



Rights-based approach to care and support for older persons*

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Introduction

This policy brief presents a conceptual framework for a human rights-based approach to care and support for older persons. The authors developed the framework as part of an ongoing research project aimed at building and piloting an index of rights-based policies in the area of long-term care. The purpose of the index, soon to be finalised, is to enable states to monitor and compare the extent to which their care and support policies uphold older persons' rights (for further details and updates, please visit the project website: <https://www.euro.centre.org/projects/detail/85>). Though the study focuses on the European context, the emerging observations and findings are widely applicable. The two-year study was commissioned and funded by the Swedish Ministry of Health and Social Affairs.

Why a rights-based approach to care for older persons and why now?

Keywords:
Ageing, Human Rights,
Long-term Care

Population ageing is a global phenomenon. While Europe and North America are the regions most advanced in the demographic ageing process (more than 1 in five persons were aged 60 and above), almost 1 billion people around the world were 60 or older in 2017 (UN, 2017). What is more, the ageing process is projected to continue over the next decades, picking up speed in low- and middle-income countries. By 2050, the number of older people in the world is expected to double, while the number of the very old (80 and above) will more than triple to reach 425 million (UN, 2017). As older age groups account for an increasing share of the total population, social and economic policies will need to adapt in order to respond to both the challenges and the opportunities arising from this phenomenon.

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Though people are living longer, not all life years gained will be lived in good health, especially for the very old. The subsequent increase in the need to provide care and support to growing numbers of older individuals is calling into question the sustainability of traditional social protection systems, strained as they are by public sector funding constraints and welfare retrenchment in the aftermath of the economic crisis. Already faced with age-based discrimination both at a structural level and in day-to-day interactions, older people – and among this heterogeneous group, particularly those with long-term support needs – are vulnerable to marginalisation, disempowerment and limited access to needed support services.

In light of these dynamics, international advocacy groups, including HelpAge International and AGE Platform Europe, national advocacy organisations, and national human rights institutions are calling for a paradigm shift in the way societies think about ageing and the ‘aged’, shifting the policy discourse to focus squarely on states’ responsibilities to protect and work towards realising older individuals’ human rights. A human rights-based approach to care puts older people with support needs at the centre, empowering them to participate in decision-making and to claim their rights. At the same time, a rights-based approach demands accountability from the state and from institutional actors who bear the responsibility to uphold these rights.

Key policy developments in the area of older persons’ rights and the right to long-term care

The Madrid International Plan of Action on Ageing (MIPAA) emerged as a key policy instrument at the beginning of the new millennium, intended as a guide and monitoring tool for countries in their response to the economic and social challenges raised by widespread population ageing. Around the same time, the World Health Organization’s Active Ageing Framework (2002) sought to move the discourse away from ‘problematizing’ ageing in favour of highlighting the opportunities it could hold for the individual and for the society (WHO, 2002). Despite criticism from certain quarters for being overly normative and for marginalising those older people who for various reasons were not able to age ‘actively’ and were instead in need of care (Timonen, 2016), the Active Ageing approach was widely taken up in European policy and research programmes and continues to be prominent.

**A paradigm shift
in how societies think
about ageing and the
‘aged’ is needed**

More recently, ageing is being framed in terms of human rights. This year marks the 70th anniversary of the 1948 passage of the Universal Declaration of Human Rights (UDHR), a watershed moment in the establishment of an international,

legally binding framework for human rights. The 30 articles of the UDHR laid the foundation for all subsequent multilateral human rights instruments. The Convention on the Elimination of all Forms of Discrimination Against Women (1981) and the Convention on the Rights of Persons with Disabilities (2008) both contextualise the UDHR's universal rights, identifying substantive or 'incidental' rights that are specifically relevant for their respective population groups (Harpur, 2012).

While the rights of older persons are technically protected by these and other binding instruments, their rights generally, and more specifically in long-term care settings, have not been contextualised as they have been for other vulnerable groups. Since 2010, the UN Open-ended Working Group on Ageing has been laying the groundwork for enacting a new UN convention on the rights of older persons, but the process is not without its detractors. There is ongoing debate about whether documented violations of older persons' rights are the result of gaps in implementation of existing rights, or conversely, the result of a more fundamental normative gap in the language and formulation of existing rights.

