

AIM EXPERT TALK REPORT

Provision of high-quality, sustainable and accessible non-residential LTC



Focus on Access

On 9 February, AIM organised the first Expert Talk of its series on the “provision of high-quality, sustainable and accessible non-residential LTC”. The meeting gathered distinguished speakers to discuss the issue of access: Dr Stefania Ilinca, Technical Advisor on long-term care at WHO Europe; Susanna Ulinski, Policy Officer, Unit D.2 Social Protection, Directorate-General of Employment, Social Affairs and Inclusion, European Commission; Professor Jozef Pacolet, Emeritus Professor with formal duties in the ‘Social and economic policy & social inclusion’ unit of HIVA; and José Carlos Ortega Regalado, Health Policy Modeller, Health Division, Organisation for Economic Cooperation and Development (OECD).

Introduction

As an introduction to the discussions, the chair of the AIM Long-Term Care (LTC) working group, François Perl, shared some information on the context of the series of Talks. AIM is convinced that the publication of the European Care Strategy is only the beginning and that the most important part starts now with its implementation. With the Talks, AIM wants to keep the momentum for Care alive. The deliberate focus on non-residential care is justified by a felt need for a model for the provision of that type of care. AIM’s objective



“At AIM, we are still on the ball. We still think it is very important to take advantage of this momentum to raise the profile and increase awareness on the importance of long term care into in the global issue of social and health policies. As data shows, the foreseen spendings and expenditures on long-term care are a huge issue, which is probably not enough tackled by governments at the moment. So AIM will keep on advocating!”

François Perl, Chair of the AIM LTC working group

is to develop some type of recommendations and to that end, they organise the series of Talks to discuss the aspects of access, quality and sustainability with experts, hoping that the meetings will be an added value to all.

AIM will organise two other Talks on the aspects of **quality** on 20 April 2023 and **sustainability** on 22 September 2023.
[Contact us](#) if you wish to join the discussions.



INSIGHTS FROM THE EXPERTS

Dr. Stefania Ilinca, Technical Advisor on LTC, WHO Europe

Dr Stefania Ilinca highlighted that strengthening long-term care (LTC) service delivery is essential to support healthy ageing and longevity, but also the sustainability of both health and social protection systems. LTC investment and reform of LTC systems are an essential priority given the increasing needs and demand for care and support. Despite gains in life expectancy, there is unfortunately no or very little evidence on compression of morbidity and functional decline towards the end of life. On the supply side, there is a contraction of LTC resources and, while there is an increase in the supply of formal care services across European countries, models of care might not be the most efficient. They are in any way not sufficient to compensate for dwindling informal care resources. Informal care remains the main long term care resource, even in countries with very developed long term care systems.

Dr Ilinca stressed how LTC is vital for the achievement of Universal Healthcare Coverage (UHC). UHC refers to ensuring access to the full range of health and care services that people need whenever and wherever needed, without financial hardship. It covers the whole continuum. That includes prevention, treatment, rehabilitation, assistive and palliative care. Long-term care is an essential part of the universal health coverage agenda to ensure human rights are respected. It

is therefore the basic LTC services that are necessary to fulfil these rights, while locating LTC care services within the UHC agenda and associated policies.

Dr Ilinca then commented on the definition of access, which is much more complex than the notion of availability. She described the essential aspects to ensure appropriate access to care. She stressed the need to provide the kind of care that people want, that respects their preferences and their needs. That explains the necessity to focus on community-based care because strong evidence suggests that home-based and community-based care better reflects the preferences of care users and their families. Availability is certainly a very important aspect of access and a very sore topic in European countries. Affordability is another key topic and remains probably the first, if not one of the main concerns and barriers to access. Finally, appropriateness: care should be of good quality, which notably depends on the coordination and continuity of care.

WHO identified key priorities for action to strengthen long term care: the improvement of integrated care delivery and promotion of a prevention-oriented approach to LTC, focussing both on quality and accessibility, and supporting informal care.

Dr Ilinca highlighted three



important dimensions that need to be considered when we speak of integration across sectors, across governance level and across formal and informal care resources. First and foremost, integration across sectors. The division of health and long-term care services as it currently stands in many European countries is artificial and leads to inefficient processes, duplication of tasks that can be very costly and in turn lead to less-than-optimal outcomes.

Dr Ilinca recommended to reorient care models to emphasise person centeredness, which in itself is a focus on community-based care, to strengthen cross sectoral coordination mechanisms, to promote the integration of formal and informal care; and to invest in training and upskilling both the formal and informal care workforce. She also stressed that the

integration across governance levels needs more attention.

