting research evidence

Research evidence (e.g. Ayalon, 2016; Westerhof et al., 2015) suggests that relocating to a long-term institution may hinder a resident's capacity to be autonomous (i.e. deciding over one's own affairs, including the way to be cared for) and to exert agency (i.e. capacity to control events and experiences in one's daily life). In many institutions, these capacities can be in effect assumed by care staff who have the power to decide for a resident on the grounds of their professional expertise and status. Research has shown that giving back autonomy and agency to residents increases their wellbeing and reinforces their independence, reducing care burden at the same time (e.g. Villar et al.. 2018). In the case of residents with severe cognitive deficits, promoting their involvement in self-care and taking advantage of their remaining competencies has significant benefits both for residents and for staff. Studies have shown how the efforts of care staff to adjust the complexity of decisions and to 'scaffold' the capacities of those with cognitive impairment can sustain personhood and bonds with social agents, including relatives (Sabat, 2005; Hydén and Antelius, 2017). For other residents, empowerment could involve facilitating their participation in the design of leisure and therapeutic activities, as well as in the organization of daily care tasks (Baur and Abma, 2011). Promoting residents' participation and autonomy is a basic tenet of person-cantered care (Lines et al., 2015), which is considered critical in best practice long-term care provision (American Geriatrics Society, 2017), and is recognized as one of the rights of citizens in their interaction with health and social services (WHO, 1999). There is a need for determined policy efforts to ensure the rights of older people living in long-term institutions to exercise their agency and capacity to decide on issues affecting their life.

Some considerations for indicator development

1. Approximate the degree to which care assessment instruments not only focus exclusively on physical and cognitive limitations, but also consider remaining competencies and the potential to improve.
2. Assess the extent to which activities and participation for residents are based on an understanding of their life stories and individual preferences and values.
3. Measure the level of resident participation in the design of activities and in the organization of tasks within the institution (e.g. by means of residents' councils).

Policy Message 4

Migrant care workers

The growing role of migrant care work in everyday long-term care (LTC) provision, and in undeclared forms within private households, requires stronger and more comprehensive policy interventions to integrate the migrant care workforce into the formal LTC system and to prevent worker exploitation, and care drain risks in source countries.

Why this message? Supporting research evidence

An increasing number of care workers with a migrant background are providing LTC to our ageing populations, especially in case of recipients with severe care needs (OECD 2015, WHO 2017). While in some North-Western European welfare states this has mainly occurred within traditional care provider organizations, in many Mediterranean, and in some Continental and even Eastern European countries, it is taking the form of direct employment of migrant workers by private households. This has been facilitated by the growing role of cash-for-care schemes, often in unrestricted forms, that due to financial constraints have been proposed as a cost-saving solution to tackle growing LTC challenges (Barbabella et al 2016). In less regulated care regimes, where low-skilled migrant workers are often hired, issues of care quality and care worker exploitation can emerge as critical concerns and are compounded by the lack of qualification requirements, the lack of monitoring mechanisms and the presence of undeclared work. In source countries, and despite the economic benefits of remittances, the left-behind children and families of care workers can experience social deprivation due to the deficient parental support (Fellmeth et al. 2018). For returned migrant care workers, mental health issues (like paranoia and depression) have been shown to be disproportionally represented amongst these individuals with many people experiencing difficulty in accessing to local, specialised services due to having been undocumented in the destination countries (WHO 2017). At a macro-level, while receiving countries have benefited from significant cost savings as a result of care worker migration, training costs continue to be borne by sending nations. In order not to undermine care system development in the latter, nor to exploit care migrants themselves, a balance is required between "integration" strategies in destination countries and programmes promoting international cooperation and return migration. Research evidence suggests that it is often the receiving countries that benefit most, followed by the sending countries, while the needs of individual care migrants can be often overlooked.