Notably, just last year the European Union committed to the European Pillar of Social Rights. Though not legally binding, the Pillar marks an important landmark in the movement to ensure older people's right to care is upheld within the European Community. For the first time, the right to affordable, good quality long-term care (with an emphasis on home care and community-based services) is explicitly stipulated as one of the Pillar's 20 principles.

Any discussion of older persons' rights is incomplete without consideration of their rights in the context of long-term care and support. Substantial research and advocacy work have focused on the right to care, yet to our knowledge, no prior study has explored in-depth a rights-based approach to care and support for older persons. The noteworthy exception is the European Network of National Human Rights Institutions' project "Human Rights of Older Persons in Long-term Care" (2015-2017), which focused on older persons' rights in residential long-term care settings.

The theoretical basis for the framework

The disability rights discourse is a fruitful starting point for thinking about a framework conceptualising the rights of older persons with care needs. Among the great achievements of the disability rights movement was overturning the dominant medical model of disability in favour of a social model of disability.

According to this model, it is not an individual's impairment that renders him/her 'disabled', but rather his/her environment and the physical and non-physical barriers therein. Accordingly, solutions must also be located within the individual's environment (Stein, 2007).

**First in-depth
investigation of older
persons' right to
care & support**

In recent years, long-term care practitioners and researchers have called for a model of care that is less curative and less medicalised in nature and more focused on quality of life, and on empowering older people to exert their will and preferences in care decision-making. That said, persons with disabilities requiring assistance – people *ageing with a disability* – and older persons with functional impairments likewise requiring some form of support – people *ageing into disability* – are distinct groups with distinct characteristics and viewpoints. For example, the two groups have very different perceptions and attitudes when it comes to the concept of care itself. While for many disability rights advocates, 'care' is a value-laden concept that runs contrary to the core principles of autonomy and dignity, there is more tolerance and indeed an embracing of the relational aspects of care from within the long-term care literature (Fine & Glendinning, 2005). Similarly, many older people with impairments may not want to identify as having a disability due to the stigma still associated with this term. Also particular to the discourse on older persons' rights is the phenomenon of ageism, defined as direct and indirect discrimination on the basis of an individual's age (AGE Platform Europe, 2016). Increasingly, however, persons with disabilities are living into older age and are thus subject to multiple and intersecting forms of discrimination on the bases of disability and age (and potentially other statuses), rendering the delineation of people with disabilities and older persons into separate groups artificial. Yet this reality has been slow to be accepted in the public discourse.

These and other concepts particular to older persons' rights in the context of care were given careful consideration in the development of the framework. A narrative review of academic and grey literature was carried out in the first stage of the project (see Schulmann et al., 2017). The literature review findings were validated and expanded on in an expert workshop with nine multi-disciplinary experts from five European countries.

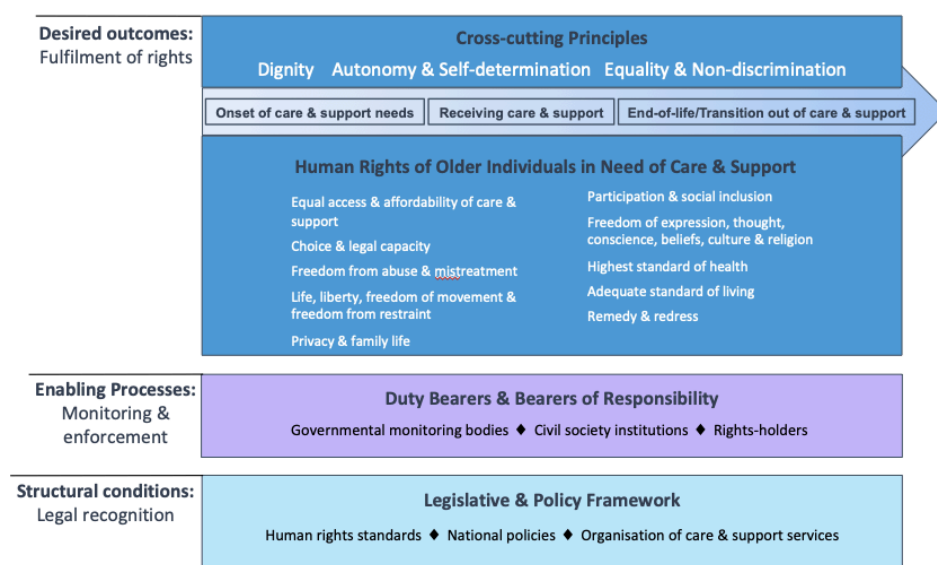
The framework, its domains, and key measures

