AIM EXPERT TALK REPORT

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

Focus on Quality

On 20 April, AIM organised the second 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 quality: Tadas Leončikas, Head of Unit, Employment, Eurofound; Dr. Lamura Giovanni, Research Affiliate, Centre for Socio-Economic Research on Ageing; Diana Eriksonaite, Policy Officer – LTC, DG EMPL, European Commission; Claire Champeix, Policy Officer, Eurocarers; Philippe Seidel, Policy Manager on Social Protection and European Parliament, AGE-Platform Europe; and Cornelia Moseid, certified EQUASS Auditor and Quality Strategist at VästKom, Sweden.

Meet the Experts

Claire Champeix, Policy Officer, Eurocarers

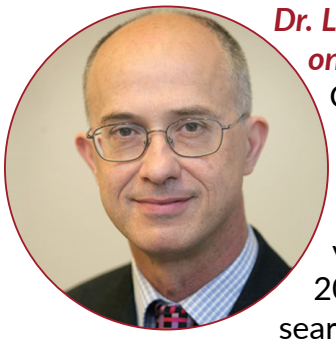
Claire has extensive experience in policy work, lobbying, research, and project coordination in the social field at local and European levels.

Before joining Eurocarers in 2016, Claire worked with various Brussels-based NGOs and collaborated with different EU institutions, notably in the social and human rights sectors. More specifically, she has focused on the fight against poverty and social exclusion, effective participation in policy-making, and the rights of persons with disabilities. She also worked for the social department of different local authorities in France for 7 years. Claire is a graduate of the Institut d'Etudes Politiques (Paris) and Université Paris Sorbonne (Sociology).

At Eurocarers, Claire is involved in various projects and policy initiatives, particularly in the domains of integrated Long-term Care, Cancer Care, training and skills, social rights, EU funds and policy coordination through the Semester.

Diana Eriksonaite, Policy Officer – LTC, DG EMPL, European Commission

Diana Eriksonaitė is a policy officer in the Unit for "Social Protection" in the Directorate General for Employment, Social Affairs and Inclusion of the European Commission, where she is focusing on long-term care and contributing to the European Care Strategy. She has been working in the European Commission since 2002. Her previous work focused on the EU skills policy, employment and social policy in the context of the European semester and the European Social Fund



Dr. Lamura Giovanni, Research Affiliate, Centre for Socio-Economic Research on Ageing

Giovanni Lamura leads the Centre for Socio-Economic Research on Ageing at INRCA (Italy's National Institute of Health and Science on Ageing). He graduated in economics, achieved a PhD in "Life course and social policy" at the University of Bremen (Germany), and was visiting fellow at the University of Hamburg-Eppendorf (Germany) in 2006-2007 and the European Centre for Social Welfare Policy & Research in Vienna (Austria) in 2010-2011. His research interests are focused on international research on family & long-term care; migrant care work; prevention of elder abuse; ICT-based support for informal carers; intergenerational solidarity; interdisciplinary research on ageing.

Tadas Leončikas, Head of Unit, Employment, Eurofound

Tadas Leončikas is Head of the Employment unit at Eurofound. Previously, he was a senior research manager in the Social Policies unit, managing the European Quality of Life Survey (EQLS) and developing Eurofound survey research. Since joining Eurofound in 2010, he has worked on various topics including survey methods, quality of life, trust, social mobility, social inclusion, care services, and housing inadequacies. Tadas's background is in sociology and in his earlier career, he headed up the Institute for Ethnic Studies in Lithuania working on studies related to the situation of ethnic minorities, migrants and other vulnerable groups. As a researcher, he has previously collaborated with the European Union Agency for Fundamental Rights, the United Nations Development Programme and the International Organization for Migration.

Cornelia Moseid, certified EQUASS Auditor and Quality Strategist at Väst-Kom, Sweden

Cornelia has for 9 years been a certified auditor with The European Quality in Social Services (EQUASS), which is an initiative of the European Platform for Rehabilitation (EPR). EQUASS enhances the social sector by engaging social service providers in continuous improvement, learning and development, in order to guarantee service users quality of services throughout Europe. Cornelia also works as a Quality Strategist for an association encompassing 49 municipalities in Sweden, focusing on comprehensive services within the health care and social services. She has also worked with development of Long Term Care in the City of Gothenburg. She holds a Master in Economics and Business Administration, as well as Master level education in Project management and Leadership.

Philippe Seidel, Policy Manager on Social Protection and European Parliament, AGE-Platform Europe

Philippe Seidel is responsible for AGE's policy work in the social protection, including the issues of pensions, old-age income, social inclusion and long-term care and the social protection aspects of health. He also aims to coordinate AGE's work on gender equality. Philippe coordinates AGE's relations with the European Parliament (EP) and the EP Interest Group on Intergenerational Solidarity together with Sarah Loriato. Philippe's academic background is in political science and human rights. His work experience prior to joining AGE were in children's rights.