WHO's work notably focusses on improving health and long-term care coordination. Dr Ilinca shared some data from the baseline report for the UN Decade of Healthy Ageing, which showed that 46 out of 53 Member States in the European region have a LTC policy. LTC is thus clearly a

comprehensive assessments that include both health and long-term care needs; and strengthening case management programmes. There is a very large evidence base that continues to grow that nurse-lead or multi-multidisciplinary-team-lead case management programmes have positive outcomes both for the users but also for the service

care a stabilisation- and prevention-oriented focus while being accessible to all, rather than only on those who have intensive care needs. It is equally important to preserve independence and avoid institutionalisation by creating supportive, caring ecosystems and communities.

Dr Ilinca ended by promoting an equity-oriented approach in all preventive and health promoting interventions, but more generally in the way LTC systems are designed, and by stressing the need to support and sustain informal care resources. To be able to continue to rely on these sources, it is important that they're sustained and then they're optimised: achieving a better understanding of informal care and the needs of carers through better data collection, protecting the health and socioeconomic well-being of carers, and improving training, information and coordination of informal cares with formal care teams.

"Accessibility criteria, needs assessment criteria, and eligibility need to be redefined to give care a stabilisation- and prevention-oriented focus while being accessible to all, rather than focussing only on those who have intensive care needs. It is equally important to preserve independence and avoid institutionalisation by creating supportive, caring ecosystems and communities."

Dr. Stefania Ilinca, Technical Advisor on LTC, WHO Europe

recognised policy priority in the region. Yet, the understanding of the necessity to integrate health and care services is not quite as commonly accepted: only 24 out of 53 countries have in place national policies that support comprehensive assessment of needs.

Dr Ilinca made some recommendations on how to promote integration, especially at the boundary between primary care and community-based long-term care: developing harmonised standards, procedures and care pathways (e.g. the ICOPE approach); ensuring increased access to

providers themselves. She also stressed the importance of a prevention-oriented approach to LTC, with the aim not only of mitigating functional decline, but also preventing, rehabilitating, and slowing it down whenever possible.

Investing in screening and early intervention to address the risk factors of functional decline, focussing both on clinical and socioeconomic risk factors, is key, just as the timely identification of decline in capacity and improved access to low intensity care. Accessibility criteria, needs assessment criteria, and eligibility need to be redefined to give



INSIGHTS FROM THE EXPERTS

Susanna Ulinski, Policy Officer, Unit D.2 Social Protection, Directorate-General of Employment, Social Affairs and Inclusion, European Commission

Susanna Ulinski started by presenting the [European Care Strategy](#), announced in September 2021 by President Von der Leyen in her State of the Union speech. The objective of the Strategy is to ensure quality, affordable and accessible care services for all. It aims at improving the situation for both care receivers and formal and informal carers. It follows a life course perspective, from childcare to long-term care. The care package was then adopted in September 2022, and it consists of a Commission Communication on the European Care Strategy that sets out a vision in the area of care, including supportive actions at EU level and also calls for action at national level. In addition, the package includes two Council Recommendations on the revision of the Barcelona targets and early childhood education and care and also on access to affordable, high quality long term care that were adopted by the Council in December 2022. The package is also accompanied by two Staff Working Documents.

Why a Care Strategy? Ms Ulinski started by recalling principle 18 of the European Pillar of Social Rights, which states that everyone has the right to affordable long-term care services of good quality, in particular home care and community based care. She shared some data from the European Health Interview Survey focusing on people living in private homes, which showed

that half of people aged 65 or over with long-term care needs report having an unmet need for care. In addition, the number of people in need of long-term care will increase by 23% until 2050, to reach 38.1 million across the EU. Data also shows that 52 million Europeans provide informal care, and care responsibilities keep 7.7 million women out of the labour market. In addition to informal care, problems also arise when it comes to formal care: staff shortages, bad working conditions, and low pay. However, the European Care Strategy also highlights the big job creation potential in the sector. More than 1.6 million long term care workers will be needed by 2050 just to keep long-term care coverage at current levels. Ms Ulinski presented how the Council LTC recommendation defines long-term care needs, looking at the baseline of who should actually be covered by LTC services. LTC means a range of services and assistance for people needed as a result of mental and/or physical frailty, disease and or disability over an extended period of time. Those services include activities of daily living (ADLs) such as bathing, dressing, eating, getting in and out of bed. They also include instrumental activities of daily living (IADLs), like preparing meals, managing money, shopping, and even performing some housework.

