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Mutual learning workshop on adequate social protection in long-term care

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Summary report

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Unit D2 — Social Protection

Contact: Susanna Ulinski

E-mail: empl-d2-unit@ec.europa.eu

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1 Introduction

This report summarises findings from the 'Mutual learning workshop on adequate social protection in long-term care', which was held from 23 to 24 of November 2023 in Brussels. The event followed a meeting of the national long-term care coordinators for the implementation of the Council Recommendation on access to affordable high-quality long-term care on 23 November.

The aim of the workshop was to facilitate mutual learning on the topic of adequate social protection in long-term care to support Member States in implementing the Council Recommendation on access to affordable high-quality long-term care (hereafter the Council Recommendation). It focused on three different aspects of social protection: comprehensiveness, timeliness and affordability of long-term care. Selected Member States presented examples of improvements in long-term care systems regarding these aspects in plenary sessions. Through facilitated small group discussions and a world-café session, participants from all Member States could share their national successful practices, challenges and plans for ensuring adequate social protection.

The event brought together representatives from 21 Member States, including national long-term care coordinators and thematic experts from the respective ministries, as well as relevant stakeholder organisations (International Social Security Association, Organisation for Economic Co-operation and Development, European Social Network, Federation of European Social Employers, European Association of Paritarian Institutions, International Association of Mutual Benefit Societies, Age Platform).

2 Policy context

The EU population is ageing, and with this comes an increased demand for long-term care. To meet this demand, Member States have to reform and invest in long-term care with a focus on ensuring adequate coverage and meeting the preferences of older people towards more independent living. As highlighted by the Council Recommendation, key areas for ensuring adequate social protection are comprehensiveness, timeliness and affordability of long-term care. The thematic discussion paper of this event further elaborates on these three areas:

- Comprehensiveness relates to both the needs assessment process for long-term care and the provision of services. To achieve comprehensiveness, all relevant needs of a care recipient have to be taken into account. A range of services should be available and new types of services might need to be developed.
- Similarly, timeliness is necessary both in terms of a swift needs assessment and regarding the provision of services. Interventions to improve timeliness also focus on prevention and thus take place before (additional) care needs have developed.
- Affordability of long-term care requires public investment. The lack of financial resources is the main reason preventing people in need to use long-term care services. This is further underlined by the fact that without public support, even individuals with higher incomes would be faced with unaffordable long-term care in most countries.

Beyond affordability, availability of long-term care is still an issue, particularly regarding home and community-based care, and in rural and depopulating areas. Availability and an adequate workforce are further dimensions of high-quality long-term care which were not the focus of this mutual learning event.

Member States are invited through the Council Recommendation to make further progress towards these policy objectives. Some Member States can benefit from developing a

national framework for data collection which should include information on gaps in long-term care provision, gathering lessons learned on long-term care practices and policies, and taking measures to raise awareness and encourage the take-up of long-term care services.

EU funding and technical assistance support Member States in implementing the Council Recommendation by planning and implementing reforms. In particular, implementation measures can use the following sources of funding and technical support: European Regional Development Fund, European Social Fund Plus (including its Employment and Social Innovation strand), Just Transition Fund, Horizon Europe, EU4Health Programme, Digital Europe Programme, Technical Support Instrument and the Recovery and Resilience Facility. One year after the presentation of the European Care Strategy, 18 Member States have been tapping into the Recovery and Resilience Fund in reforming and investing in long-term care.[1]

3 Comprehensiveness

The Council Recommendation calls on Member States to improve the adequacy of their social protection for long-term care so that it is timely, comprehensive, and affordable. Comprehensiveness is described as "covering all long-term care needs, arising from mental and/or physical decline in functional ability, assessed on the basis of clear and objective eligibility criteria and in coordination with other support and welfare services". This requires that long-term care is designed and delivered in an integrated manner with healthcare and social services, including effective coordination across governance levels, but also that the needs assessment process takes into account the diverse needs of a person requiring long-term care. Integrated care is a way to address all needs of a service user in a comprehensive way.

