



The time to care about care:

Responding to changing attitudes, expectations and preferences on long-term care in Europe

Stefania Ilinca, Cassandra Simmons
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EUROPEAN CENTRE FOR SOCIAL WELFARE POLICY AND RESEARCH



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InCARE Project



- Aims to promote participatory, innovative and integrated approaches to long-term care (LTC) policy and service development
- InCARE emphasizes **four key aspects** for system sustainability and innovation capacity:
 - Multi-stakeholder cooperation;
 - Community engagement;
 - Evidence based decision-making;
 - Capacity building through mutual learning
- **Person-centred care:** Essential that policy reflects the voices of care users and their families in all decision-making processes
- **InCARE Survey** as one component: collecting information on attitudes, experiences and expectations for long-term care

InCARE

- Publication submitted to EU Care Strategy consultation in May 2022
- Full publication found on the InCARE website: <https://incare.euro.centre.org/publications-tools/>



It is high time to care about care!

Care is the fabric that holds our societies together, across all generations & the full life cycle.

It has to be:

- ✓ Available
- ✓ Accessible
- ✓ Affordable
- ✓ of appropriate Quality

#EUCareStrategy



EU Justice and 5 others

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InCARE Policy brief No. 2 - April 2022

Authors Stefania Ilinca and Cassandra Simmons // Address correspondence to: ilinc@euro.centre.org

Executive summary Fifteen years after the Special Eurobarometer 283 on Health and long-term care in the European Union, the results of the cross-national InCARE survey bring to light significant changes in the attitudes, expectations and long-term care experiences of Europeans. As momentum for reform is building both at national and European level, we find the policy discourse has not kept up with dynamic preferences and attitudes towards care, especially among younger cohorts. Overwhelming support for increasing the role of the State in long-term care organization, provision and financing and shifting the burden of care away from families and individuals, is improperly reflected in current policies. What is more, a failure to do so is negatively affecting trust in care systems, as well as increasing the reliance on informal carers at the detriment of their health and wellbeing. Since 2007, the ability of care systems to adequately address evolving care needs has declined: residential care is unaffordable for many, and the supply of community-based services is falling considerably behind a rising demand. Rural communities and poorer individuals bear the brunt of growing capacity gaps, while women are disproportionately affected by the burden of frequent, intensive and undesired informal caregiving spells. A reorientation towards person-centered, participatory, equitable and accessible care models is urgently needed to rebuild declining public trust in the ability of care systems to respond to the preferences and expectations of individuals and communities.

INTRODUCTION

Notwithstanding remarkable gains in healthy life years individuals can expect to enjoy, the number of people in need of long-term care and support is projected to rise to over 38 million by 2050, as the European population ages (1). But even as the demand for long-term care increases, the availability of families and local communities to provide needed support is being eroded by rapidly evolving social, economic, cultural and population migration patterns. In order to respond to the combined effects of these trends, long-term care systems throughout Europe must strive for significant transformations, by strengthening and reorienting care models to better respond to population needs and preferences.



