



Taking a human rights-based approach in monitoring policies for older people in Europe¹

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Introduction

Countries across Europe, and indeed around the world, are confronted with the social, economic and political challenges of an ageing population. Among the most pressing of these challenges is securing adequate and sustainable long-term care and support for older people. There is growing consensus that long-term care services should look beyond a medical model of 'care'. Instead, policies and practice should take a broader, more holistic view in which older people's wellbeing and quality of life and their preferences regarding care and support are central to the design of services in line with existing human rights standards.

Keywords:
Ageing,
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While existing human rights standards do set provisions for the fulfilment of the universal rights (including civil and political, as well as social, economic and cultural rights) of all individuals including older adults, there is currently no distinct international convention specifically addressing the rights of older people.² The provisions set down in the UN Convention on the Rights of Persons with Disabilities (UN CRPD) come closest to providing a legal framework for the protection of the rights of older people with care and support needs. Building on the achievements of the disability rights discourse, a conceptual framework for a human rights-based approach to care and support for older persons was developed and presented in detail in another Policy Brief (see Schulmann et al., 2019). The conceptual framework is grounded in a critical review of the scholar-

¹ The Policy Brief is based on the findings of Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people* (Vienna: European Centre) prepared in the frame of the project 'Towards a rights-based approach in long-term care' (see <https://www.euro.centre.org/projects/detail/85>). This research project has received financial support from the Swedish Ministry of Health and Social Affairs. The authors are also grateful for the editorial comments received from Kai Leichsenring and Sonila Danaj and would also like to thank Willem Stamatou for language editing and layout.

² The UN Open-ended Working Group on Ageing has been discussing the possibility of a new UN convention on the rights of older people generally (i.e. not restricted to older people with care and support needs). Advocacy groups like AGE Platform Europe, HelpAge International, and ENNHRI have advanced the discourse in this regard, indicating widespread agreement that the rights of older people are not considered adequately within current human rights standards.

ship on the application of a rights-based approach to care and support for older people and reflects the particularities of caring for older people in their daily lives.

The aim of this Policy Brief is to present and discuss two tools that can contribute to monitor the evolution of policies and their outcomes for older people in Europe. These two tools are, respectively, the Rights of Older People Index (from hereafter ROPI or the Index) and the Scoreboard on Outcome Indicators. Together, ROPI and the Scoreboard fill an important gap as multi-dimensional tools to monitor the situation of older people with care and support needs, based on a human-rights approach. They highlight gaps in legislation and the implementation of policies as well as gaps in data. The combination of these tools offers the opportunity to jointly assess the existing legislation and policies (through ROPI) and how they translate into better outcomes for the older population (through the Scoreboard).

The Rights of Older People Index and the Scoreboard on Outcome Indicators³

The Rights of Older People Index facilitates the monitoring and assessment of a country's legislative and policy framework (structures), as well as national standards, guidelines, monitoring mechanisms and resources (processes) in relation to the rights of older people with care and support needs. ROPI includes 35 indicators which are categorised under 10 domains.⁴

Box 1: The ROPI domains

- I. Equal access to & affordability of care & support
- II. Choice, legal capacity & decision-making capacity
- III. Freedom from abuse & mistreatment
- IV. Life, liberty, freedom of movement & freedom from restraint
- V. Privacy & family life
- VI. Participation & social inclusion
- VII. Freedom of expression, freedom of thought, conscience, beliefs, culture & religion
- VIII. Highest standard of health
- IX. Adequate standard of living
- X. Remedy & redress

³ For detailed information about the indicators and the calculation of the index and the scoreboard, please read the final report: Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K. (2019). *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*. Vienna: European Centre.

⁴ The information on the indicators that comprise ROPI was provided by country experts through a standardized questionnaire and supplemented by desk research.

ROPI includes 35 indicators and the Scoreboard includes 17 indicators, categorized under domains relevant for the rights of older people with care and support needs

The Scoreboard on Outcome Indicators, henceforth Scoreboard, measures country performance in actual outcomes (i.e. achievements in the fulfilment of rights). The Scoreboard is comprised of 17 indicators which are grouped under 8 of the domains used for ROPI.⁵ The Scoreboard complements the Index by assessing the results of legislation and policies. The Scoreboard has an additional instrument that assesses gender inequalities separately in each indicator through a ratio between the outcome for women and for men.