INSIGHTS FROM THE EXPERTS

What is quality?

There is currently no overall definition of long-term care (LTC) quality at national level in any EU country. And only a few countries have a very broad definition of health and social care quality. Given the lack of definition at national level, it might be utopic to think we can agree on a common definition at EU level. Should we spend time in looking for a definition? What precisely should that definition consist in?

Diana Eriksonaite explained that there is no common definition of long-term care quality but rather a common understanding as reflected in the principles set out in the Council Recommendation on afforadble high quality long-term care that was adopted unanimously by Member States in 2022. The document puts forward a set of quality principles which can be applied to long-term care and long-term care systems.

The principles are based on the voluntary quality framework for social services adopted in 2010. The Recommendation proposes to move away from the understanding of quality in the mere medical clinical sense to a greater focus on quality of life and the ability to live as independently as possible with LTC needs. The principles cover many areas: the need to respect people in need of care and their dignity, fundamental rights, choices, and ability to live independently. They also state that long-term care should be provided without discrimination and that people should be protected from abuse, harassment, neglect and all sorts of violence.

When it comes to practice, an operational definition can be expressed in terms of compliance with safety standards, for example ethical guidelines, procedures for signalling potential cases of abuse and harassment, etc. The Recommendation also includes prevention and the need to restore and prevent deterioration of physical / mental condition as much as possible. Different prevention measures are considered: healthy and active ageing, rehabilitation and support to autonomy. Another very important element is person centeredness, which entails that long term care should be based on and address the changing personal needs of individuals, taking into account gender, linguistic and all other diversities. This could be done by involving people in need of care and their families in assessing their needs and planning their care.

Comprehensiveness and continuity are other principles included on the list, what we sometimes call integration. Care is often fragmented between different ministries and between different providers etc. An integrated approach provides care on the basis of the person-based approach. Services should be organised around the person. They should be uninterrupted and smooth transitions should be ensured between different services. Case and care managers can organise those services, in collaboration with multidisciplinary teams and involving all care providers.

Quality should also and mostly be about outcomes, the main outcome of high quality long-term care being a high quality of life and the ability to live independently. The difficulty is to measure that outcome. The European Commission is therefore engaging with Member States in mutual learning to discuss all principles and share good practices.

The Council Recommendation also includes principles related to transparency. Making information about care services, about the quality assessments of care providers, public and accessible, understandable to people. There is also a whole set of guidance on addressing workforce issues. In the body of Recommendation, there is guidance on working conditions and skills. One key element is ensuring an appropriate worker ratio. In addition, there is guidance on facilities and health and safety rules and on quality assurance, on how it should be

organised and achieved.
On the question of the concrete role that the EU can play in the implementation of frameworks and in improving systems in general, Diana reminded of the limited competences of the EU in the field of LTC. The European Commission can organise mutual exchanges and publish toolkits but the responsibility of implementing is in the hands of Member States. As invited by the Council Recommendation, Member States have to launch a process of consultation with stakeholders to analyse the national context and see what needs to be improved. They have to come up with plans to improve their national policy and inform the European Commission by June next year. In parallel, the European Commission organises exchanges, mutual learning to inspire reforms. In addition, a gentle push comes also via EU funds and the preconditions to obtain them.

Giovanni Lamura welcomed the fact that the European Commission's list starts with the issue of respect. According to him, it is the overarching and holistic attitude and approach required to ensure that, no matter how care is delivered, it takes place in forms that do not violate and rather reinforce human dignity of care recipients. On the background of the empirical evidence from cross-national studies, and given its importance in the eyes of recipients in many countries, the issue of timeliness of care delivery should receive more attention. In many countries, long waiting times for accessing services are a real problem, a growing problem after the pandemic especially. They do not allow people with long term care needs to receive adequate support, even if the technical quality is appropriate. Care sometimes comes either when it is too late or at the wrong time of the day (e.g. night care) or on the wrong day of the week. Services on weekends are very rare. Long-term care is a 24-hour, seven-day-per-week issue for many households. Explicit reference should be made to this aspect. It is not surprising that many households end up hiring privately home based care workers, often with a migrant background, to fill in this gap. This issue has a lot of quality aspects to be considered, starting by exploitation risks on both sides and care drain.