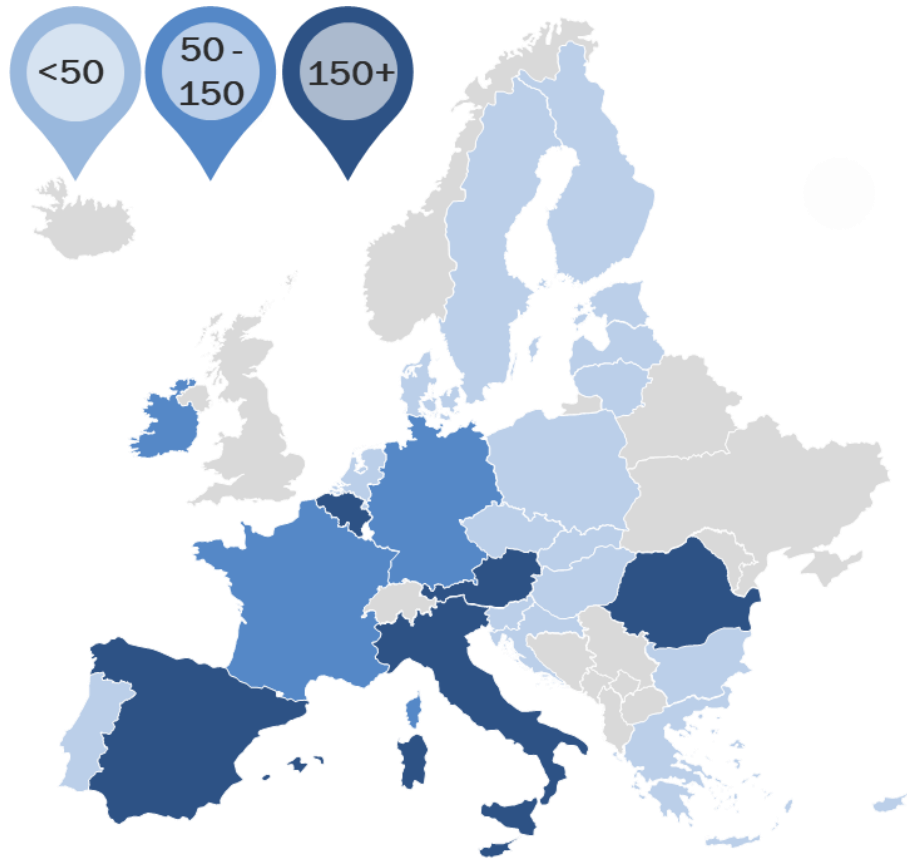
“It is high time to care about care!”

- Increasing challenges with long-term care alongside demographic ageing
- Policy discourse has not seemingly kept up with attitudes and preferences towards care
- Capacity gaps, unaffordable costs, large range of quality
- Gender and socio-economic inequalities in care provision
- Reforms at the national (Recover and Resilience Facility) and European level (EU Care Strategy)

Data Collection

- InCARE survey
 - Modelled after 2007 Eurobarometer 67.3
 - Questions relating to attitudes, experiences and expectations for long-term care
 - Data collection: online from Sept 2021 – Mar 2022
 - Dataset used here: N= 2,373 in 26 EU countries
 - 9 EU countries with 50+ observations (AT, BE, DE, ES, FR, IE, IT, MT, RO)
- Comparison to Eurobarometer data (2007); over 28.000 Europeans

Sample characteristics



- Over-represents middle-aged individuals (half of sample), while under-representing 18-29 year olds (18%) and 60+ (33%)
- Skewed towards women (77%)
- Higher-educated individuals over-represented; 70% have either a university or post-graduate degree
- Most live in large towns (40%) followed by small/mid-sized towns (35%)

Aims

- 1) To look at how attitudes, expectations and preferences on long-term care changed since 2007
- 2) To identify major challenges to be addressed in the design and provision of LTC systems