ROPI and the Scoreboard currently cover 12 European countries: Austria, Finland, Ireland, Italy, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, and the UK. The selected countries represent a wide geographical mix within Europe, with different care systems but with similar challenges caused by the growing ageing populations.

Results of ROPI and the Scoreboard on Outcome Indicators

None of the 12 countries belong to the highest or to the lowest score range and there is no obvious geographical clustering in the overall ranking results

In ROPI, Sweden has the highest overall score. Finland positions itself second, slightly ahead of Slovenia, Ireland and Austria on the overall index. Switzerland, Italy and Poland have the lowest index score. However, even among countries that are front-runners in ROPI there is substantial room for improvement. There is no obvious geographical clustering in the overall ranking results.

Table 1: Index and domain scores for ROPI

	SE	FI	SI	IE	AT	PT	UK	ES	SK	CH	IT	PL
ROPI	2.2	2.1	2.1	2.1	2.1	2.0	2.0	1.9	1.9	1.8	1.8	1.8
I. Equal access to & affordability of care & support	3.0	3.0	2.2	2.4	2.2	2.1	2.0	2.0	2.0	2.7	2.3	1.7
II. Choice, legal capacity & decision-making capacity	2.3	2.1	2.2	2.3	2.2	2.1	2.1	2.2	1.8	2.0	1.5	1.8
III. Freedom from abuse & mistreatment	1.7	3.0	2.4	2.0	2.4	3.0	3.0	2.4	1.4	3.0	1.7	1.7
IV. Life, liberty, freedom of movement, from restraint	1.7	1.0	3.0	1.4	2.4	1.4	3.0	2.0	1.4	1.4	3.0	1.4
V. Privacy & family life	1.7	2.1	1.4	2.6	1.4	1.8	1.7	1.0	2.6	1.4	1.4	2.3
VI. Participation & social inclusion	2.3	2.6	2.6	2.6	2.6	2.3	1.6	2.6	2.3	1.8	2.0	1.8
VII. Freedom of expression, freedom of thought, etc. ...	3.0	3.0	2.4	3.0	2.4	2.4	2.4	1.4	2.0	1.4	2.0	1.7
VIII. Highest standard of health	3.0	2.1	2.6	2.0	1.8	3.0	1.4	2.1	2.3	2.0	1.6	2.1
IX. Adequate standard of living	1.9	1.6	1.6	1.6	1.6	1.6	2.3	2.1	1.6	1.6	1.6	1.6
X. Remedy & redress	2.1	2.0	1.4	1.4	1.7	1.4	1.4	1.7	1.9	1.7	1.4	2.1

Score: 3.0-2.6 2.5-2.1 2.0-1.6 1.5-1.0

⁵ The scoreboard indicators are based on statistical information collected from European comparative datasets. In the absence of finding suitable and reliable outcome indicators for Domains III (Freedom from abuse & mistreatment) and IV (Life, liberty, freedom of movement & freedom from restraint), these two domains are not included in the scoreboard.

Box 2: Aggregating the index

A key criterion in selecting the most suitable method for constructing ROPI, is the possibility to monitor and assess policies and actions aiming to uphold the rights of older people with care and support needs. The chosen method allows for the index to be easily replicable (in the context of Europe and other developed countries), transparent and simple to understand. After a careful consideration of various aggregation and weighting methodologies and reviewing existing index constructions (e.g. OECD, 2008; Bradshaw & Richardson, 2009; Klugmann et al., 2011; Zaidi et al., 2012; Huddleston et al., 2015; Schulmann et al., 2018b), ROPI uses an aggregation method based on the geometric mean, thus penalizing those with very low scores. In line with the conceptual framework, no explicit weights were assigned either at the indicator or the domain level, which reflects the indivisibility of human rights.

The building of the index can be summarised in the following methodological steps:

1. For each indicator, the information collected through country experts and desk research is coded using the 1,2,3 category scale, with 1 and 3 as the lowest and highest value respectively.
2. For each domain, the geometric mean of individual indicator values is calculated assuming equal weights.
3. The overall index value is obtained by aggregating the domain values using the geometric mean of each domain (again assuming equal weights).