Philippe Seidel described the principles proposed by the European Commission as very good and appropriate. According to him, they take the right angle, the angle of empowering the people who need care to be independent and to improve their quality of life, which should constitute the cornerstone. Indicators in terms of staff ratios or in terms of training provided to care workers etc are process indicators or standards for quality processes. However, what really matters is the outcome (for which processes need to be put in place). The framework is relatively abstract so it allows to accommodate many of these principles, but according to AGE, the devil is really in the implementation. It is easy for a Member State or for a care provider to place emphasis on one aspect and pretend they are implementing the recommendation. Implementation should take on board all the principles at once and avoid cherry picking. Covering the medical needs is not sufficient to reach a high quality of life, which is why the principles proposed by the European Commission are really appropriate. It could have proposed more concrete frameworks such as the competency frameworks that the EU implemented across Member states within national education systems. Those are sufficiently abstract in terms of defining outcomes to inspire action, but they also create frameworks for action at national level. That is something that AGE would like to see now for the care strategy in the follow up.

What does quality depend on?

A key determinant of quality is the availability of qualified workforce, which in turn depends, amongst other things, on ensuring proper working conditions (together with appropriate skills & wages).

According to ***Tadas Leončikas***, quality can only be manageable looking directly atquality can only be ensured by those who deliver the services. However, people working in care experience particularly challenging working conditions. In addition, the sector suffers from pervasive labour shortages. Retaining and attracting workers is a challenge, and workers are ageing, many being close to retirement. In its European Working Conditions Survey, Eurofound has developed indices for job strain (difficulty) considering many elements from wages to support by the managers or colleagues. Healthcare and long-term care are the two sectors that stand out with the highest rates of workers suffering from job strain. It is thus key to support them and provide them with resources. This needs to be addressed if we are to achieve a breakthrough in the quality of care delivered.
Eurofound has also noted that wages in LTC are lower than average in all EU countries. However, as stressed by Tadas, it is not only a matter of remuneration but rather of job quality as a whole. LTC workers encounter many specific challenges such as adverse social behaviour from the patient, their relatives or colleagues that can range from verbal abuse to harassment. There is a general hope that technological progress will help achieve a breakthrough and improve care jobs as well as quality of care . Yet, 20% of workers in LTC say they never use a digital device in their work, even though the survey was carried out in 2021 - during lockdown. In addition, there is a correlation between the use of the digital devices and training: the lower the proportion of workers using digital devices in a sector, the lower number of them received training (Eurofound, *Social services in Europe: Adapting to a new reality*). It is vital to improve access to quality training as well as the general digital skills of of both care workers and care receivers.

Informal carers are also a player in our systems. They fill in the gaps of formal care. Therefore, to ensure quality of overall care, it is vital to also support the informal carers – not least via respite care services.

Claire Champeix stressed that the quality of informal care is important but can of course not be controlled in the same way. A consistent and integrated framework for supporting informal carers is needed. Such a framework should include information, training and recognition and more importantly recognition by formal providers so as to ensure cooperation on an equal footing.
The quality of the care experience is another key aspect to pay attention to. Improper and badly supported informal care responsibility can have devastating consequences for the mental and physical health of both carers and care recipients. That impact should be contained as much as possible with solid prevention, the guarantee of social rights (financial compensation, pension rights, etc.), proper work-life balance, and measures to support carers in retaining employment as much as possible. The case or care manager is also a key player in ensuring that users and their needs remain at the centre of that collaboration between all services and providers.
Claire shared the example of Sweden, where a survey, organised jointly by municipalities and care organisations, is open to informal carers. It allows them to share their opinion on questions such as whether the support received was sufficient and timely. That survey is then the basis of dialogue between local authorities, carer organisations and informal carers. Claire highlighted the need for more transparency as carers often complain about not being aware of the services which are available, neither about their cost or quality. She also stressed the need for training and for the creation of synergies between formal and informal carers' training.

How can quality be measured?

In 2010, the European Commission adopted a Voluntary European Quality Framework for Social Services. ***Diana Eriksonaite*** briefly described the Framework. It is broad and in line with the principles of the Council Recommendation on LTC. It includes the need for integrated and patient-centred care. Yet, the challenge lies in the implementation. The framework does not enter into details such as the time to be

allocated by each provider or the responsibilities to be endorsed. In addition, it applies to all types of social services. Therefore, the framework covers LTC too but it needs to be specified, which is what the Council Recommendation on long-term care has done for long-term care.