Some considerations for indicator development

1. Proportion of households, with an older adult occupant (aged 75 years and over), who employs a migrant care worker;
2. Proportion of care workers with a migrant background within the total care work force;
3. Estimation of the proportion of undeclared care workers within the total care work force;
4. Capture the profile of migrant care workers (including 'sending' country and region, frequency of return, sending country family situation) working within national/European care workforces;
5. Proportion of care workers who work in sending countries relative to those who migrated to work in receiving nations ('brain drain').

Policy Message 5

Cultural and resource diversity

Effective long-term care systems must ensure that high quality, equitable care is provided to all older people, irrespective of their economic resources and socio-economic background, and in a manner that is culturally and ethnically appropriate for heterogeneous sub-groups of the older population.

Why this message? Supporting research evidence

Research evidence indicates that low-income groups of older people continue to experience barriers to accessing adequate long-term care and are more likely to experience poor health outcomes. Furthermore, older people who have lower economic resources can often experience social exclusion or social deprivation and can as a consequence posses more complex sets of health needs that require long-term care. Nevertheless, these groups also experience a greater likelihood of not having their care needs met (Laferrère and Bosch, 2015). Possessing adequate economic resources, therefore, remains a key determinant of long-term care outcomes and health status (Sraker et al., 2015). In a similar manner, providing adequate services to a culturally and ethnically diverse older population remains a core challenge for long-term care providers. Research has shown that culturally appropriate care provision can enhance older people's experience of care receipt, and enhance trust and well-being outcomes. However, research has also shown that there can be significant in accessing care that respects and supports the expression of the cultural values and religious beliefs of ethnic and cultural minorities. Language and communication difficulties have been found to compound these issues further, complicating care relationships and undermining their affective and instrumental dimensions (Greenwood et al., 2015). Similarly, older adults who are members of the LGBT+ community are more likely to experience negative outcomes in institutional/residential long-term care environments, and experience difficulties in securing and sustaining care relationships with care provider personnel (King and Dabelko-Schoeny, 2009; Brotman et al., 2015; Henwood et al., 2017).

Some considerations for indicator development

1. Measure socio-economic gradients in relation to accessing long-term care, with a focus on those at risk of relative and consistent poverty, and material deprivation;
2. Assess quality of care in relation to culturally appropriate care delivery and care options;
3. Develop inclusion health measures as a means of assessing access to long-term care by those who are most excluded;
4. Integrate measures of social exclusion into assessments of long-term care effectivenes for marginlased groups of the older population.

Policy Message 6

Environment and community

The spatial environment within which long-term care is provided is crucial. Policy should focus on harnessing care settings to enhance older adults' mobility and mastery (choice and control) within the care environment, and to connect people to the wider community in which they live. These priorities apply to long-term care in both institutional/residential facilities and in domestic settings.

Why this message? Supporting research evidence

Scientific evidence documents how environmental design can support activities of daily life, general mobility, care outcomes and overall psychological and physical well-being (Parker et al., 2004; Burton and Sheehan, 2010). Research on specially designed housing, and stock housing with retrospectively fitted user-centred home modifications, points to the enhanced functionality for the older care recipient and a greater sense of environmental mastery (Powell et al., 2017). Where the focus is on supporting older people to leave their homes and to use and interact with outside and community environments, studies report greater neighbourhood and social connectedness and a stronger sense of belonging to the community (Peace, 2015). Research on institutional and residential care facilities suggests that the use of supportive design, in the form of spatial cues and interconnectedness between spaces, can improve residents' capacity for navigation and orientation. Together with the use of design aesthetics and consideration of the diversity of spaces within a facility, such measures can generate opportunities for stimulation and well-being (McIntyre and Harrison, 2017; O'Malley et al., 2018). Where planned institutional/residential environments have implemented philosophies of care and spatial design that enhances connectivity and integration with the wider community, evidence suggests enhanced well-being, relational connectivity and a sense of belonging for residents (Walsh and Waldmann, 2008). Models that embrace these principles and address such aspects of accommodation and care – whether housing with support, Green House initiatives, or co-housing schemes – can nurture solidarity between home/community residents and facilitate reciprocal care exchanges (Jolanki and Vikko, 2015). Research on domestic and institutional/residential care facilities offers powerful evidence that fostering a sense of home is central to successfully harnessing spatial aspects of the environment to deliver effective forms of care (Bartlam et al. 2013; Cutchin 2013). Characterised by feelings of security, familiarity and continuity, a sense of home can imbue care environments with important aspects of subjective and symbolic meaning (Peace 2015; O'Shea and Walsh 2013).