The conceptual framework presented below adheres to the structure-process-outcome model of care quality evaluation and is composed of three levels: 1) Desired Outcomes: Fulfilment of Rights; 2) Enabling Processes: Monitoring and Enforcement; and 3) Structural Conditions: Legal Recognition. In anticipation

of the comparative index to be constructed at a later stage of the project, each level corresponds with a measure of implementation, respectively: 1) Results (outcome indicators); 2) Effort (process indicators); and 3) Commitment (structural indicators). Figure 1 provides a graphic presentation of the conceptual framework for a rights-based approach to care and support for older persons.

A discernible gap in the literature led us to focus our attention on the first level, **Desired Outcomes: Fulfilment of Rights**, specifically on identifying and elaborating the 10 universal rights *most fundamental to older persons with care and support needs* emerging from a review of the literature and consultation with experts. These 10 rights are centrally placed within the first level in Figure 1 below.

Figure 1: Conceptual framework of a rights-based approach to care and support for older persons



Perched at the top of the first level and underpinning the 10 universal rights listed below them in Figure 1 are three *Cross-cutting principles*: Dignity, Autonomy & Self-determination, and Equality & Non-discrimination. These principles are enshrined in all human rights instruments and are widely considered the cornerstone of a human rights approach (see Schulmann et al., 2018a). Running across the width of the framework is the *Care trajectory* arrow. The care trajectory represents the dynamic nature of the interaction between older people and the providers of care and support, from *Onset of care & support needs*, to *Receiving care & support*, through to *End-of-life care OR Transition out of care & support*. The idea being that depending on the point at which an individual finds him- or herself in the care trajectory, the application of

**The framework's
core principles are
Dignity, Autonomy,
and Equality**

each of the 10 universal rights will likely be qualitatively different due to shifting care needs and preferences.

The second level, **Enabling Processes: Monitoring & Enforcement**, signifies the duty of national governmental bodies to uphold human rights through well-defined monitoring and enforcement instruments. Importantly, it considers the initiatives and efforts of governmental institutions in achieving the fulfilment of rights.

Lastly, the third level, **Structural Conditions: Legal Recognition**, reflects the legislative commitments of states to the human rights of older persons with care and support needs, and serves to cement the importance of *legally binding standards* for human rights at the international, regional and national level. A human rights approach that has no basis in law is likely to suffer from poor implementation and will always be subject to political cycles.

Following development of the framework, we used the 10 universal rights identified in its first level (*Desired Outcomes: Fulfilment of Rights*, see Figure 1) as the starting point for formulating structure-, process- and outcome-measures for each. These are detailed in Table 1. The measures were validated with a Delphi survey and form the skeleton for the indicators of the comparative index of rights-based policies for older persons with care and support needs (Schulmann et al., 2018b).

Table 1: Structure-, process- and outcome-measures of a rights-based approach to care and support for older persons

Domain	Key theme(s)	Structure measure(s)	Process measure(s)	Outcome measure(s)
I. Equal access to & affordability of care & support	1. <i>Accessibility of care and support services</i>	Existence of legal recognition of equal access to long-term care (e.g. universal, non-means tested coverage)	Allocation (e.g. public expenditure) and equitable distribution (e.g. across geographic territories, type of service) of public resources to long-term care	Older persons ¹ have access to long-term care
	2. <i>Access to enabling environment</i>	Existence of legal obligation to make barrier-free living environments accessible, including adaptations to private housing (e.g. through assistive devices, re-arrangement of space)	Equitable allocation of public resources to make living environments barrier-free for persons with physical and cognitive disabilities in a fixed period of time	Older persons have access to barrier-free living environments
II. Choice, legal capacity & decision-making capacity	3. <i>User choice</i>	Existence of legal provision for choice in type of care, provider, carer or tasks	Participatory needs assessment and decision-making process are in place	Older persons report being able to choose from among a range of long-term care services and providers according to their needs and preferences
	4. <i>User-centred care</i>	Existence of a legal obligation to provide information to and consult with older persons in decisions concerning their care (including use of assistive and monitoring devices/technologies) and place of residence	Person-centred care programmes or mechanisms (e.g. case management) are in place	Older persons reporting that their preferences are respected by the care and support services they receive
	5. <i>Legal capacity</i>	Existence of legal provisions guarding against older persons' loss of legal capacity	Care provider organisations have guidelines in place for implementing supported decision-making (e.g. training materials, reporting templates)	
	6. <i>Advanced care planning</i>	Existence of legal provisions for Advanced Care Directives	Administrative authority/framework for processing Advanced Care Directives (e.g. a database or registry) is in place	