The results for ROPI show that, when it comes to having adequate legislation and policies that promote and protect the rights of older people, there is considerable room for improvement in most countries. There are four areas where the need for improvement seems to be especially pressing in view of the scores:

- Domain IV: Life, liberty, freedom of movement & freedom from restraint
- Domain V: Privacy & family life
- Domain IX: Adequate standard of living
- Domain X: Remedy & redress

Among the areas in need of improvement in Domain IV is the use of restraints, as legislation or guidelines on minimizing the use of restraints (physical or chemical) are still missing in many countries, or at best confined to institutional care. In Domain V, the lack of sufficient safeguards (both in the form of legislation and guidelines) to allow older people living in institutions to maintain their family or community life, needs to be addressed. As for Domain IX, the right to affordable and adequate housing is often not sufficiently addressed in the legislation. Finally, there is a dearth of mechanisms to specifically promote, protect or raise awareness of the rights of older people.

The areas where countries performed well in ROPI by having legislation and policy frameworks to protect older people in place, included:

- Domain VI: Participation & social inclusion
- Domain VII: Freedom of expression, freedom of thought, conscience, beliefs, culture and religion

In the area of social inclusion, recent developments in the human rights protection of persons with disabilities with specific regard to accessibility policies (e.g. public spaces and transportation) and the transition from institutional to community-based care, probably contributed to this positive result.

In the Scoreboard that evaluates the policy outcomes, Sweden and Finland perform the best among the 12 countries, as they have the highest number of indicators with “good but to monitor” values (Table 2). On the other extreme, Poland and Slovenia seem to perform the worst among the countries considered.

When it comes to policy outcomes, either most countries perform well, or poorly in a given domain

The Scoreboard results show a remarkable degree of consistency in the performance of countries across domains. Either most or all countries constantly perform well, or most or all countries constantly perform poorly in any given domain. Areas where all countries perform well when it comes to policy outcomes for older people, include:

- Domain VII: Freedom of expression, freedom of thought, conscience, beliefs, culture and religion
- Domain IX: Adequate standard of living

Areas where weak or critical policy outcomes are found for older people in all, or in most countries, are:

- Domain I: Equal access to & affordability of care & support
- Domain X: Remedy & redress (including the frontrunners Sweden and Finland)

These areas deserve dedicated investment in appropriate policies across all countries considered in this study. In particular, results for Domain I still reflect the gaps in access to adequate care services by older people with care needs across Europe (with Sweden as the notable exception). For Domain IX, there is clearly a lack of awareness among older people concerning their rights, which could have far-reaching consequences in terms of hampering political processes to bring about improvements in the fulfilment of these rights. The greatest inter-country variation is shown in Domain VIII – achieving the highest standard of health.

Table 2: Scoreboard on outcome indicators

		SE	FI	SI	IE	AT	PT	UK	ES	SK	CH	IT	PL
I. Equal access to & affordability of care & support	Care & support received female	●	●	●	●	●	●	●	●	n.a.	●	n.a.	●
	Care & support received male	●	●	●	●	●	●	●	●	n.a.	●	n.a.	●
	Have access to housing modifications & assistive devices	●	n.a.	●	n.a.	●	●	n.a.	●	n.a.	●	●	●
II. Choice, legal capacity & decision-making capacity	Feel free to decide how to live life	●	●	●	●	●	●	●	●	●	●	●	●
	Satisfied with care received	●	●	●	●	●	●	●	●	●	n.a.	●	●
V. Privacy & family life	Have frequent (at least weekly) contact with family	●	●	●	●	●	●	●	●	●	●	●	●
	Trust in health & medical institutions to protect personal information	●	●	●	●	●	●	●	●	●	n.a.	●	●
VI. Participation & social inclusion	Have access to public spaces	●	●	●	●	●	●	●	●	●	n.a.	●	●
	Not reporting feeling lonely	●	●	●	●	●	●	●	●	●	●	●	●
VII. Freedom of expression...	No experience of being discriminated on grounds of religion/belief	●	●	●	●	●	●	●	●	●	n.a.	●	●
VIII. Highest standard of health	Received vaccination for influenza	●	●	●	●	●	●	●	●	●	●	●	●
	Have regular consultation with dentist	●	n.a.	●	n.a.	●	●	n.a.	●	n.a.	●	●	●
	Satisfaction with personal attention received from GP/family doctor	●	●	●	●	●	●	●	●	●	n.a.	●	●
IX. Adequate standard of living	Not experiencing housing deprivation	●	●	●	●	●	●	●	●	●	●	●	●
	Not in relative poverty	●	●	●	●	●	●	●	●	●	●	●	●
X. Remedy & redress	Being aware of rights	●	●	●	●	●	●	●	●	●	n.a.	●	●
	Able to exercise rights	●	●	●	●	●	●	●	●	●	n.a.	●	●