Perceptions of care systems

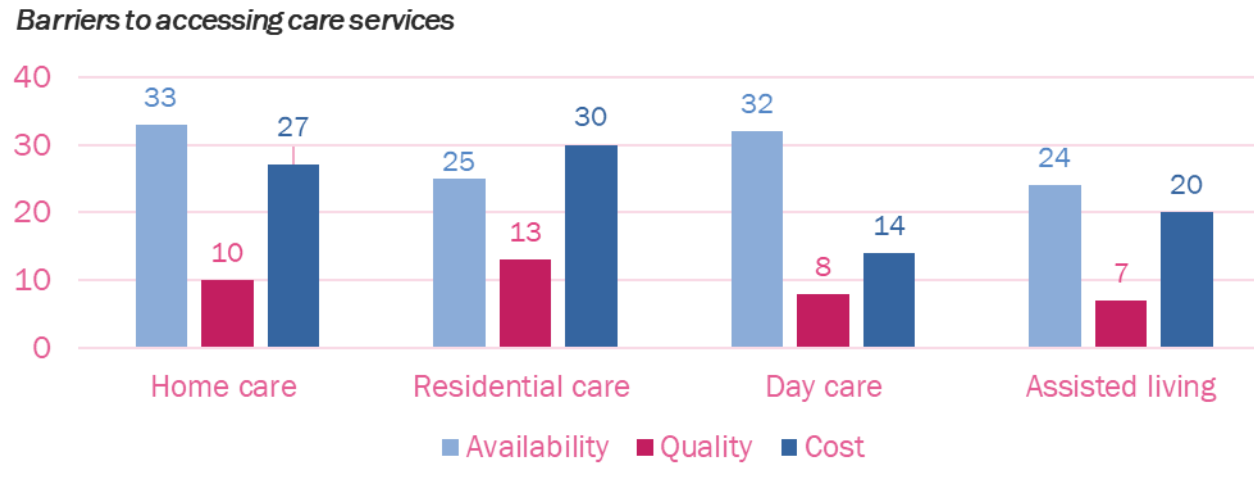
Share of European respondents rating home and residential care as difficult to access, unaffordable, and of low quality in 2007 and 2021 (%)



- Increased availability issues: potentially due to general deinstitutionalisation efforts
- Cost identified as major issue, even more so for residential care in 2021
- Quality is perceived as less of an issue, but still significant

Barriers faced

Share of European respondents facing barriers in accessing home and residential care in 2021 (%)



- Availability barriers tend to be higher in more rural areas for both home care and residential care
- Lower income individuals more likely to face cost barriers than higher income

Impact of informal caregiving

Share of respondents in the EU who perceive pressure to provide informal care in 2021 (by gender)



Share of respondents in the EU who experienced negatives impacts on their career due to informal care in 2021 (by gender)



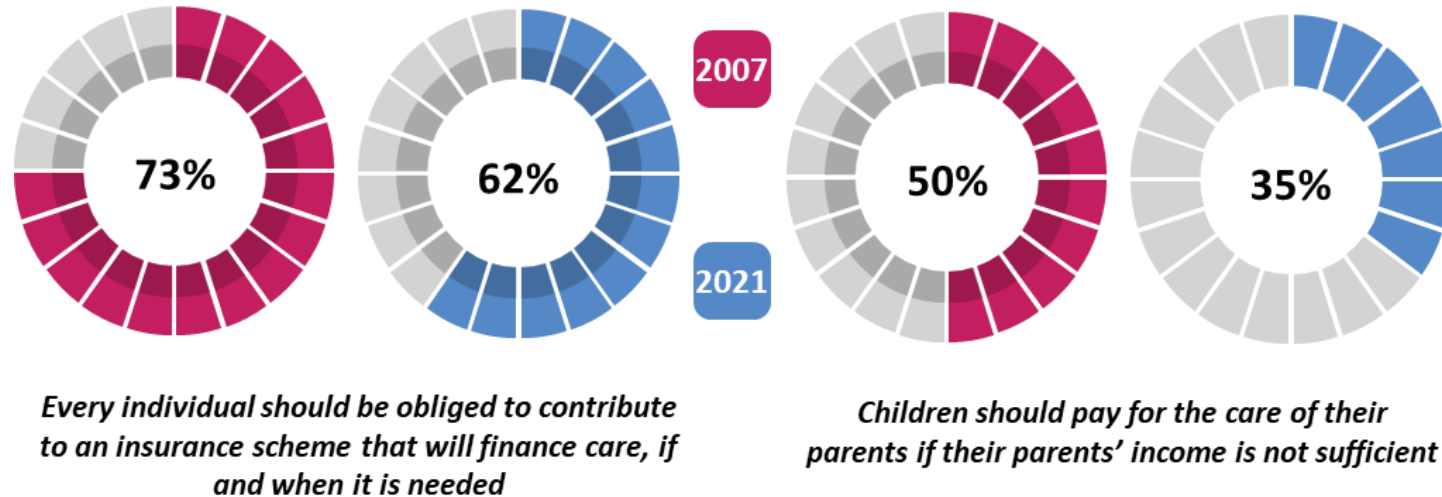
- Larger proportion of informal carers reported (50% vs. 33% in 2007), likely bias of sample
- Large proportion of individuals that feel obligated to provide care
- Negative impact on career
- Highly-gendered impact