Member States are faced with a number of challenges in designing and developing long-term care systems in a way that ensures care is provided in a comprehensive manner. Most challenging is the persistent fragmentation across different levels of the care system:

- Firstly, as the provision of long-term care services is often carried out at the local or regional level and often by individual providers, fragmentation across different institutions and governance levels challenges the provision of care in a comprehensive and integrated way.
- Secondly, the collaboration and coordination between professionals equipped with adequate professional skills and competences is needed to tailor care to the person's comprehensive needs, including those related to physical, cognitive and mental health, and also to social needs.
- Thirdly, the incompatibility of health information systems with sporadic and unsystematic data collection efforts for long-term care limits the possibilities for delivering care in an integrated, comprehensive manner. The fragmentation of data even within the long-term care sector also challenges prospects of evidence-based decision- and policymaking.

Other common challenges faced by Member States that hinder efforts to provide comprehensive care are persistent labour shortages of long-term care workers. The lack of available services also poses an issue, particularly in rural and sparsely populated regions.

It is difficult to capture and transfer effective comprehensive and integrated care delivery to other contexts. Individual care pathways are complex and vary extensively from person to person, and therefore it remains a challenge to determine what factors and enablers

[1] European Commission (2023) Factsheet: European Care Strategy - first anniversary (2023) https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=10654&furtherNews=yes

contribute to their success. Individual factors, such as the means of communication between providers, key concepts and ways of working amongst different professional groups, are crucial for the success of integrated care, yet are difficult factors to capture, analyse and learn from.

Addressing these challenges to achieving comprehensiveness of social protection in long-term care raises a number of considerations for Member States. Firstly, defining and operationalising care needs should be broader than functional limitations. Secondly, comprehensive, personalised care plans rely on comprehensive tools and procedures that are not only more comprehensive in their scope, but that can bring together multidisciplinary teams. These processes necessitate involving care users (and their families) as much as possible to ensure that their preferences and needs are taken into account. While standardisation of processes is crucial for ensuring equity of access, at the same time, there is a need for flexibility depending on the individual's circumstances and preferences, and the setting in which care is being provided, to ensure that tools and processes do not limit the ability of professionals to implement person-centred care.

Three main points of discussion were raised during the Mutual Learning Workshop in terms of how Member States can better achieve comprehensive coverage of long-term care needs. These points centred around the needs assessment process and criteria, the need to rethink care models and ensure a range of intermediary care services, and finally the use of digital technology.

Needs assessment

The needs assessment process is one key area that Member States can target to achieve comprehensive coverage of social protection in long-term care. The needs assessment process is fundamental in determining an individual's level of care needs and for subsequently informing about their eligibility for long-term care benefits. Needs assessments were priorly dominated by a focus on functional limitations, often measured by limitations in (Instrumental) Activities of Daily Living (ADL/IADL) or based on tasks with which individuals require assistance.

However, there has been an increasing trend of countries moving away from a strict focus on functional impairment or medical needs, and instead amending the needs assessment processes and criterion to incorporate a more comprehensive, holistic and person-centered approach to defining care needs. This approach recognises that more must be considered in accessing the need for care beyond functional capacity and what can objectively be captured. This more comprehensive view of the needs assessment process takes into consideration cognitive health and limitations, as well as the individual's social and community participation and environment. While standardisation and harmonisation are still crucial with this approach, there is also a need for adaptability / flexibility in the needs assessment process based on the individuals' needs, preferences and environment. Germany presents as one example of this shift to a more comprehensive, person-centered approach to assessing care needs, described below.

Box 1: Germany's 'Acts to Strengthen Long-Term Care'

In 2017, the needs assessment system was majorly reformed in terms of defining need. While priorly capturing mostly physical and time-based tasks, in 2015, this shifted to also focus on the psychological, cognitive and social needs of individuals, and rather on how independent a person is. Similarly, Slovenia is adapting the needs assessment process based on the example of Germany, which is currently being piloted

Several other countries also incorporate a more inclusive approach to assessing care needs than strictly functional limitations, by also including mental health and cognitive decline/limitations, and social participation and inclusion as part of the criteria (BE, BG, LV,

CY, HU, EE, DE, MT, IT). Other countries, such as Sweden, follow a comprehensive approach by allowing full flexibility of municipalities to assess care needs and provide services. Belgium uses the BelRAI home care tool and BelRAI LTCF (long-term care facilities) for residential care which evaluates physical, psychological, cognitive and social functioning of the person in a uniform and systematic way, based on the setting in which they need care.