● Good but to monitor ● To watch ● Weak ● Critical

In terms of gender, the Scoreboard shows a number of indicators where there is a clear gender gradient. These are access to long-term care services, feeling lonely, or having sufficient material resources. Men are relatively disfavoured in access to care services, as they usually receive informal care instead (due to differences in living arrangements and prevailing gender norms regarding care-giving). Conversely, women are more likely than men to feel lonely and are usually disfavoured in access to material resources. Some indicators do not show a clear pattern in terms of gender inequalities (e.g. access to housing or indicators in Domain II), hinting at the possible relevance of country-specific factors.

Discussion

Legislation and generous entitlements do not always translate into the enjoyment of rights for all older people

Based on the results of the Index and the Scoreboard, there is often disconnection between the rights that are granted by legislation to older people and the outcomes that are observed. There are three areas where apparently generous entitlements do not fully translate into the enjoyment of rights:

- Domain I: Equal access to & affordability of care & support
- Domain VI: Participation & social inclusion
- Domain VIII: Highest standard of health

Interestingly, all (or nearly all) countries either perform well or badly across a given domain, which is a remarkable finding given the mix of countries included in this study. Whether this pattern holds will be tested when more countries are included in ROPI and Scoreboard. However, as it stands, it seems that certain domains consistently stand as laggards and frontrunners in terms of rights of older people in need of care and support. The domains lagging behind should stand as priorities for policy-makers committed to improving the rights of older people in need of care and support.

Box 3: Gaps in data

The piloting process of the two instruments identified many gaps in existing data, specifically concerning data on the quality of long-term care, or elder abuse. Data gaps were more visible in the Scoreboard tool, as it relies on existing data. One sub-population for which only limited data exist are people in institutional care. Lack of disaggregation of indicators based on socio-demographic variables (ex. gender and income) was an additional challenge.

Recommendations

The challenges and needs of older people to be mainstreamed into Agenda 2030 and policy discussions at EU and national levels

Policy-makers and other stakeholders should pay more attention to the needs and situation of older people during the implementation of Agenda 2030. While none of the Sustainable Development Goals focus explicitly on older people, many elements could directly contribute to improving their situation.

The challenges and needs of older people should be mainstreamed into policy discussions, both at national and EU levels, with special regard to the gender dimension and other intersectional issues. The European Pillar of Social Rights with its dedicated principle on long-term care is a key framework to address the needs of older people in a pan-European policy process. An additional element is to directly involve older people and their representative organisations in decision-making processes affecting their life.

At national level, more efforts should be made to have measures tailored to the specific needs of older people. Areas that require more attention refer to remedy, prevention and community-based support, among others. The achievements of the disability rights movements could have a positive impact on older people in need of long-term care. For instance, supported decision-making systems, accessibility, or transition from institutional to community-based care have improved, but national policies should ensure that these legal guarantees are implemented, and progress could be measured. Regular monitoring of both institutional and home-based services is essential. The results of piloting the index show that a specific focus should be placed on monitoring institutional and home-based care.

More research and data are needed to better understand the impact of the existing legislation and policies on the quality of life of older people. Disaggregated data are needed along all domains. A first step to improve the situation at EU level could be to include indicators on long-term care in the “Social Scoreboard” that was developed by the European Commission to assess trends and performances across the EU when implementing the European Pillar of Social Rights.⁶

⁶ The European Pillar of Social Rights is accompanied by a ‘social scoreboard’ which will monitor the implementation of the Pillar by tracking trends and performances across EU countries in 12 areas and will feed into the European Semester of economic policy coordination. The scoreboard will also serve to assess progress towards a social ‘triple A’ for the EU as a whole. See: <https://composite-indicators.jrc.ec.europa.eu/social-scoreboard/>

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