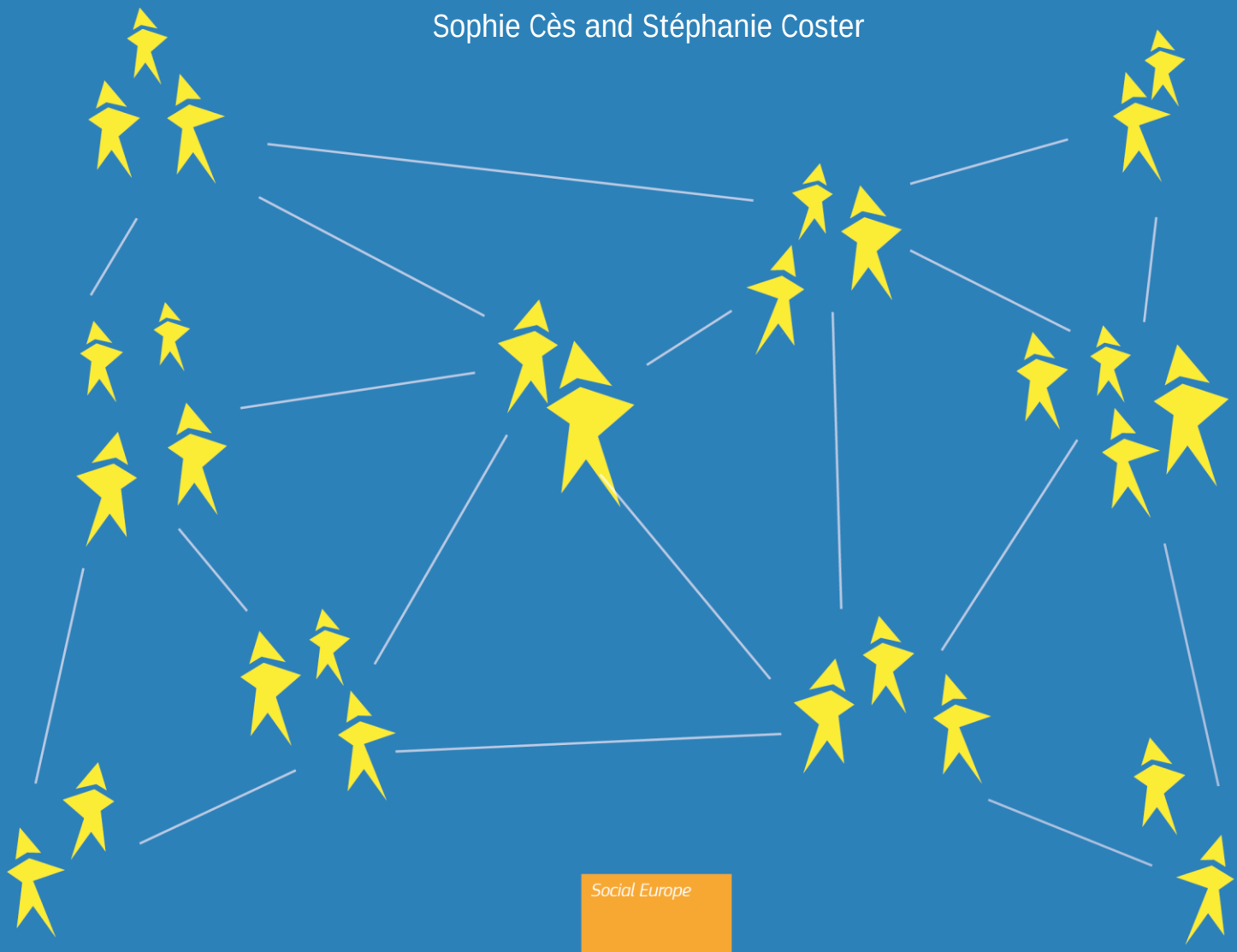
European Commission

EUROPEAN SOCIAL POLICY NETWORK (ESPN)

Mapping long-term care quality assurance practices in the EU

Summary Report

Sophie Cès and Stéphanie Coster



Social Europe

EUROPEAN COMMISSION
Directorate-General for Employment, Social Affairs and Inclusion
Directorate C — Social Affairs
Unit C.2 — Modernisation of social protection systems
Contact: Giulia Pagliani
E-mail: Giulia.PAGLIANI@ec.europa.eu

European Commission
B-1049 Brussels

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Directorate-General for Employment, Social Affairs and Inclusion

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The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.

The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

The ESPN is managed by the Luxembourg Institute of Socio-Economic Research (LISER), APPLICA and the European Social Observatory (OSE).

For more information on the ESPN, see: https://ec.europa.eu/social/main.jsp?catId=1135&langId=en

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Contents

Introduction

In support of the European Commission's ongoing work in the broad area of social protection, the European Social Policy Network (ESPN) was asked to provide the Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL) with a synthetic overview of LTC quality assurance systems and practices in the 28 Member States.

