



Supporting inclusive development of community based LTC through research

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EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH

Empowering Informal Carers in Montenegro, Serbia, and Austria – Approaches and good practices for
informal carers

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The European Centre for Social Welfare Policy and Research

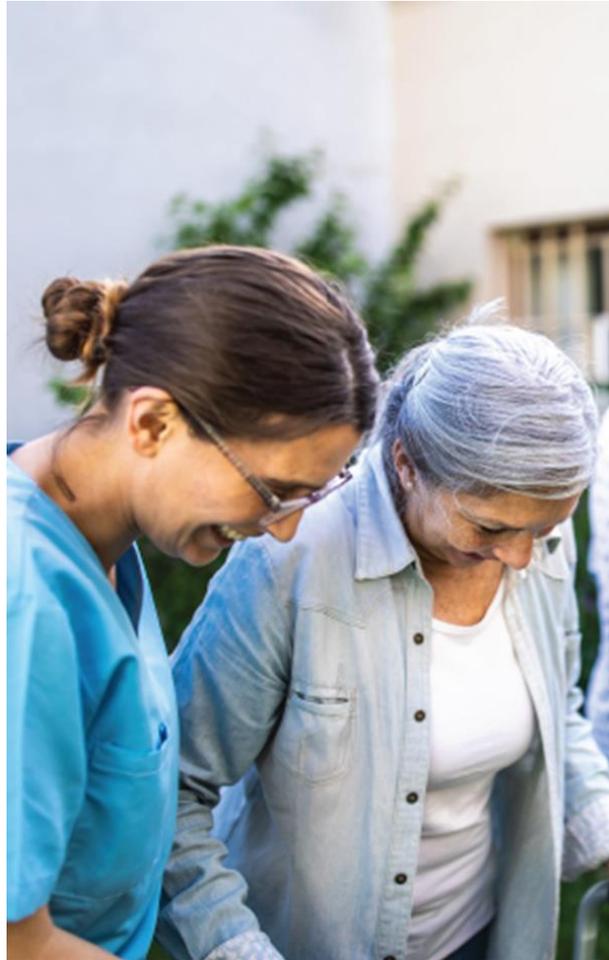
The European Centre for Social Welfare Policy and Research (the European Centre) is an intergovernmental organisation affiliated to the United Nations. Its purpose is to foster the collaboration in social welfare between governments and organisations by

- providing applied social science and comparative empirical research
- forging the evidence-base for social policy making and mutual learning
- initiating future-oriented public policy debates by networking

Bridge-building - assisting in improving social welfare policies within the UN-European region, namely European Union Member States and Accession Countries, the Eastern Partnership, and including Israel and North America

3 Research Groups: Health & Care, Social Protection & Inclusion, Employment & Labour Mobility

Overview



3 different ways in which research can contribute to the development of LTC systems:

- **Research to better understand later life and care**
What does a good life in later life look like?
- **Research to provide an input for policy makers**
Which types of LTC needs often remain unmet?
- **Research to develop LTC together with older people, informal carers and other stakeholders**
How can we develop LTC through inclusive and participatory processes?

Research to better understand later life and care

- Care is often ignored as long as possible
- Negative images of ageing and care have consequences (e.g. on health and mortality, internalized negative age stereotypes)
- Longer lives include more healthy years and more years lived with disabilities and care needs
- Policy processes to improve the situation of older people (UN Decade on healthy ageing, efforts to draft UN Convention of the rights of older persons, preparation of European Care Strategy,..)
- Debate to develop an understanding of what a good life in later life is and also how different people might have diverse understandings of it

Research to better understand later life and care

FutureGEN project: **How do older people themselves define ageing well?**

funded through Gender ERA-Net 3/2019-05/2022

60 semi-structured interviews on ageing well with individuals who are 60+ in Austria, Sweden and Canada (20 in each country); recruitment of participants through diverse organisations and snowballing; video and phone interviews; analysed with framework analysis;



Research to better understand later life and care

FutureGEN project: **How do older people themselves define ageing well?**

Ageing well as a multidimensional and participatory process (social context, independence, participation), health sometimes but not always most important part of ageing well, disability compatible with ageing well, support throughout life and through reduction of ageism



*“Ageing well means continuing to keep as active as one can in doing the same things you like to do...So keep active, **keep having some fun, and also staying connected with my kids and family et cetera”***

Canada, man, 62 years

*“It means having as little worry as possible, I think. Then **you must first hope that you are healthy.** Otherwise it’s ... none of the other things matter.”*