How should LTC be organised?

		2007	2021/22
State's role	<i>"Public authorities should organise and provide appropriate home care and/ or institutional care for older people in need"</i>	96%	97%
Family's role	<i>"Care should be provided by close relatives of the older person with care needs, even if that means that they have to sacrifice their career to some extent"</i>	38%	17%
	<i>"Care should be provided by close relatives of the older person, even if that means that they have to sacrifice their health and wellbeing to some extent"</i>	n.a.	14%

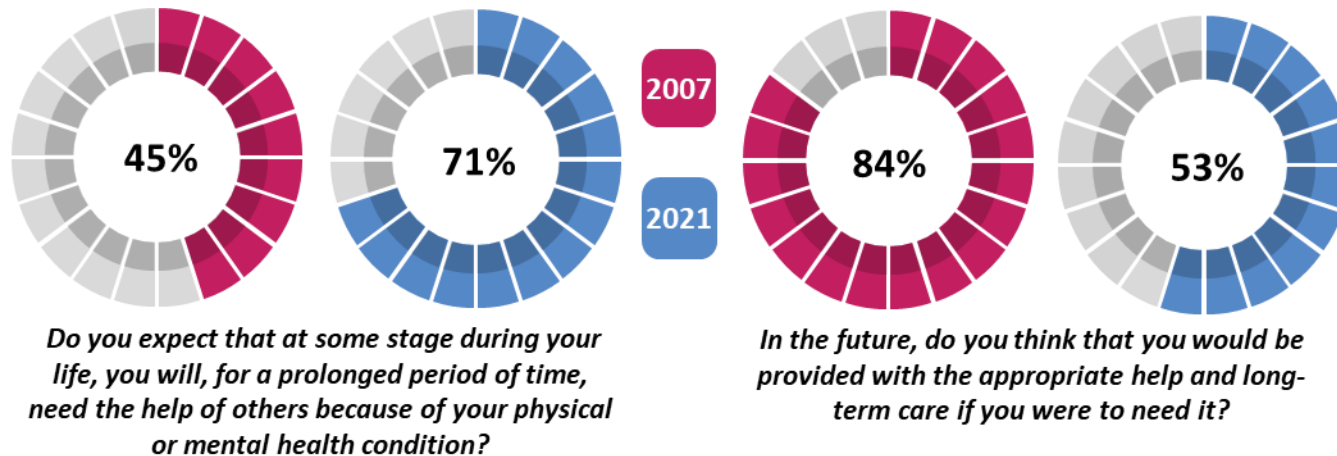
How should LTC be financed?

Share of respondents in the EU who agree with the statements ...



- Strong support for LTC insurance
- Reduced support for children's responsibility in financing parents' care
- Strong age gradient in views on state and user responsibility in financing care; stronger support for full state responsibility among younger individuals