The present Summary Report identifies long-term care (LTC) quality assurance policies and practices in place (or being debated) in Member States and flags the main gaps in policy making, legislation and implementation in this area. The Summary Report's primary purpose is to illustrate the main existing national policies and practices through a limited number of examples. In this respect, countries with similar developments are listed in brackets (e.g. BE, BG, DE). This Summary Report is based on unpublished succinct national contributions prepared by the 28 ESPN Country Teams from the EU Member States. It was written by Sophie Cès and Stéphanie Coster of the ESPN's Network Core Team[1], with helpful comments and suggestions from colleagues in the Network Management Team[2]. Valuable comments and suggestions from European Commission colleagues (DG EMPL) are also gratefully acknowledged. The usual disclaimer applies.

In the next few decades, fast-growing demand for LTC services is expected in most Member States. Firstly, the number of persons in need of assistance in old age is increasing significantly. Secondly, there is a risk that the supply of informal care may decrease relative to the growing demand, as a result of societal evolutions such as increasing workforce mobility, greater labour force participation of women and increases in the retirement age.

Many Member States, faced with this major challenge, are operating a shift in current LTC policies towards home-based support (as opposed to institutional care)[3]. The formal supply of LTC may not adapt rapidly enough to the huge and rapid increase in need[4]; this may in turn lead to a serious shortage of formal support. As a result, relatives may face increasing pressure to commit to supporting family members in need of assistance. Increased hiring of undeclared care workers is also likely to compensate (temporarily or permanently) for the insufficient supply of formal LTC services. For both types of care, quality is difficult to ensure and monitor, since the provision of support does not need to be declared formally and is thus likely to remain hidden from the competent authorities.

In this context, it is vital to ensure affordable quality care in order to prevent major adverse consequences. Indeed, insufficient quality of LTC may put care recipients seriously at risk (e.g. of serious deterioration of their health because of unmet needs), while it may also affect various other aspects of their well-being (e.g. social isolation). For relatives, the support may be provided at a high cost in terms of quality of life, health status (e.g. for older informal carers), working conditions with serious negative repercussions (e.g. strain, possible stigma at work as the employee is perceived as less motivated, the stress of juggling work and care), impact on the working time of formal employment or tensions within the family.

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[1] The two authors are from the European Social Observatory (OSE), Brussels.

[2] The authors wish to thank the ESPN Country Teams for their national contributions, as well as Slavina Spasova and Bart Vanhercke for their useful comments on the draft Summary Report.

[3] Spasova, S., Baeten, R., Coster, S., Ghailani, D., Peña-Casas, R. and Vanhercke, B. (2018). *Challenges in long-term care in Europe. A study of national policies*, European Social Policy Network (ESPN), Brussels: European Commission.

[4] The 2014 joint Social Protection Committee and European Commission report on 'Adequate social protection for long-term care needs in an ageing society' reported that, over the next five decades, the number of Europeans aged over 80 requiring LTC is expected to triple. The dependency ratio (population 65 and over to population 15-64 years) is expected to increase in the EU from 30.5% in 2018 to 49.9% in 2050 (Eurostat, Demographic balances and indicators by type of projection, 2019).

1 Long-term care quality: existing frameworks

1.1 Dedicated LTC quality frameworks

In most EU countries, no quality framework specific to LTC exists. However, a few countries (e.g. DE, LU, PT) have developed a LTC quality framework, i.e. there are dedicated legal regulations on LTC quality which are applicable to all types of facilities and providers. Several bodies may be responsible for the quality monitoring of LTC facilities, using a wide range of evaluation criteria that pertain to the structure, processes and outcomes of LTC services.

In Germany, besides health care quality requirements, a separate quality framework applies to all LTC services (codified in the Long-Term Care Insurance Act[5]). This framework is mainly a broad range of requirements applicable to any residential or community setting, emphasising structure (e.g. qualifications of the workforce), process quality (establishing an internal quality management system, guidelines on processes to prevent particular problems such as bedsores), as well as outcome quality. It also defines the responsibilities of the different stakeholders: the long-term care insurance (LTCI) funds, the *Länder (*responsible for ensuring the accessibility of care facilities and the adequate LTC infrastructure*),* the municipalities and LTC providers (including informal carers). Insurance funds (statutory or private) are mandated to audit quality in LTC facilities (mainly on processes and outcomes) at least once a year. Results are publicly available.

In Luxembourg, the LTC quality framework[6] is legally binding and applies to all care providers (including informal care[7]). The main body responsible for quality control is the independent State Office for Assessment and Monitoring of the long-term care insurance (*Administration d'évaluation et de contrôle,* AEC)[8]. Minimum standards to be met by staff are legally defined and monitored to ensure quality of care. For process quality, the quality of the documentation is verified, notably information on the dependent person cared for, the care provided, the health situation, a typical week of care and a transfer form providing any information about transfers to another institution. Besides, quality indicators are also used to measure processes (e.g. pain evaluation, regular weight measurement or existence of formal complaints procedures) and negative outcomes (e.g. adverse health events or incidents such falls).