The European Health Interview



Survey showed that 26.6% of people over the age of 65 have a need for long term care and the need for long term care is higher among women than among men. Across the EU, 28.6% of people aged 65 plus say that they're using professional Home Care services. In addition, 35.7% say that they either do not use long term care at all or more long-term care services because they would need more financial resources. For that reason, according to Ms Ulinski, comprehensive social protection coverage for long term care is essential to ensure access. Yet often people still face significant out of pocket payments for long term care even after social protection, spending 50% or more of their income on LTC services. Public spending on long term care was on average 1.7% of GDP in 2019 and is projected to increase to 1.9% in 2030 and 2.5% in 2050. Spending is also unevenly

or differently distributed. Some Member States like Finland for example, spend 75% on home care, whereas other Member States might only spend 10% of overall long term care expenditure on home care.

The European Commission also commissioned a study on the value of informal care, which stressed that it amounts to around 2.4% to 2.7% of GDP across the EU. The study also calculated the public costs of informal care giving (around 1% of EU GDP), including the loss of social protection revenues, for example, lost tax contributions. It showed that informal care is not a cost-free option.

The European Commission advocates for an integrated approach to care and to see long-term care as a social investment. The Care Strategy is divided into 5 areas of actions: improving care services, improving working conditions in the sector, a better balance between work and care responsibilities, investing in care and improving the evidence-base and monitoring progress. The LTC recommendation provides a policy framework for reforms and investments at the national, regional, local, local level. The Communication identifies the common challenges and announces actions to support the implementation. For example, the Commission offers technical support from the Technical Support Instrument to Member States under the new flagship projects towards person-centred integrated care. They are also pursuing a strategic partnership with the WHO to provide country-specific support to design and implement policy measures for high quality long term care.

Though technology, of course, cannot and should not replace

human interaction, there are innovative and digital solutions that can improve access to care and aid independent living, and increase labour productivity. Under the upcoming Horizon Europe Partnership, the EC has also set up a knowledge hub for innovative technologies and digital solutions in healthcare provision.

Ms Ulinski then presented the main building blocks of the LTC recommendation. Those call for social protection for long term care to make it affordable and highlights that services should be timely, comprehensive and also adequate. Regarding the availability of long-term care services, the recommendation specifies that services need to cater for different needs and to support the personal freedom to choose the most suitable care option setting by developing further home care and community-based care by closing

characteristics and to apply them to all long term care providers. Member States are invited to put in place a quality framework for LTC which is guided by the quality principles set out in the annex of the recommendation.

The EC also calls for an investment in the formal workforce to improve working conditions, education and training, career pathways into long-term care established and also pathways to regular employment for undeclared workers and strengthened professional standards. In addition, it recommends the proper support (training, counselling, respite care) to informal carers.

Member States will now appoint national long term care coordinators

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Susanna Ulinski, Policy Officer, Unit D.2 Social Protection, European Commission

territorial gaps in care provision, in particular in rural areas, rolling out accessible innovative technology and digital solutions to help provide services and support independent living and making sure that LTC services and facilities are accessible to persons with specific needs and disabilities.

Regarding long-term care quality, the EC advises Member States to establish high quality criteria and standards for all long-term care settings tailored to their specific

that will also submit reporting to the European Commission. The EC will also monitor progress via its European Semester. The EC, in collaboration with the Social Protection Committee (SPC) is developing a dedicated framework of indicators to monitor the recommendation. Within five years, the Commission will report to the Council on the progress.



INSIGHTS FROM THE EXPERTS

Professor Jozef Pacolet, Emeritus Professor with formal duties in the 'Social and economic policy & social inclusion' unit of HIVA and member of the High-Level Group on the Future of Social Protection



Professor Jozef Pacolet started highlighting how the challenge of care coordination is not new and has been discussed for over 10 years. The main question, according to him, is about the responsibility of that coordination. Should it be the role of a social worker of a sickness fund, of district nurses, general practitioners...?

He referred to a report from 1999 on social protection for dependency in old age. The study highlighted at the time that services (residential, semi-residential and at home) existed but there were problems of availability (supply side) and affordability (financing). The report also stressed the fading

principles as a steering wheel. Principle 18 of the Pillar of Social Rights is a great achievement but at the same time it leads to a risk of separating LTC from healthcare. However, it makes the additional need for further development of this specific services clear. Professor Pacolet underlined that it is important to address both community-based and residential care.

