

# AGE summary and reaction to the report on a rights-based approach to long-term care in Europe



The [European Centre for Social Welfare Policy and Research](#) published in 2019 a [report](#) on the outcomes of a multi-annual project on older people's right to long-term care.

Funded by the Swedish Ministry of Health and Social Affairs this piece of work aims to fill in an important gap in monitoring the situation of older people with care and support needs, based on a human-rights approach.

## What is it about?

The project developed two complementary tools that can facilitate assessing and monitoring governments' policies and the outcomes of those policies in upholding the rights of older people with care and support needs.

- The **Rights of Older People Index (ROPI)** includes a set of indicators that can capture a country's legislative and policy framework (*structures*) and its national standards, guidelines, monitoring mechanisms and resources (*processes*) in relation to the realisation of the rights of older people with care and support needs. The ROPI gives a snapshot of the commitments made by States to promote and protect the rights of older people and of the mechanisms that they have put in place to make these rights a reality. It does not however reflect whether these laws and policies are sufficient, whether they are implemented in practice and how they affect the lives of older people who need care and support.
- This is why the project has also developed a **Scoreboard** that gathers information on the *outcomes* of these policies and measures, with a view to understanding the extent to which these improve the enjoyment of human rights.

These two tools cover 10 domains:

1. Equal access to & affordability of care & support
2. Choice, legal capacity & decision-making capacity
3. Freedom from abuse & mistreatment
4. Life, liberty, freedom of movement & freedom from restraint
5. Privacy & family life
6. Participation & social inclusion

7. Freedom of expression, freedom of thought, conscience, beliefs, culture & religion
8. Highest standard of health
9. Adequate standard of living
10. Remedy & redress

The two sets of indicators included in the ROPI and the Scoreboard have been used to gather results from 12 European countries, namely Austria, Finland, Ireland, Italy, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden Switzerland, and the United Kingdom.

## Why is it important?

- Together ROPI and the Scoreboard are a useful tool for governments to **assess** how they can improve their policies and for civil society to **monitor** how well their countries are doing in respecting the rights of older people in the context of long-term care.
- The tools developed by the European Centre for Social Welfare Policy and Research use *structure*, *process* and *outcome* indicators based on the [framework](#) developed by the United Nations (UN) Office of the High Commissioner for Human Rights (OHCHR). This three-step approach can reveal the **relationship between commitments, efforts and results**. In other words, it can give us information about what needs to be improved to further the implementation of human rights, as opposed to simply measuring the magnitude of a problem.
- It is anchored on human rights, which means that the financing and provision of long-term care services are seen as **States' obligations vis-à-vis their citizens**. This is particularly important bearing in mind that in many EU countries families continue to provide the bulk of care. These tools can therefore be used to encourage more formal care provision.
- This rights-based approach **expands the understanding of what long-term care systems should aim at**, by introducing for instance - in addition to concerns about the safety and health of older persons - issues of freedom of choice, maintenance of family relations, accessibility of the built environment, respect for cultural or religious beliefs, access to remedy and so on.
- It identifies the precise changes that need to be made so that human rights can be guaranteed in the **specific context of long-term care**. Since there is currently no human rights instrument on the rights of older persons, we lack specific standards and guidance about how human rights need to be interpreted and applied for those people who need care and assistance. The indicators provide some concrete ideas about how to achieve this in practice.

## What are the findings?

The report illustrates that there is a lot of room for improvement.

### **No right to long-term care**

Based on the findings access to different forms of care to live independently is not yet a guaranteed right by law (unlike access to health care, for example), outside of Sweden and Finland, and to some extent Switzerland. All other countries either restrict access based on income or devote too few resources to care despite seemingly generous legislation (e.g. Portugal).

### **The most problematic areas**

There is no great variation in the countries' performance to promote and protect the rights of older people with care and support. All studied countries do not do extremely well or extremely bad but are in the middle range. There are however some domains in which overall countries lag behind. First, there are no sufficient guidelines and measures to avoid the use of restraints in care settings. Second, there are key concerns in terms of allowing older people living in institutions the possibility to maintain their family or community life. Third, there is lack of entitlement to adequate and affordable housing for older people. Finally, consistently, there was lack of awareness of rights among older persons and lack of mechanisms to promote awareness and to provide support and redress in case of breach of rights.

### **The gap between commitments and practice**

The comparison between structure, process and outcomes indicators demonstrated that there are areas where generous entitlements in paper do not fully translate into fulfilment of rights in practice. For example, although national laws and policies do not include restrictive conditions for accessing care, in practice, poor financing, strict needs assessment, means-tested benefits and the high co-payment requirements, among others, effectively create barriers to fully meeting long-term care needs. Similar barriers exist in accessing health care, but here also ageism plays a key role in lack of equal access to services. Finally, although countries have adopted laws to promote accessibility, older persons report that public transportation and indoor recreational spaces (e.g. cinemas and theatres) remain relatively inaccessible.

### **Gender differences**

Although it was not always possible to disaggregate data by gender, differences between men and women have been raised in the findings. Women rank worse in terms of enjoying an adequate standard of living, which is not surprising bearing in mind the gender pension gap and their primary role in caregiving. Women also present higher levels of loneliness and lack of access to public spaces. On the other hand, men are less likely to receive formal care.