Sweden, man, 63 years

*“Since, unfortunately, the times are such, **older people are not taken into consideration** in any way anymore. It is sad to hear: ‘You have lived long enough, you should actually die already’”*

Austria, woman, 69 years

Research to better understand later life and care

FutureGEN project: **How do older people themselves define ageing well?**



Women are perceived as 'having it easier' when it comes to ageing well because they are perceived as being more interested in social connections, ageing and health. Men are perceived as having more difficulties due to a different retirement experience → In contrast to findings of disadvantages women face in several areas in later life (e.g. health, financial resources)

Research to provide an input for policy makers

- Continuous development of our understanding of the types of LTC services needed (e.g. health & social care; person-centred care, de-institutionalisation) and of quality of care (e.g. structure/process/outcome measures)
- Which unmet LTC needs can we identify?

Research to provide an input for policy makers

Det_Caremix: **unmet needs of care receivers and informal carers**
funded through FWF, Slovenian Research agency 6/2017-11/2020

Dyad study, interviews with older people with care needs living in the community and their informal carers in Austria and Slovenia on experience of caregiving and care receiving; separate interviews of dyad members unless requested otherwise; all care receivers used formal and informal care (48 interviews in Austria, 110 interviews in Slovenia); data collection in 2019, recruitment through snowballing, GPs, churches and LTC providers; interviews in day care centres, homes, work places; data analysis with qualitative content analysis.

Research to provide an input for policy makers

Det_Caremix: **unmet needs of care receivers and informal carers**

Unmet care needs linked to approachability (information access), acceptability (values; rarely mentioned, if in connection to bodily care), availability and accommodation (e.g. socializing and emotional wellbeing), affordability, appropriateness (needs; how care is delivered, most frequent type of unmet need)

“Well, in short, I have to say as next of kin, even more if this happens as suddenly as it happened with mum, one is totally overtaxed and, well, I haven’t had any private life ever since.”

Informal carer, Austria

“Yes, they would need additional help in the afternoon, but there is a financial problem.”

Informal carer, Slovenia

“Then, it can be that during one day, three times someone else is coming. And this seven times a week and of course, since then mum is a bit ... I don’t know how to say, not good somehow” Informal carer, Austria

Research to develop LTC together with older people and their carers

- From best practice to best fit for purpose: need to adapt LTC innovations to a local context
- Involvement of diverse stakeholders to adapt a LTC innovation to the local context
- Older people who are or will receive LTC should be involved → their wellbeing that should be supported

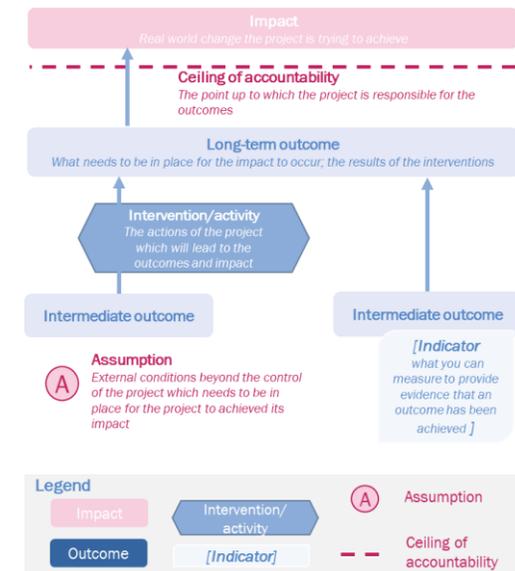
Research to develop LTC together with older people and their carers



InCARE project: **Theory of Change methodology**
funded through EaSI, FGÖ 11/2021-10/2023

3 pilot projects in Austria, North Macedonia and Spain to develop LTC in the community

A series of workshops with diverse stakeholders, in which a ‘Theory of Change map’ is drawn, including impact, outcomes, assumptions, a ceiling of accountability and different indicators to measure success



Research to develop LTC together with older people and their carers

InCARE project: Theory of change methodology



- Structured engagement with stakeholders
- Guiding development, implementation and evaluation
- Connecting diverse stakeholders
- Sustaining stakeholder engagement
- Contextualisation of projects
- Resource intensive process, non-hierarchical communication



Conclusion

- Older people themselves should define what a **good life in later life** is; we need to have more debates on ageing well, raise awareness on groups that face particular difficulties and develop social policies to support them
- **Unmet care needs** can occur even in the case of access to formal and informal care; it is important to bring the needs of informal carers in the debate on unmet LTC needs
- We need **participatory approaches** to adapt LTC innovations to local needs, Theory of Change Methodology is one tool that can be used to successfully include older people, informal carers and other stakeholders in LTC development

Thanks for your attention

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