In Portugal, LTC services are covered by the National Network for Continued and Integrated Care (RNCCI). The LTC quality framework, drawn up and legally formalised (with recent developments for the 2016-2019 period), is mandatory for any LTC services — convalescent care, post-acute rehabilitation services, medium- and long-term care, homecare and palliative care — without any distinction between sectors (health or social care) or care settings (institutional versus community care) or nature (public, for-profit private). The 2016-2019 development plan for the national network states that a set of various quality objectives have to be established, such as the development of quality criteria and procedural norms to prevent critical events. The network also has to establish a set of mandatory display indicators on organisational processes, the use of drugs, the incidence of critical events, the health and functional status etc. Quality is mainly ensured by the setting of minimum quality standards applicable to providers in the national network (covering the structure and quality of care) and the use of indicators on processes and outcomes. Quality is also monitored through client complaints, surveys (for users, family members, informal carers and professionals), internal audits and inspections. Several reports are issued by the Ministry of Health (for some

[5] Pflegeversicherungsgesetz resp. in Social Code Book XI (Sozialgesetzbuch XI – SGB XI).

[6] To implement the law (Law of 29 August 2017) and the quality system described, the government issued a range of regulations on qualifications and staffing standards, quality indicators, etc. (Règlements grand-ducaux 2017).

[7] More information is provided in Section 4.

[8] According to the new article 384bis of the Social Security Code.

particular indicators regarding access to healthcare in national health service units and those operated by contracted private entities), alongside monitoring reports from RNCCI. The LTC quality framework is regularly assessed by the Health Regulatory Authority, with regard to access, quality and competition in long-term and palliative care.

1.2 Distinct general quality frameworks for the healthcare and social care sectors

At national level, Member States often establish a general quality assurance approach[9] in the areas of healthcare and social care (e.g. CZ, ES, FI, FR, HR, HU, IE, LU, LV, MT, PL) for a broad range of services (specific or not to LTC services), sometimes with additional local regulations (e.g. ES[10], EE, LT). In other countries, LTC quality assurance is mainly regulated at local, regional or municipality level (e.g. AT, BE, DK, SE). ESPN experts raise the issue of geographical disparities in LTC supply, notably when both LTC provisions and quality assurance are decentralised (e.g. EE, SE, DK).

Quality in LTC care facilities is most often regulated separately for the social care and healthcare sectors: this is, for example, the case in BE, CZ, EE, FR, HU, LT, PL, SI, SE and SK. In these Member States, separate quality frameworks are developed and applicable to these sectors, with separate regulations, including quality principles, guidelines, requirements and standards, for social services and healthcare. For instance, in Poland, distinct frameworks are in place to ensure the quality of LTC services. In the healthcare sector, the quality framework is set out in two regulations: the regulation on medical activities (2011) and the regulation on state-funded healthcare services (2004). These regulations set general rules for medical facilities, standards with regard to equipment and monitoring in the healthcare system (in both residential and home-based settings). The social assistance act of 2004 (with amendments) and other regulations governing the social sector (e.g. standards of care in residential settings) are also the legal basis for monitoring LTC quality.

2 Long-term care quality: definitions

There is no overall official definition of LTC quality at national level in any EU country. In spite of the absence of a specific definition of LTC quality in most Member States, the overall approach to LTC quality can be described using the existing broad quality definitions applicable to health and social care services (including LTC) or the elements provided in regulations or official recommendations. In Sweden, the legislation[11] regulating health and social care services underlines the importance of the quality of services (including LTC services), but no precise definition of this notion is provided: the regulations mention that health and medical care/social services shall be of good quality and that quality shall be systematically and continuously developed and ensured.

2.1 Definitions of quality in the health and social care sectors

Only a few countries have a broad official definition of quality in the healthcare sector (e.g. BE, SI) or social care sector (e.g. BG). In Finland, a broad definition of quality of services exists and is applicable to both the healthcare and social care sectors, but this definition does not refer specifically to the long-term care sector. According to the Finnish Institute of Health and Welfare: '*people receive services according to their needs at the correct time and from the correct service provider*'. In other countries, in the absence of an official definition of quality, some of the main principles of quality

[9] This may include various aspects of LTC quality: predetermined requirements on structure, processes, outcome monitoring, *ex-post* evaluations (audit, inspections, regular reporting) and consultations between stakeholders.

[10] In Spain, there is a general national framework 'Law on Dependency' (1 January 2007) guiding local regulations and Autonomous Community plans for social care services.

[11] The Social Services Act (1980:620) (SoL), the Act Concerning Support and Services for Persons with Certain Functional Impairments (1993:387) (LSS) and the Health and Medical Services Act (SFS 1982:763) (HSL).

can only be derived from legislation or other sources, such as the official main stated objectives or the indicators used to assess quality (e.g. CZ, FR, LT, PL). In Poland, experts derived a common definition applicable to both healthcare and social care sectors from legal regulations: *'increasing quality of life for dependent people and their families, as well as increasing access to care services of different types for the eligible population, is stated as a foundation for providing nursing and care services in healthcare, social sector facilities and home services.'*