## Insufficient data

The report uncovers important gaps in data. First, existing datasets do not cover people in institutions, which by itself does not give a full picture of the situation of older persons in need of care and support. Second, when data for older age groups exist, the samples are typically low, which both makes disaggregation by age, gender and other factors difficult and also skews the representativity and relevance of the results. Data on the domains of elder abuse and the use of restraints are generally unavailable and therefore, these issues are not included in the scoreboard.

## Recommendations

- Collect more disaggregated data along the 10 domains presented in this study. For example, indicators on long-term care as one of the principles of the European Pillar of Social Rights could be included in the Scoreboard of the European Commission. Additionally, data should cover those living in residential care settings and other marginalised populations
- Mainstream the challenges and needs of older people in policy discussions both at the EU and national levels that feed into cross-European developments, like the European Pillar of Social Rights, is essential.
- Involve older people and their representative organisations directly in decision-making processes affecting their life.
- Make sure measures are tailored to the specific needs of the older population, for instance in the areas of remedy, prevention and community-based support, among others. These measures should place specific focus on those who are in institutional care.
- Ensure that both institutional and home-based services are regularly monitored to avoid violence and abuse and to assess if there are any differences in terms of the protection of human rights and available monitoring mechanisms.

## How can the indicators be improved?

AGE has contributed to the development of the conceptual framework and the initial iterations of the indicators and warmly welcomes the two tools. We also however acknowledge their limitations.

The report highlights that the list of indicators presented in the index and scoreboard is not exhaustive. **Although the indicators aim to cover the whole range of human rights, including civil, political, economic, social and cultural rights, some of the rights are defined in narrow terms.** For example, the right to participation and social inclusion is defined based on whether there is legislation around the accessibility of public spaces and whether older people feel lonely. It does not cover however whether older persons can effectively participate in activities, engage in the community and interact with others, which depends on whether the level of support provided also covers these aspects or is strictly limited to

basic needs, like eating and bathing. Additionally, this domain does not reflect whether there are opportunities for education and lifelong learning, which should be available regardless of one's need for support.

Moreover, **the indicators fail to highlight non-discrimination as a general state obligation.** As a result, several of the inequalities faced by older persons who need care and support cannot be captured by the two tools. For example, while looking into whether access to care is restricted the tools do not necessarily surface whether the schemes targeting older persons are different from or less advantageous than those offered to other groups. Yet, based on [AGE's work](#), which has also been reflected in a recent [report by the UN Special Rapporteur](#) on the rights of persons with disabilities, there are important discrepancies between the services and benefits offered to older persons compared with younger people with disabilities. We have also noticed that in some cases deinstitutionalisation efforts primarily target the younger age groups. Neither are the indicators able to expose different experiences and measures for those who acquire disability for the first time in older age, as opposed to those who age with a pre-existing disability. **The ROPI should at least include a structure indicator regarding legislation or policy regulating equal access to care and support regardless of age.**

**In their current form the indicators cannot give a clear picture about the challenges faced by older persons who are at risk of multiple discrimination**, for example whether older LGBTI couples also have a right to receive care in the same residential facility, whether older migrants can equally access the services and so on. Certainly, this is not just an issue of the indicators, but is also due to the lack of available data about these populations. But perhaps structural and process indicators could be further developed to encourage considering the challenges of these groups in the development of policies and measures targeting older persons in need of care and support.

The indicators should also clearly ask whether there is an entitlement to homecare, because countries that rank high in terms of access to and affordability of services, may only provide institutional care and support. **The results should also be read with caution, as restrictions may not exist in law but in practice. For example, lack of service providers in rural areas may still prevent older people from choosing freely the type of care service.**

Moreover, even though still **the bulk of care is offered by informal carers**, the indicators do not indicate whether there is some level of support (be it in terms of financial compensation, respite care or accumulation of social protection rights) for informal caregivers. This aspect needs to be further developed.

Although the indicators look into whether the existing **national human rights bodies** (i.e. ombudsperson, equality bodies) include older persons, it would also be worthwhile to know whether they have **the mandate to cover age discrimination** beyond the field of employment and whether long-term care services, including when these are provided by

private actors are under their purview. Some national bodies have such limitations in their mandate, which effectively limit possibilities for redress.

Finally, the report concludes that 'services must respect the human rights of all older people and ensure that they can live independently and in dignity *for as long as possible*'. But if human rights are to be respected equally at all ages, then they should not be available 'for as long as possible', but rather '*on an equal basis with others*'. People face limitations that may impede their full participation in society or create a need for care and support at all ages. **By insisting that rights in older age can be limited, we give permission to states and other actors to treat older persons differently. Instead they should strive to ensure the same level of autonomy and independence that is possible for a person with the specific care and support needs regardless of age.**

## Resources

- <https://www.euro.centre.org/projects/detail/85>
- [https://www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](https://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf)
- <https://www.age-platform.eu/policy-work/news/older-persons-disabilities-fall-between-cracks-human-rights-protection>
- <https://www.age-platform.eu/policy-work/news/ageing-disability-age-replies-un-consultation-rights-older-persons-disabilities>