In a subset of countries, informal carers are also included in the needs assessment process, whether as part of the social support network or circumstances attributed to the individual with care needs, or as an individual themselves in need of support. For example, in Estonia, municipalities assess the support needs of informal carers alongside assessments of need for care users. This takes into consideration the caregiving responsibilities and the circumstances affecting their ability to cope and participate in social life. Since June 2022 in Belgium, the BelRAI social supplement was added to the BelRAI home care assessment tool which evaluates the context of the person with care needs, including taking into consideration the availability and use of informal care.

While the needs assessment process tends to be reactive to care needs as measured by functional and cognitive impairments at the time of assessment, representatives from Member States also raised the view that prevention should play a larger consideration in the needs assessment process as means for delaying the worsening of impairments, but also for better meeting the needs of individuals as care needs progress.

Finally, there is a need for developing further a multidimensional approach in the process of carrying out needs assessments. On the one hand, this requires a shift to a single needs assessment process that is inclusive of both health and care needs, coordinated across both types of services, as a starting point. For example, in Malta, there is a single needs assessment process used to avoid duplication of work, which considers the holistic needs of the individual, including medical/nursing care, but also cognitive decline, nutrition and medication issues, the social situation and general dependency based on the Barthel scoring. Based on this assessment, further assessment is done in specific areas depending on the individuals' needs. Poland is also currently working on amending the needs assessment process to make it unitary and integrated between health and social care services. On the other hand, a multidimensional approach of the needs assessment process includes incorporating a broader range of long-term care workers and care professions in the process. Exemplifying this, ongoing reforms in Italy include the development of a single access point system for a multidimensional needs assessment, which will be carried out by integrated teams composed of personnel from the National Health Service and the Local Social Welfare Division.

In several countries, there are no harmonised/standardised approaches or tools for the needs assessment process. In Italy, while IADLs, mental and cognitive health, and social participation and inclusion are part of the needs assessment process, these criteria can vary extensively from region to region, thus inspiring the development of a single needs-assessment process. Ireland is also in the process of implementing the use of the InterRAI as a standardised care needs assessment tool for services for older people and eventually across the wider health and social care system. In Sweden, municipalities are responsible for the needs assessment and provision of care services. The Swedish Social Services Act states that care for older people should focus on a worthy life and well-being for older people, leaving municipalities with the flexibility to carry out the assessment based on the criteria they believe are meaningful. As Slovenia mentioned above, Estonia is also currently developing a standardised assessment tool which will use a common language between social and health services.

Rethinking care models

Another focus of discussion during the workshop centred around the need to rethink and expand care models to ensure a continuum of different types of care for intermediary levels of need and address a more comprehensive definition of care needs. This idea stems from the recognition that care needs are not linear, and thus approaches to long-term care cannot be linear and restricted to a binary approach of home care and residential care provision. Instead, a circular approach is needed which recognises that care needs change and that individuals transition between settings throughout their life. Care services must be centred around the individuals in their home, helping them to remain at home for as long as possible. This therefore makes the case for expanding the coverage and scope of services that are covered publicly to ensure a comprehensive set of services for intermediary levels of need along the care continuum. The diversification of residential care services and other intermediary models between home and residential care, such as community-based and intergenerational-models, or non-traditional forms of residential care[2], can be means of achieving this to ensure that intermediary levels of needs are also covered.

The Netherlands exemplifies this through its approach to supporting older adults to live as independently as possible in their own homes. For instance, home adaptations are covered publicly for individuals that are independent enough to continue living in their home but would require some modifications to make this possible. The Netherlands is also working to build housing models for older adults that are adapted to their needs, including cluster homes where individuals live alone but with some common living space.

The promotion of reablement was also highlighted as an approach that would allow for a more comprehensive coverage of long-term care needs in line with the goal of maintaining quality of life and autonomy. Reablement is a person-centred approach that suggests a stronger focus on teaching individuals to (re-)learn skills required to be independent in their everyday lives.