In the healthcare sector, a few ESPN experts underlined a specific official definition of quality. In Belgium, there is an overall definition, provided by the Health Care Knowledge Centre (KCE)[12]: *'the degree to which healthcare systems, services and supplies for individuals and populations increase the likelihood of positive health outcomes and are consistent with current professional knowledge'*. By contrast, in Slovenia, the definition of quality of health care is enshrined in law[13]: *'those services which consistently achieve outcomes of care that are comparable to the appropriate standards or to best practice, while at the same time taking into account the basic principles of quality, such as efficiency, safety, timeliness, continuity, effectiveness, equity and patient-centeredness.'*

In the social care sector, in many countries, there is no national statutory definition of quality (e.g. BE, CZ, EE, IT). In this sector, the different levels of governance (i.e. national alongside sub-national, or sub-national only) are mentioned as a source of significant geographical disparities (e.g. DK, EE, IT). In Denmark, local authorities are responsible for organising the provision of LTC services, defining quality standards and monitoring quality; this results in significant variation of quality in practices. In Estonia since regulations are independently set at sub-national level by local authorities, there are no common minimum criteria established for social care providers. In the Czech Republic, there is no explicit official definition of quality enshrined in law. However, ESPN experts derived a definition from the legislation in place in the social care sector: quality service can be defined as *care* that allows the user to live a normal life (inclusiveness of services), responds to his/her needs (services are tailor-made) and protects his/her rights and interests (security of services). In Bulgaria, the quality of social services is defined[14] by recent legislation as *'a set of characteristics of social services that meet the needs of those who use them and lead to prevention and/or the overcoming of social exclusion, realization of rights and improvement of quality of life.'*

2.2 Defining LTC quality from the perspective of different actors

Defining quality in LTC may be challenging. While countries may develop *ex-ante* regulations and monitoring systems in order to enforce quality assurance criteria, some countries also create favourable conditions to push forward quality improvement processes, in particular to foster collective consideration of the components of quality. In Bulgaria, providers have an opportunity to develop their own practices, based on discussion between professionals and clients. An interesting initiative also exists in Finland where clients (so-called 'experts by experience') participate collectively in the reflection on how to define quality by encouraging client participation in improving the quality of municipal services. In Luxembourg, a consulting commission ('*Advisory Commission*') made up of representatives of the government, LTC clients, providers and the National Health Fund is responsible for providing opinions on various aspects of implementation of LTC services.

[12] Devos C, Cordon A, Lefèvre M, Obyn C, Renard F, Bouckaert N, Gerkens S, Maertens de Noordhout C, Devleesschauwer B, Haelterman M, Léonard C, Meeus P. Performance du système de santé belge – Rapport 2019 – Synthèse. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE). 2019.

[13] Patients' Rights Act, 2008.

[14] The Social Services Act regulates the provision, use, planning, funding, quality, control and monitoring of social services in Bulgaria. Adopted at the beginning of March 2019, to come into force on 1 January 2020, it introduces an entirely new philosophy and changes the legal framework for planning, providing, quality and financing and monitoring of social services.

From the description of the main quality principles applicable to LTC, different perspectives can be identified for the various stakeholders involved: a) clients; b) informal carers; c) care professionals; and d) stakeholders funding LTC services

a) The perspective that is most frequently taken into consideration is that of the *client* (e.g. BG, FI, IE, SK, FR, UK). Several major principles are mentioned:
   - The respect of fundamental human rights (e.g. BG, EE, FI, FR, IE, BE, SK, SE, MT) to ensure equality of treatment (e.g. FI, SE), to avoid discrimination (e.g. BE, FI) and respect of dignity (e.g. FR, MT, SE, UK[15]).
   - Care recipient safety is also often considered as a major principle of LTC quality (e.g. BE, CZ, FI, FR, IE, IT, LT, MT, NL, SE, SI, UK).
   - 'Person-centeredness' (e.g. explicitly mentioned in NL, SI, UK) is reflected in specific aspects of care processes, such as the participation of care recipients in the elaboration of their care plan (e.g. BE, FR, FI). Sometimes there is an explicit reference to other important principles, such as autonomy in Portugal and freedom of choice in Finland as well as in England. In Finland, clients have to define in advance what they value and expect in their everyday life in order to then propose provision of services suited to their own anticipated decisions (e.g. in the case of neurodegenerative disease).
   - Achievement of client outcomes, which may be subjective — for instance, well-being (e.g. IE, DK), quality of life (e.g. PL), a sense of being included (DK) — or objective, for instance health status (e.g. IE).

b) The *informal carer's* point of view on the perceived quality of LTC services may differ from that of the care recipient. Additionally, the characteristics of the LTC services are also likely to have an impact on how the informal carer experiences the situation (as, for example, acknowledged in Portugal, with considerations[16] relating to the quality of life of relatives/informal carers).

c) The perspective of care professionals may concern not only the quality of care as perceived by professionals, such as criteria on evidence-based practices or application of current knowledge (e.g. SE). It may also reflect the experiences of individual care providers. Overall, the care professionals' assessment of service quality is rarely mentioned. However, good working conditions, as perceived by care providers, are widely agreed to be necessary to ensure LTC quality for the client/relatives (to prevent, for instance, a high turnover rate, mistreatment or inadequate or insufficient care provision).

d) Some countries also include the perspective of stakeholders funding LTC services, by referring to cost-related considerations (e.g. LV, FI, SI). In Finland, for example, the ESPN expert reports that quality also means acting in accordance with the expectations of good care while working within the framework of the available financial resources. For instance, in Slovenia: 'efficiency' is one of the basic principles of quality.