Philippe Seidel referred to the WeDo Framework, developed in a 2010 project in which AGE participated. The main objective of that project was to prevent abuse and neglect. That project nurtured the EC framework. Yet, Philip agreed that reworking the framework would be beneficial as the vision of LTC has changed. Earlier, the understanding was rather negative ("do no harm") and has moved to a more positive approach in line with the UN Convention on the Rights of the Persons with Disabilities, which focusses on empowerment and the right of people to maintain their independence and autonomy as long as possible. The WeDo Framework for Quality and Long-term Care Services is not very much adapted to non-residential care. It would be positive to update it to that type of care as it is more empowering and less intrusive. Abuse and neglect prevention should be a focus for all services. Setting up a framework allows not to miss out on these aspects which might be neglected. It enables to establish report mechanisms and redress procedures. If we are to update the Framework, we should ensure that it is flexible enough to accommodate for all settings and types of care. Access to all types of care should be guaranteed. Care at home should be possible but also care in community-based settings and residential care, which is also sometimes wished for, especially in cases where people have strong mobility impairments and have no relatives to look after them. The system should be flexible and answer people's wishes. It is also important to have a preventative approach so as to avoid or delay those impairments as much as possible.

Cornelia Moseid explained how the European Quality in Social Services (EQUASS) framework is based on the European Quality Framework for Social Services from 2010. The EQUASS assurance system directs itself to the individual service providers. It has been divided into 10 principles that, in various parts, encompass all the principles included in the Council Recommendation. For instance, the focus both on empowerment and quality of life and outcomes is very important and it is based on the organisations setting policy and goals for all these aspects. Then planning and executing different activities to achieving these long-term goals step by step. There are specific indicators that need to be met. Other important aspects are the evaluation and ability to learn from its own processes and exchange experience with others as the ultimate goal is a transformation of the sector, moving everyone along. Another priority is to institute a process of continuous improvement, which will be self-sustained in the long term.
EQUASS is a normative system. It states the approaches that need to be fulfilled to get the assurance or excellence certificate. A minimum level is required on all 10 principles. Certification is granted for 3 years and is not granted again if no improvement has been made.
The framework is now being reviewed with the objective of adapting it better to LTC services. It has also been used in many other areas of the social services already and can be applied to non-residential long-term care. It requires services to be person-centred, to involve users in the development of services, creating a partnership to ensure the comprehensiveness of those services.

Overcoming Challenges in Implementation

Recognition of Informal Carers

Cornelia Moseid shared the example of Sweden, where a law requires that people with disabilities are provided with a personal assistant who will help in their everyday lives. Most individuals choose their next of kin to be that assistant. The informal carer then moves into the formal sector. They do not get paid but they integrate a structure and can get training etc.

Claire Champeix commented on the issue of the recognition of pension rights for carers. According to her, it is a very

complex administrative issue which is often limited to granting pension rights in line with some period of care leave and recognising that period as part of the career of someone in a given employment. Yet, it does not cover for example women who have not been working at all for all their lives because they take care of a child born with a disability. Most countries grant no pension to those women. The fact that time spent on informal care is not recognised as an activity, as employment, creates an obstacle to other rights such as formal mobility in the EU because they cannot prove that they are formally employed.

Fragmentation

A key issue when it comes to quality services is fragmentation. LTC provision is often fragmented, which has a negative impact on quality. It is spread across healthcare and social care and other types of support, and its governance is also spread across national, regional or local level. Fixing that fragmentation is probably impossible.

Giovanni Lamura highlighted the different dimensions of the fragmentation of LTC. There is a need to coordinate formal and informal care; health social and in some cases long-term care (which in a growing number of countries is a separate sector); in kind and cash schemes; local, regional and national governance levels; and different service providers both formal and informal. A proper coordination is vital to ensure the care continuum, putting the individuals at the centre and ensuring that they are accompanied along the care path. Concretely, it starts with an initial multidisciplinary evaluation of needs through multi-professional care teams. A national local participatory approach between institutional and civil society actors should also be ensured, just as the proper monitoring of quality along the whole system regarding processing and outcomes.
On the question of people's preferences, Giovanni referred to an Italian study which shows that people living alone in their own homes prefer to remain there until a certain level of disability. When that level increases and no community services are available around them that can allow them to keep an acceptable daily life, they prefer to shift to residential care. Another possible option is to hire a carer to remain at home. Yet that requires financial resources and a house that is big enough.

Claire Champeix mentioned the project InCare, which Eurocarers is piloting in three different local areas. It is about applying a methodology to bring together stakeholders at local level and to initiate an improvement based on a participatory innovative dialogue including user, service provider, and all stakeholders in a given local area. Through a series of workshops, stakeholders are invited to build together a common approach, shared objectives and a common roadmap to achieve those, mapping expectations, possibilities and respective contributions. Such a method allows to improve coordination, communication, and mutual understanding and to implement some improvements in different aspects of care. The method is based on a detailed evaluation of the situation in the country and locally so that the objectives are adapted to a given situation, resources and capacities of stakeholders. Scaling it up is therefore complicated as the whole exercise needs to be redone, but it is possible to build on InCARE experimentation and methodological tools produced. .

AIM will organise another Talk on the aspect of
sustainability on 22 September 2023.
Contact us if you wish to join the discussions.