Longer life expectancy and a shrinking population will require much more professionalisation in order to address complex needs. For those with more severe care needs, the Netherlands aims to cluster care providers based on needs, so that staff and certain providers are specialised to provide care for specific target groups, such as people living with dementia. In Malta, there is a specialised training centre to increase carers' expertise on working with people with dementia. In Estonia, there is a Centre for Competence on Dementia that facilitates good practice learning between municipalities.

Rethinking care models is not limited to the actual design and provision of services, but also in how long-term care is reimbursed by public authorities. The design of reimbursement for long-term care services can be an important incentive to motivate care providers to provide care in a more person-centred, integrated, comprehensive manner. For example, France is currently carrying out a local pilot where care providers will be reimbursed based on a package/plan of care, rather than the current approach of fee-for-services based on working hours and/or specific tasks. The intention behind this pilot is to provide space and resources for care providers to provide care in a way that aligns with care users' needs and preferences. An evaluation of this pilot will inform whether this model will be scaled up across settings.

A stronger focus on incorporating care users into the care planning process and in quality protocols is key to improving the comprehensiveness of long-term care systems. This was particularly raised as a focus for Poland and Spain. An extension of this was the deployment of case management and care coordinators for facilitating a more person-centred,

[2] Examples could be care homes that implement care according to Montessori principles (Montessori for Dementia, Disability & Ageing | Association Montessori Internationale (montessori-ami.org) or green care farming that combine care with agriculture (https://doi.org/10.2147/JHL.S202988).

comprehensive approach to addressing care needs. Finally, one-stop shops which integrate and coordinate between all services along the continuum of health and social care needs can also be a means for improving the comprehensiveness of coverage. These places facilitate the sharing of information and ensure that care users are informed of the availability and their eligibility for services. Ongoing reforms in Slovenia for example include developing centres for social work that act as one-stop shops.

Digital technology as a way to improve comprehensiveness

Digital solutions, targeted based on the circumstances and needs of individuals, but also as a means for better integrating and coordinating care, can contribute to improving the comprehensiveness of long-term care. The Flanders region has been undergoing a care reform since 2016. Part of this reform has included the development of a tool called Alivia which aims to promote goal-oriented and integrated care by connecting social care and healthcare. With this tool, care users will be able to access their care plan, which will comprise both health and social care-related services. The app will be goal-oriented, taking into consideration the goals that care users want to achieve, and customising their plans based on this. Doctors and care providers will have access to the tool, thus helping to facilitate interdisciplinary care planning and transparent, secure communication between stakeholders. The app is currently in development and will be piloted in April 2024 with 40 patients and their care teams across two cities. Croatia is also currently developing an app that will help facilitate better integrated and coordinated care across service providers for older people.

Countries like Bulgaria, Germany, and Sweden mentioned telecare, i.e. video calls with professionals, as one approach to address care needs. This however requires digital skills from care staff and care recipients, as well as access to devices and internet. The balance between digital solutions and human interactions is important for social participation: for instance, this may be achieved through the combination of video calls and local community activities.

While digital technology holds promise for helping to improve the comprehensiveness of care systems, there are a number of challenges that were raised by participants. In addition to fragmentation of long-term care and healthcare information systems, there is a large disconnect across providers in terms of the data they collect in many countries. Data collection efforts are seldom systematic and harmonised, thus making it difficult to analyse the situation of care users and develop/target care policies subsequently. Protection of data and privacy issues are also a concern that limit the linking of data across providers and systems. Another issue is that digital tools are often not co-designed with care users, thus risking their limited usability by individuals once launched. These issues call for investing in harmonising data collection efforts nationally and in improving the operability of health and long-term care information systems.

4 Timeliness

The second component highlighted by the Council Recommendation to improve the adequacy of social protection for long-term care in Member States is the timeliness of the needs assessment and services provided. There are two main areas to improve timeliness of long-term care needs assessment and provision:

- timeliness of the needs assessment itself;
- timeliness of service provision;

Timeliness can also be an issue where there is a qualifying period to access long-term care provision. Currently, however, most Member States do not have a qualifying period to access long-term care provision.