[15] In the UK, there are different approaches in the four countries. This dimension is listed by the Care Quality Commission (CQC) in England among other requirements that clients have the right to expect.

[16] A quality policy includes a set of key-processes (*Entidade Reguladora da Saúde*, 2015), notably on the provision of LTC by units and teams which take account of the impact on the quality of life of users and their relatives/informal carers.

3 Certification, accreditation and economic incentives

3.1 Registration process and accreditation scheme

Most EU Member States show willingness to guarantee high quality in the LTC sector and ensure that care provision meets the needs of LTC users, albeit with varying degrees of implementation. LTC quality is mainly ensured through the setting of pre-determined standards and requirements. The minimum requirements usually involve *structure-oriented standards*, covering standards for infrastructure and building, safety, hygiene, nutrition, and workforce (ratio of staff and qualifications of staff), which are usually compulsory. Additional requirements may also include p*rocess-oriented standards*[17] or *outcome-related aspects*[18], although the latter are less common.

The requirements vary substantially according to the type of support (home-based or residential) and some sectoral specificities exist (healthcare sector and social care sector). Many Member States traditionally have a strong set of regulations and standards applicable to residential care. For home care services, the requirements in place vary widely across Member States. While some countries have no or limited standards in place (e.g. CY, IE, PL), others have developed requirements for home care services (e.g. AT, BE, CZ, DK). Member States have developed a set of pre-determined standards, using a registration[19] process (e.g. DK, LV, UK) or accreditation schemes (e.g. BE, ES, IT, LU, LT, MT, NL, RO)[20]. In England, as part of the registration process of long-term care providers, applicants must write a statement of purpose, and must prove that the director and the service manager are able to work with vulnerable persons and that they have sufficient financial resources. The Care Quality Commission, in charge of registering LTC providers, carries out comprehensive inspections of newly registered LTC services. Various dimensions are covered during this assessment: safety, effectiveness, caring, responsiveness and leadership. In Luxembourg, LTC providers in community care and residential care must follow an accreditation process in order to obtain the authorisation to practise in the sector. The requirements for accreditation are specified in the legislation and relate to staff qualifications, infrastructure, documentation requirements, opening days and hours, the existence of a provider's action concept (*projet d'établissement*) etc. In Lithuania, procedures differ according to the sector. Providers of social care services (residential care homes, nursing homes and some day-care centres) — be they public, private or NGOs — are required to obtain a license. The standards include norms for accommodation, nutrition, residents' rights, wellbeing, staff, care plan etc. The quality of social services is monitored through compliance assessments conducted (at least) every five years. LTC providers in the healthcare sector must be accredited by the State Healthcare Accreditation Agency and obtain a license for practising. The license must be renewed every five years.

The required standards underlying the registration or accreditation processes are mostly structure-oriented (e.g. workforce standards) and occasionally relate to processes or

[17] Some examples of process-related standards: quality of coordination between professionals and services, compliance with health and safety standards, rules to ensure the respect of patients' rights, care protocols for different types of LTC needs, risk management procedures.

[18] Outcome-related aspects are for instance the number of falls, the frequency of infections, client satisfaction surveys.

[19] Many Member States require providers to comply with quality standards, using a registration or authorisation process, licenses, certification or accreditation schemes. Although the procedures and standards underlying these processes tend to have similarities, the terms used are not unified. For the sake of clarity, we use the terms 'registration' and 'accreditation'. In some countries, the requirements regarding re-evaluation are less clear.

[20] Usually, the registration process refers to official recognition (without further or with limited requirements and no regular or limited evaluation), allowing providers to operate in the LTC sector; accreditation schemes provide evidence that residential care facilities or home care providers conform to required operating standards. An external body usually performs a quality evaluation. The result of the quality evaluation often determines whether there will be public funding or access to the sector.

outcomes. Significant differences exist with regard to process-oriented standards. While in some Member States, process requirements remain limited, other countries (e.g. BE, FI, RO) have developed more person-centred processes to improve quality. In Belgium, nursing homes have to design a 'Life project' ('Projet de vie') in order to obtain accreditation. The 'Life project' takes into account the aspirations of residents and sets out the objectives pursued by the institution to promote their well-being and development.

Quality control measures are performed over differing time periods in order to ensure that quality criteria and standards are being met. These quality control measures may involve two types of evaluation with different objectives: self-assessment by care providers in order to promote internal quality improvement (e.g. BG, CZ, FI, HR, LV); or external assessments by independent bodies to evaluate conformity with established quality standards, usually involving planned or unannounced on-site inspections. The content of the evaluation varies significantly: recording of indicators (on processes or outcomes), client complaints, compliance with structure and staff requirements and completeness of patient records. Some ESPN experts have underlined the lack of resources for carrying out inspections (e.g. LV), a lack of qualified inspectors, or insufficient harmonisation and transparency in the inspection process (e.g. CZ).