After the Conference on the Future of Europe in May 2022, the Council recommendation on access to affordable, high quality LTC were adopted. In the meantime, the High Level Group for the Future of Social Protection, announced in the

challenges, in a medium to long-term (looking ahead to 2030), to inform debates at EU and national levels and inspire reforms. The results of the High-Level Group will feed into reflections at European level and national level, involving Member States, social partners and key stakeholders, such as civil society organisations or social security organisations. The report has a look at the expected impacts of megatrends (demography, changing world of work, digitalisation, climate change and green deal) on the needs for social protection and on the welfare systems and their financing and on their implications for the design and scope of social protection systems and for the financing of social protection. Finally, it provides key strategic recommendations for the future of social protection: 21 new recommendations

"The 1999 report on social protection for dependency in old age already highlighted the problems of availability and affordability of LTC services, stressing the fading borderline with housing and the unbundling of service provision as well as the role of coordination. 25 years later, we are on the High Road forward!"

Professor Jozef Pacolet, Emeritus Professor at the HIVA and member of the High-Level Group on Social Protection

borderline with housing and the unbundling of service provision (also of cost of care and cost of housing) and the role of coordination.

25 years later, according to Professor Pacolet, we are on a high road forward, with the WHO

Action Plan for the European Pillar of Social rights, was set and published its final report on 7th February. The High-Level Group had as a task to develop a vision on how to reinforce social protection systems and welfare state in light of ongoing and new

for the 21st century. The report puts forward policy options to adapt the design and scope of social protection systems along three life-course phases (early and family life, working lives, old-age) and the three pillars of welfare production (labour market regulation, (classical) social protection systems, (perhaps also classical) social services, preventive function and social investment). It also explores the implications on the financing of social protection, in particular viable ways to secure a fiscal basis and diversification: the mix of social contribution/taxation revenue to finance the welfare state needs, and the potential of alternative tax revenues in addition to the “double dividend” of social investment.

The report also includes a specific recommendation on LTC but also many other recommendations cover the complete live course

and are of relevance for LTC. For example, it introduces the concept of social investment capacitating the population, from the very beginning, starting strong, over the complete live course; highlights the importance of healthy lifestyle and prevention; promotes pension credits for care activities and underlines the role of non-profit (private and public) and social economy in the provision of LTC services.

The High-Level Group also recommends the introduction of a ‘golden rule clause’ in the EU governance of public finances, allowing lending for investment in social infrastructure. According to the group, LTC would also benefit from the ambition to increase life-long learning and digital solutions. Experts recommend improved financing of the welfare state by maintaining the present sources, topped up with all kinds of efforts to broaden the tax base and the

financing mix. Professor Pacolet underlined that it is vital for access that LTC is covered by social protection as an additional branch. They also encourage to guarantee adequate pensions in all its dimensions, which will facilitate access to LTC, by making it further affordable.

Professor Pacolet also stressed the importance of ensuring freedom of choice while continuing developing residential care, as an alternative when community-base and home care are no longer possible. To conclude, he highlighted the need to include social participation and the fight against loneliness in the picture when we talk about LTC services.



INSIGHTS FROM THE EXPERTS

*José Carlos Ortega Regalado, Health Policy Modeller,
Health Division, Organisation for Economic Cooperation
and Development (OECD)*



José Carlos Ortega Regalado started by providing a broad picture of the current long-term care situation. He first showed that the prevalence of long-term care needs is high. It is increasing and is expected to continue doing so. Among the 24 countries for which estimates are available, between 13 to 21% of the population aged 65 or above have any type of long term care needs. That means that, on average, one in six older adults have long term care needs, which, combined with population data, accounts for 19 to 32 million people for those countries. There is a wide variation in the relative prevalence of long-term care needs across countries. For example, the Netherlands has a very low prevalence compared to Romania, even though these countries have similar old age population. Differences in prevalence are, among other factors, related to differences in access to long term care services.

Data analysed by OECD showed that older people with estimated LTC needs are more likely to be 80 years and older, more likely to be women, more likely to live in single households and more likely to have lower incomes. There is thus a combination of factors that are all related to the prevalence of LTC needs.

Data indicates that the majority of people receiving long-term care are doing so at home. Across the 20 OECD countries, an average of 68% of those receiving LTC were living at home in 2019. Preferences partially explain the high percentages, however, access issues related to the

high costs of institutional care, as well as a strong reliance on informal care, can also explain these high figures. In response to these challenges, many countries have developed services to support LTC in a home-based environment. However, changing the policy priorities has not always resulted in a significant move away from institutional care. Indeed, between 2009 and 2019, the proportion of long-term care recipients who receive care at home has barely changed. It went from 67% to 68% (average).

Current expenditure on LTC varies widely across countries, and it is projected to increase by 2070 in all OECD and EU countries, even under the best-case scenario for these projections, which is the healthy ageing one.