Some considerations for indicator development
1. Assess care recipients' environmental mastery in relation to their perceived capacity to exercise choice and control within their care setting.
2. Capture older people's perspectives on how supportive their care environment is in relation to internal mobility and support for activities of daily life.
3. Measure care recipients' sense of connectivity to the external neighbourhood and community relational environment.

Policy Message 7

Role of State in long term care

States should ensure regulation, monitoring and enforcement of accreditation and quality standards of care and support based on human rights principles. These should be provided by both the state and private entities, including for and not-for-profit organisations or religious bodies. States should also guarantee access by ensuring the availability of a wide range of long-term care services that older people can choose from, including those delivered at home, in the community and in residential settings. Guaranteeing access involves that states develop adequate social protection for long-term care needs that allows individuals to afford the costs associated with care.

Why this message? Supporting research evidence

Research evidence indicates that…

EU member states are characterized by great diversity of long-term care, both in terms of the type of entitlements available, the quality of services and the funding systems. The situation may change, if the European Union keeps up its promises for a better balance between financial and social concerns. (Arrue Astrain, *Growing demand, precariousness and austerity: The long way to universal and quality long-term care in Europe,* 2017). Among twenty principles, the European Pillar of Social Rights proclaimed by EU member states in 2017 introduces for the first time in a European-level policy a specific right to long-term care.

There are a number of policy and strategy planning frameworks that highlight how older people should have the right to care and support services that are adapted to their individual needs, that promotes their wellbeing, maintains their autonomy and independence and supports their participation in the community and in social, cultural, public and political life on an equal basis with others (WHO, 2017; Colombo and Murakami, 2013). Within these perspectives, all care and support service providers, including informal or family providers, should receive education, training, supervision and support, including respite. The state should ensure appropriate resourcing and training of care and support providers and raise public awareness to safeguard the rights of older people using care. These perspectives also suggest that states should have an obligation to develop and implement policies to address public and private financing of care and support services so they are affordable to everyone who needs them.

Some considerations for indicator development
1. Measure quality, access and sustainability – in line with current ongoing work of the EU Social Protection Committee. Indicators on quality should be based on available human rights standards, build on ongoing discussions on human rights of older people and the existing soft instruments that reflect the views of older people, such as the European Quality Framework for long-term care services (see www.age-platform.eu/qualitycare).
2. Differentiate between measures of structure, process and outcome; discuss prioritisation and consequences.
3. Measure unmet needs, as a part of an assessment of the weakness of long-term care systems.

4. Include the opportunity-costs for informal carers, in terms of personal, social and economic costs, as indicators of sustainability.
5. Older people and representative organisations should be involved in the development of indicators, pursuing a proper mix between academics, policymakers and end users in discussions.

What these messages are responding to:

These messages have been developed in line with principle 18 of the European Pillar of Social Rights calling for access to affordable and good quality LTC services.

"Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services."

Who developed these messages:

These messages have been derived from expertise and active research programmes within the ROSEnet COST Action, with direct contributions from the following ROSEnet members:

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About ROSEnet

ROSEnet (Reducing Old-Age Exclusion in Europe – www.rosenetcost.com) is an innovative networking partnership between policy stakeholders, researchers and older people from 41 countries, involving over 170 members.

ROSEnet aims to overcome critical knowledge gaps in research and policy to tackle social exclusion amongst older people in Europe.

Funded by the COST Association, and focusing on different forms of old-age social exclusion (economic, social, services, civic, and community and spatial), members are engaged in a four-year (2016-2020) programme of research, dissemination and networking activities. ROSEnet is dedicated to developing shared understandings of old-age exclusion, that are underpinned by state-of-the-art research and innovation, and that help to direct meaningful policy and practice development.

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