In the event of non-compliance, sanctions are imposed. The sanctions may vary according to the degree of non-compliance; and may go as far as withdrawal of accreditation, funding phase-out or fines. Some ESPN national experts mentioned the possibility for users and their relatives to express their dissatisfaction and to appeal to the ombudsman's office (e.g. CZ, FI, IE, LV). Quality inspections and sanctions appear to be a first step in ensuring quality. Nevertheless, some ESPN national experts express concerns regarding the poor quality of certain residential care facilities which fell through the cracks of the registration process (e.g. CZ), or the absence of mechanisms to compel providers to eventually comply with quality standards (e.g. LT).

Making information available to users is sometimes also a means to foster quality improvement in the LTC sector. Some Member States make inspection reports publicly available, as well as information on the standards of care provided by service providers (e.g. DE, DK, IE), with the objective to ensure transparency and provide information to users and their relatives.

With regard to the home care sector, some national reports still mention frequent use of undeclared workers (e.g. EL, IT). In these cases, quality is only monitored by care recipients and/or relatives.

Some Member States are experiencing changes within the LTC sector with regard to quality (e.g. BG, SK). In Slovakia, there are currently new developments with regard to quality assessment, with the national project 'Quality of Social Services'. Regular mandatory assessments started in September 2019 and will have a considerable impact on the sector. Only those providers who meet the minimum level of quality (60% of total score) will remain in the register of social services providers. In Bulgaria, while providers previously only had to register, from 2020 onwards private providers will have to obtain a licence to operate in the social care sector, and municipal services will have to meet the same quality standards. The Agency for the Quality of Social Services, answerable to the Ministry of Labour and Social Policy, will be in charge of ensuring that care respects the rights of users of social services, monitoring national performance and delivering licenses.

3.2 Voluntary initiatives: quality labels and ISO norms

Alongside the mandatory requirements, LTC providers can, on a voluntary basis, obtain certification such as the International Organization for Standardization (ISO) standards (e.g. SK, PL) or European Quality in Social Services (EQUASS), quality labels (e.g. FR, NL) or voluntary accreditations (e.g. BE, UK, PT). In France, various quality labelling procedures exist: '*service commitment*' and '*homecare services*'

for social services; or the *'healthcare user rights'* label for the health care sector. In Belgium, more precisely in Flanders, an integrated quality system for LTC residential care coexists alongside the formal accreditation process –*'PREZO Woonzorg' (PREstaties in de ZOrg in Dutch*). This voluntary quality system covers various topics such as medication, prevention of falls, privacy and sexuality, but also includes corporate social responsibility, client and employee participation, continuity of care, … (more than 140 residential care facilities have already started to use this system). In Lithuania, some social services facilities may choose to commit to the EQUASS requirements. The EQUASS certification process is an initiative of the European Platform for Rehabilitation aiming to develop continuous learning and enhance quality in the social services sector. By 2022, Lithuania expects that 120 facilities will obtain EQUASS certification.

3.3 Economic incentives

In most countries, there are no positive economic incentives implemented to foster quality in the LTC sector. In Portugal, performance incentives are being considered, to reward units and professionals based on the evaluation of results: this is a new responsibility of the National Commission for the Coordination of the national network for continued and integrated care, RNCCI. Some countries (e.g. BE, FI, HU) apply negative incentives – fines in the case of non-compliance with quality standards.

It is worth underlining that in some countries, there are public subsidies to implement quality improvement programmes (e.g. ES, NL). In the Netherlands, although the system does not offer any conditional payments or rewards, the government provides subsidies (temporarily or on an ongoing basis) for quality improvement programmes/initiatives (e.g. the programme supporting the transformation of youth care, technological innovations, the Foundation for Quality Impulse LTC). In Spain, regional and local authorities occasionally support initiatives by private providers to evaluate and improve services. However, the level of resources dedicated to promoting evaluation remains unknown.

4 Quality of informal care

Although most of the care given to persons in need of assistance living in the community is provided by relatives, family or friends, quality of informal care is not defined in any EU country. Informal carers are often not formally acknowledged, which makes it difficult to identify them. Granting legal entitlements to informal carers or care recipients makes it possible to clearly identify such carers and allows the implementation of a systematic approach to help them to fulfil their role or to replace them if their situation deteriorates. Informal carers are likely to remain unknown to the LTC services, especially when the care recipients are receiving no formal support. This problem is particularly acute for disabled elderly persons who gradually lose their functional capacity to perform daily activities. Spouses help them in their daily life without any self-identification as informal carers, since their commitment to helping is perceived as part of their spouse's role. Another invisible category is that of young carers providing care to a parent. They are the most likely to be unaware of their role as informal carers and thus will not seek formal help.