* Unless explicitly noted otherwise, all references to 'older persons' imply equality and non-discrimination on the bases of age, disability, gender, sexual orientation, race/ethnicity, and socioeconomic status.

Table 1 continued

Domain	Key theme(s)	Structure measure(s)	Process measure(s)	Outcome measure(s)
III. Freedom from abuse & mistreatment	<i>7. Protection against mistreatment</i>	Existence of legal protections against abuse and mistreatment of older persons (e.g. physical, emotional, financial abuse or mistreatment)	Reporting mechanism to investigate claims of abuse and mistreatment in residential, home and community care settings is implemented	No reports of older persons being exposed to physical, sexual, psychological, financial or other forms of abuse or mistreatment
IV. Life, liberty, freedom of movement & freedom from restraint	<i>8. Protection against restrictions on movement</i>	Existence of legal provisions against the use of physical and chemical restraints in residential, home and community-based long-term care	Alternatives to the use of physical and chemical restraints are in place (e.g. guidelines for providers, training programmes for professionals)	No reports of older persons' mobility being restricted by physical or chemical restraints
V. Privacy & family life	<i>9. Maintaining family life</i>	Existence of legal provisions protecting older persons' preferences vis-à-vis contact with family members (addressing e.g. living arrangements, visitation in residential care)	Care provider guidelines concerning living arrangements and visitation are in place	Older persons reporting meaningful and regular contact with family members (where desirable)
	<i>10. Privacy in care and support</i>	Existence of legal provisions for personal and medical data protection	Administrative authority/infrastructure for safe storage and use of personal and medical data are in place	Older persons not reporting violations of privacy
		Existence of legal provisions to protect physical privacy in care settings (addressing e.g. use of monitoring and assistive devices, sexual intimacy)	Care provider policies concerning user privacy are in place	
VI. Participation & social inclusion	<i>11. Age-friendly communities</i>	Existence of legal provisions and policy initiatives promoting inclusive public space and public infrastructure	Policies and guidelines exist which enable the involvement of older persons (or older persons' advocacy groups) in the planning and evaluation of public and commercial space and infrastructure	Older persons reporting feeling safe and empowered to participate in community life
	<i>12. Social inclusion in care and support</i>	Existence of legal provisions for deinstitutionalisation of care, and policy initiatives promoting social inclusion of older persons receiving care and support	Community care services are in place (includes residential care where residents are integrated in the community, e.g. through visitation policies, joint activities)	Older persons not reporting feeling socially isolated

Table 1 continued

Domain	Key theme(s)	Structure measure(s)	Process measure(s)	Outcome measure(s)
VII. Freedom of expression, freedom of thought, conscience, beliefs, culture and religion	<i>13. Respect for personal beliefs</i>	Existence of equality and non-discrimination legislation on grounds of religion, political beliefs, culture	Care provider policies addressing respect for care users' religious, political and cultural beliefs in care practices are in place	Older persons reporting that their personal beliefs are respected
VIII. Highest standard of health	<i>14. Preventive care</i>	Existence of legal provisions for equal access to preventive, mental health, palliative and dental care, and medication	Allocation of resources to preventive, mental health, palliative and dental care, and medication for older persons	Older persons or their family members reporting having access to preventive, mental health, palliative and dental care, and medication
	<i>15. Care continuity</i>	Existence of legal provisions for the integration of health and long-term care and support	Procedures to integrate access to health care services (prevention, mental health) within long-term care settings are in place (e.g. through case management)	Older persons reporting being supported in transitions between different care settings by specialised care personnel (e.g. discharge managers, care coordinators) in a timely manner
IX. Adequate standard of living	<i>16. Housing conditions</i>	Existence of legal provisions stipulating minimum housing standards (e.g. sanitation, heating, structural safety)	Administrative authority for monitoring and enforcing housing standards for vulnerable groups (including older persons) is in place	No reports of older persons experiencing housing deprivation (as defined by international standards)
	<i>17. Protection against material deprivation</i>	Existence of legal provisions establishing social protection programs (e.g. pension system; support for low-income groups of older persons)	Minimum income schemes or pension schemes that provide sufficient income (i.e. above the poverty rate) to keep all older persons out of poverty are in place.	Older persons not living in poverty or experiencing material deprivation
X. Remedy & redress	<i>18. Raising awareness</i>	Existence of legal provisions to raise older persons' awareness of their rights and how to claim them	Awareness-raising initiatives on older persons' rights and on available complaint mechanisms are in place	Older persons reporting awareness of their rights and of available complaint mechanisms
	<i>19. Complaint mechanism</i>	Existence of legal provisions for establishing independent authority/mechanisms that older persons can use to claim their rights	Complaint procedures (e.g. ombudsman; advocacy groups with representation rights) are in place	