Mr Ortega then listed some major challenges of long-term care systems. First, the major issue of the long-term care workforce. The poor working conditions and low wages in the sector are pressing challenges to maintain access for care and to ensure the quality of this care. There is also a high rate of part time work. In some countries, like in the US, over 2 out of 5 direct care workers are employed less than full-time all year around. Migrant workers also represent an important share of long-term care. In addition, there is a general lack of recognition for the work provided by this workforce. Mr Ortega highlighted that those problems affect mostly women as women account, in some countries, for almost 90% of the total of the workforce. They lead to physical

and mental problems and ultimately affect the quality of the care.

The OECD has developed a general framework with five key areas of action to develop the LTC workforce. First of all, recruitment and retention, which require improving working conditions and wages. In the US for example, they extended in 2015 the right of minimum wage to unlicensed home workers. The elimination of precarious conditions and introduction of flexible working time arrangements has also proven to be an adequate policy to reduce turnover. There is also the need to promote healthier working environments, focusing on prevention of workplace accidents and illness linked to the realisation of these jobs.

Another key aspect is the need of a social dialogue that involves all the stakeholders, families, long-term care workers, employers and the government to improve the recognition of the rights of long-term care workforce. Additional to the efforts on

improving and recruiting, it is also essential to improve productivity and eliminate repetitive and sometimes excessive administrative tasks that could be automated with the help of technology. Technology plays an important role in this regard and the pandemic shows how the use for instance of telemedicine or video calls for communication has become more prevalent and is now an option. However, this requires the proper training of the workforce and availability of resources.

Finally, according to Mr Ortega, it is key to improve the coordination across workers and care settings and to support the informal carers so as to achieve better home care and to develop community-based care settings.

When it comes to the organisation and financing of LTC systems, many countries suffer from a large fragmentation of long term-care systems and services, which, under inadequate governance frameworks, result in overlap of coverage, which in turn means resources waste or gaps in coverage, meaning high out of pocket payments or high unmet needs.

Yet another obstacle to access to public care services is the lack of harmonisation across benefits and

Then, there are additional barriers related to social protection. High out-of-pocket payments for LTC services are very common. There is high risk of poverty related to developing LTC needs.

Finally, financial sustainability is a big concern for these social protection systems. Mr Ortega underlines the need for a legal framework to ensure some level of resources for LTC systems to maintain at least the current level of access and quality and ideally improve it.

Some of the areas of action to tackle the mentioned challenges are first, the integration of LTC systems and the harmonisation of the governance. This entails a better coordination between health and social services. Countries like Finland, Denmark, or Lithuania have gone through reforms to integrate health and social services, including LTC, showing that if there is willingness there's a way to harmonise and integrate systems. It is also important to ensure single entry points for the provision of benefits and services.

Another opportunity area of building more coherent social protection systems is to harmonise eligibility criteria and its assessment tools. There is always a balance that needs

of resources. It can help to reduce unnecessary activities, overuse of services, their duplication and cost shifting. In France, for instance, since 2020, the majority of its LTC funding schemes have been pulled into the national solidarity with the aim of facilitating the collection and distribution of these funds.

The OECD risk that matters survey (2020) reveals that people are very concerned about not being able to access good quality care and that these people would also support greater spending on LTC services, even if this would mean increases in taxes and social contributions. Therefore, avenues to fund more LTC services need to be explored, through LTC insurances or through taxes to tax based system.

The final obstacle to access is the insufficient effort for preventive services and limited access to end-of-life care. Good evidence supports that some of these measures are cost-effective measures. For instance, Norway introduced preventing home visit programmes showing significant reductions in residential care while increasing home care use. Finally, the issue of access to end of life care requires attention. While most old people generally have a preference about their place of death, the actual place of death does not usually align with those preferences. It is thus important to ensure that there is qualified staff to provide those type of services and to consider individual preferences.

"It is key to improve the coordination across workers and care settings and to support the informal carers so as to achieve better home care and to develop community-based care settings."

José Carlos Ortega Regalado, Health Policy Modeller, Health Division, Organisation for Economic Cooperation and Development (OECD)

the lack of standardised assessment tools. Combining the fragmentation of the long-term care systems and this lack of standardisation and harmonisation of tools, we understand how the long-term care systems become very difficult to navigate, especially for someone that is older and with long term care needs.

to be found between efficiency and equity of the LTC system, and eligibility rules are probably the key aspect to achieve this equilibrium. More and better funding is also necessary. Pulling existing funding to improve efficiency can be a step forward, into a well-defined budget that could improve transparency and facilitate the distribution