4.1 Assessment of the situation of informal carers

There are a few countries that legally entitle informal carers to a systematic assessment of their situation (e.g. AT, BE, LU, UK, IT). This evaluation is often linked to the statutory support measures for informal carers (in-cash benefits or care leave) or care recipients (in-cash benefits), sometimes with the explicit objective of monitoring the ability of the informal carers to fulfil their role. The situation of informal carers is assessed in various ways. The objectives of such assessments vary significantly between countries.

In some countries, informal carers are entitled to in-cash benefits (e.g. BE, FR, HU, IE, SE), but when evaluating the entitlement of informal carers, such as parents of disabled children, no formal assessment is carried out of the capacity of these carers to fulfil their role. In Belgium, assessment of the capacity of informal carers is only mandatory in the case of working carers who apply for care leave[21]. In this case, the assessment is limited to their health status (the sickness fund's medical officer checks their physical capacity). Therefore, a limited proportion of working carers will benefit from this systematic assessment required by law.

Another way to systematically assess the situation of informal carers is through the in-cash benefit scheme for persons in need of assistance (e.g. AT, DE, LU). In Austria, the assessment of informal care quality is included in the 'home visit programme' carried out to assess the quality of care[22]. However, this programme is limited to only one visit to first-time recipients (the person in need of assistance) of LTC in-cash benefits (no follow-up visits or counselling are offered). In Luxembourg, dependent persons have to notify an independent agency (the State Office for Assessment and Monitoring of long-term care insurance) of the existence of an informal carer. The ability of informal carers, and particularly their availability to help, is assessed by the agency, considering major determinants of their situation (e.g. working activity, geographic location, physical skills). The allocation of the in-cash benefit is dependent on the capacity of the informal carer to provide adequate assistance (the allowance is granted by the dependency insurance to the person in need of assistance). It is calculated on the basis of the support activities provided by the informal carer (the time spent on caring). If the informal carer is assessed as being unable to provide adequate help, the person in need of assistance has to call on specialised services to provide care activities. In Germany, the regular use of counselling services is mandatory for recipients of the LTC allowance (quarterly or every six months according to the level of need of care). This service evaluates the overall situation in order to ensure the safety of care recipients and quality of care (including informal care).

Independently from any benefit, the formal assessments in the UK and Italy do not examine the capacity of the informal carer but evaluate their needs: in the UK, the focus is on the carer's needs, as well as on those of people needing care; assessments look at the impact of the caring role on all aspects of carers' life and the support they and their families need. However, this assessment is not performed on a regular basis: in 2019, only 27% of carers declared that they had been assessed in the last twelve months (a survey of about 8,000 informal carers). In Italy, the legislation requires an assessment of the informal carer's needs when drawing up the care plan. However, in practice, due to the limited availability of professionals (case managers and social workers), there is no guarantee of a systematic evaluation of the situation of informal carers.

4.2 The legal entitlement of informal carers to formal support[23]

Many countries do not legally entitle informal carers to formal support (e.g. AT, IE, LT, LV, MT, CZ, SI). In Ireland, informal carers are entitled to cash benefits, but support services for informal carers are not provided on a statutory basis. As a result, geographical disparities exist in the provision of formal support to informal carers.

[21] A new law, planned for October 2019, establishes entitlement to care leave for working carers subject to certain conditions.

[22] These visits are only for households with persons (care recipients) who have recently been granted LTC cash benefits. In 2016, around 19,515 such home visits took place – covering approximately 4% of the total number of LTC cash benefit recipients (Fink 2018, ESPN thematic report on challenges in long-term care. Austria).

[23] Formal support to informal carers refers to a wide range of services such as counselling services, training, psychological support, respite care… While some services mainly address the needs of informal carers (e.g. training), others target both the care recipients and their carers (e.g. respite care).

The entitlement of informal carers to formal support is legally recognised in a few countries, although the type of support varies significantly (e.g. FR, FI, SE, PT, NL, IT). In Portugal, the recent law[24] sets out a comprehensive list of rights of informal carers (e.g. to a carer's allowance) and support measures, such as training actions to develop their caring skills, counselling, participation in collective groups of carers, psychosocial support, individual follow-up, involvement in drawing up the care plan, respite periods. In Sweden, municipal social services have to recognise informal carers and provide them with formal support[25]. However, the content of this mandatory support is not defined. In the Netherlands, municipalities[26] are also responsible for granting financial advantages (e.g. parking permits) or providing specific formal support such as respite care, alongside the organisation (internal or external) of support activities (e.g. training and information projects developed by local interest groups).

Some countries entitle informal carers to respite care (e.g. FI, FR). In Finland, informal carers are also entitled to support services[27] such as training or respite care, but not all municipalities offer such support as it is not part of their mandatory responsibilities. In France, respite periods are granted[28] to carers of elderly persons receiving in-cash benefits.

4.3 The lack of availability of formal support for informal carers

Overall, the supply of formal support for informal carers is not sufficiently developed in many countries (e.g. BE, DK, ES, HU, IE, IT, LT, LV, RO). In several countries, experts emphasise that services to support informal carers are structurally underdeveloped (e.g. LT, LV, RO, SI). In practice, when the formal support is locally organised, some geographical disparities in supply are observed (e.g. FI, NL). In Denmark[29], the supply of formal support such as respite care services, organised at local level (municipalities), is offered on a discretionary basis.