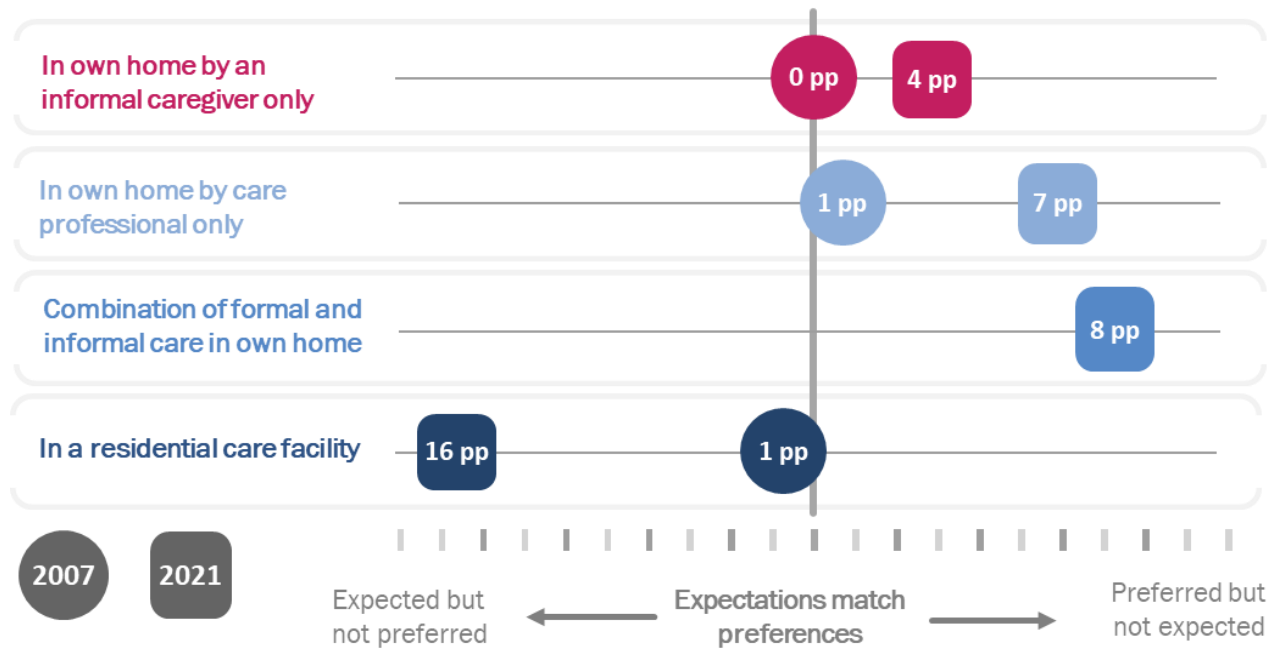
Trust in care systems



- Increased expectation of needing care at some point (26 pp)
- Diminished expectation that individuals will receive the appropriate care needed (31 pp)

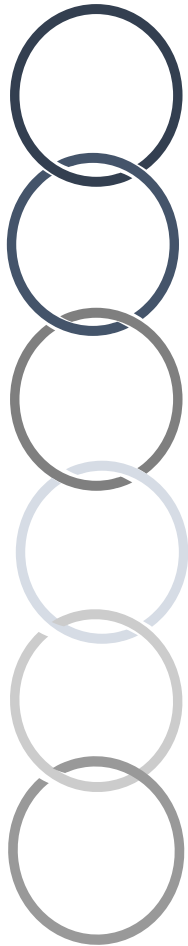
Preferences vs. Expectations

Gap between preferred and expected care arrangements in the EU, by year



- Considerable gaps in the care that respondents would prefer vs. what they expect to receive
- Decline in preference for informal care since 2007 (50% vs. 25%)
- Stronger preference for formal care provided by professional services (29% in 2021)
- Strongest preference for care in the community, whether informal, formal, or combination of both (88%)

Policy Implications



Accelerate reforms and recognize long-term care as a growing societal concern

Increase service capacity, especially in community-based care settings

Increase financial protection for long-term care, across care settings

Improve recognition, social rights, financial support and access to support services for informal carers

Expand formal care provision to levels that alleviate the burden on informal carers and ensure informal caregiving is a choice, and not an obligation

Develop processes that systematically elicit and monitor preferences and attitudes towards care in the population and reflect them in all policies



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Thank you!

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