Implications for future policymaking and service design

The framework presented in this policy brief is intended to inform the construction of an index for the assessment of rights of older people in need of care and support (see Schulmann et al., 2018a). In this sense, it is an applied framework. Its implications for policy-making go well beyond the index and the message that the latter might entail, however.

One of the fundamental takeaways from the research that went into the development of this framework is that the legislative framework in a given country, while a prerequisite for the protection of rights, is in itself insufficient for their fulfilment. Just as important are monitoring, enforcement, and the resources allocated to implement legislation – the enabling processes depicted in the framework. In turn, the structures and processes add a qualification to the achievement of outcomes or results: it not only matters that rights are fulfilled but how they are fulfilled (i.e. through the rule of law, with appropriate enforcement mechanisms and sufficient resources).

The framework's rights approach emphasises societal solutions for societal challenges

Ensuring that human rights are respected is first and foremost a function of the State; working in conjunction with other international and national judicial and civil society actors, and with rights-holders themselves (Besson, 2015). The framework's approach to the need for care and support in old age shines the spotlight on societal-level solutions for societal-level challenges. It thus presents an alternative to the active ageing discourse founded on individual-level solutions and strategies to tackle what is a societal challenge: demographic ageing (Timonen, 2016). The resulting policy message is clear. It is not only (or mainly) the responsibility of individuals to ensure that they are free from mistreatment, that they gain equal access to care, and that they have their religious beliefs or privacy respected. These are responsibilities from which the State cannot extricate itself.

For each of the universal rights it espouses, the framework formulates a number of measures. While the measures were devised with the explicit aim of subsequently constructing an index, they can also provide guidance on how policies and services should be designed in order to fulfil the rights of older people in need of care and support. One clear implication from the framework is thus the need to develop policies and services that support older people's dignity and autonomy on an equal basis with all others.

Finally, this framework and its measures may offer an important supplement or monitoring tool for the implementation of the right to affordable, good-quality long-term care (with an emphasis on home care and community-based services) enshrined in the European Pillar of Social Rights.

Conclusions

In recent years, there has been a marked increase in the interest shown by academics and policy-makers in developing and promoting human rights-based approaches in a variety of fields (e.g international development, poverty reduction, health care). Advocacy groups have been dogged in calling for a human rights-based policy framework on ageing, and they are starting to be heard in policy-making circles. This is a particularly relevant development in the context of long-term care where many vulnerable individuals are faced with systematic breaches to their rights.

The conceptual framework – and the measures derived from it – is grounded in a critical review of the scholarship on the application of a rights-based approach to care and support for older people. While it incorporates insights from the development of similar tools in other fields of interest (primarily the disability rights movement), the emphasis falls on understanding and reflecting the particularities of caring for and supporting older people in their daily lives. The possible applications of the framework are manifold. To academics it can provide a reference point for further research on the protection of human rights through social and ageing policies. For policy-makers, the framework and the resulting index could be further developed into a powerful monitoring and assessment tool; a tool to assess the extent to which the rights of older people with care and support needs are protected by a country's care policies. Finally, the framework can be an empowering tool for older persons with care needs and their advocates, by promoting a focus on well-being, autonomy and self-determination.

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