Alongside formal support provided by public authorities (often locally at municipal level) to informal carers, there are also support services provided by non-profit associations. While these initiatives may cover a wide range of support services for informal carers (e.g. FR, DK), they may also be relatively limited (e.g. to specific diseases or geographic areas).

5 Data collection and indicators to monitor LTC quality

Various tools are used to monitor quality over time; these are not usually specific to LTC services (except in countries with a specific LTC quality framework). A few Member States have implemented mandatory, systematic routine data collection of incidents: for instance, falls (e.g. BE, LU), pressure ulcers (e.g. BE, LU). In Belgium, in the healthcare sector, there are safety-related indicators for residential facilities. Most of them are generic to all residential healthcare facilities (e.g. involuntary weight loss, use of restraints or isolation measures, number of problems with medicine). Additionally, there is a specific indicator for nursing homes: prevalence of Methicillin-resistant *Staphylococcus Aureus* carriage.

Luxembourg has also developed quality indicators on processes such as, for example, the number of dependent persons cared for by the care provider for whom a pain assessment was carried out, and

[24] Law 100/2019, of 6 September, approved the status of informal carer.

[25] According to the Social Services Act (SoL).

[26] According to the Social Support Act and Child and Youth Act.

[27] According to the Informal Care Support Act and the Social Welfare Act.

[28] A right to respite subsidies of to up to €500 per year to finance temporary accommodation, day care centres or to pay an intermediate home carer.

[29] According to the Law on Social Services, para. 84.

how the pain levels has evolved; regular (at least monthly) weight measurements (and how this has evolved over time) for the dependent persons cared for by the care provider.

Quality monitoring also often uses client surveys (e.g. BE, EE, NL, UK/Scotland, SE, LT), for instance on quality of life (e.g. BE), or client satisfaction (e.g. BE, SE), examining issues such as privacy[30] or autonomy[31] (e.g. BE). Some experts raise the issue of the low response rates to client satisfaction surveys. They also question the added value of surveys for quality monitoring, as the interpretation of results is rather limited[32].

Client complaints are also a means to monitor quality (e.g. FI, HR, LT, LV, PT). The extent to which negative feedback from clients is used to improve quality in LTC facilities at meso or macro level may vary between countries.

Another tool for monitoring the quality of LTC, recently developed and used increasingly, is that of on-line quality reviews by care users (e.g. NL).

6 Conclusion

The degree of development of quality assurance mechanisms in the LTC sector varies significantly between countries. Quality assurance measures most often involve the setting of minimum requirements for inputs, with explicit standards relating to various characteristics. The required standards are mostly structure-oriented (e.g. workforce standards) and occasionally relate to processes or outcomes. However, there are significant differences in the degree of enforcement and monitoring which takes place. Many Member States traditionally have a strong set of regulations and standards applicable to residential care. For home care services, the requirements in place vary across Member States. In most countries, no positive economic incentives are offered to foster quality in the LTC sector.

There are various issues/challenges linked to the implementation of effective quality assurance mechanisms. Local governance is also often mentioned as a significant barrier to ensuring a sufficient level of quality in LTC services. Equality of treatment over the whole national territory may not always be guaranteed when local authorities (often municipalities in the case of social care services) are responsible for the provision of services. Additionally, geographical disparities in the supply of LTC services are likely to be greater when quality standards are locally determined.

In many countries, LTC services are horizontally segmented between the health and the social care sectors (organisationally and professionally). Besides, the quality approach developed for LTC is often determined separately within the healthcare and social care sectors, and there are no specific quality criteria for LTC services; this may result in greater fragmentation in LTC delivery.

For home-based support, the employment of undeclared home care workers (e.g. IT, EL) is also an important concern with regard to LTC quality, since no monitoring is possible apart from that exercised by the care recipient/family. Both care recipients and care workers are thus at risk of negative consequences.

When dependent persons living at home have significant and/or increasing needs for assistance, informal care (sometimes combined with the use of home care services) may not be of sufficient quality from the perspective of both the care recipient (whose needs may not be fully met) and the informal carer. Many countries do not legally entitle informal carers to a systematic assessment of their situation or to formal support. Support services for informal carers are also often not sufficiently

[30] Percentage of residents who feel that their privacy is safeguarded.

[31] Percentage of residents or representatives who feel that they have a say in the care and guidance they receive.

[32] The validity of client satisfaction surveys may also be questioned (e.g. clients may give only good marks or not file a complaint because they fear losing access to services).

developed or are not on offer to help them to adequately fulfil their role while ensuring their well-being. Due to the above-mentioned problems in ensuring the quality of LTC, promoting home-based support is a major challenge in many Member States.

Defining quality in long-term care is inevitably subjective, since it varies according to the perspective of the different stakeholders (care recipients, informal carers, care providers or funding stakeholders). In some countries, strategies are implemented which encourage user participation in the definition and evaluation of quality, or advisory bodies have been set up which include representatives of users, providers and funding bodies.

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