Accuracy and effectiveness of monitoring systems for waiting times can contribute to improving timeliness. Moreover, planning and improving the supply of long-term care provision and providing user-friendly information for potential and actual beneficiaries play important roles for timeliness.

In addition, legislating maximum waiting times, ensuring sufficient human and financial resources and tackling fragmentation across long-term care systems (e.g. types of services and support, activities at different governance levels) can all contribute to improvements in timeliness.

Waiting time management differs widely from one country to another. While some countries have statutory maximum waiting times both for needs' assessment and services access and waiting time monitoring systems (BG, DE, EE, FI, NL, PT), some only have maximum waiting times to access long-term care provision and a monitoring system for waiting times (ES, SE), others only have maximum waiting times for needs' assessment (FR, LV, SK) or for their main cash allowance programme (IT) and some only monitor their systems (LU, PL). Finally, some countries without statutory maximum waiting time are still able to grant a relatively timely support to the people with long-term care needs (AT, ES, LU). For countries with statutory maximum waiting times, differences can be observed in the rapidity of performing the assessment. Some countries do not have any maximum waiting time or monitoring system. Several countries are revising their policies concerning waiting times.

The majority of Member States are increasing their human and financial resources for long-term care provision, including for the coordination and the information flows among different organisations providing care which appears as a main point to address timeliness challenges. Participants presented two examples of dealing with the timeliness of provision of long-term care services.

Box 2: System for reporting insufficient access to long-term care in Sweden

In Sweden, the regulations stipulate that the social welfare boards or the equivalent of the municipalities should without delay initiate needs assessment for people in need of long-term care. The social welfare boards have reporting obligations to the Health and Social Care Inspectorate (IVO) if a person did not receive a necessary long-term care service within three months. The reporting should include which service was not provided, to which person in need and for what reason, and if any other service has been provided instead. This obligation includes home care and residential care. Non-compliance results in a financial penalty, so the inspectorate sends an application for the special fee to the administrative court. The aim of the regulation is to ensure people receive the care they need and are entitled to.

Inspectors are able to analyse the data of each municipality, they can use the report in their regular supervision of the municipalities and/or their risk analysis and base their inspections on their results. However, it takes time to report back on the service provision and therefore to implement the fines.

The system is currently being reviewed. A government inquiry was appointed to analyse the pros and cons of the fine and investigate complementary or alternative measures. Municipalities find the time limit to be an administrative burden. The reporting and fees have nevertheless helped to obtain a better overview and data on timeliness issues in Sweden for the provision of long-term care services and to ensure some level of legal obligation for providing services and protecting individuals' interests.

Source: Swedish Ministry of Health and Social Affairs

Box 3: Shock plan for dependency and reduction of waiting lists in Spain

Spain is currently working on a two-step approach of immediate actions and a mid-term strategy to develop a process toward a new model for improving waiting time for long-term care service provision. The objective is to gradually reduce the number of files that remain awaiting assessment or receipt of benefits and services, as well as to improve the processing times.

The Institute for the Elderly and Social Services analysed that the waiting time was due to various reasons including the complexity of the administrative process, the fragmentation of the process, insufficient human resources, the unavailability of adequate resources and services, the inadequacy of the resources and the lack of investments.

A shock plan for the system for attention to dependency and promotion of autonomy was adopted for 2021-2023 with various objectives: improvement of working conditions of care workers, reduction of waiting lists, improvement of benefits and services, improvement of professional qualifications, increase of financial resources, adjustment of the legal framework.

Since these agreements were reached, all the autonomous communities have submitted to the Secretary of State for Social Rights the measures and actions that they will develop immediately in their respective territories to achieve the common goal. Measures proposed include:

- Global actions to simplify the process and allow more agility;
- Integration of administrative and technical procedures;
- Development of computer systems and support, such as new functionalities, formulas for data interoperability or comprehensive file management applications;
- Strengthening human resources including for assessment and evaluation with the preparation of personal plans and follow-up cases;
- Increase of the investment in technical and material resources;
- Expansion of the availability of services and benefits with an increase of vacancies in services in shortage, increased resources allowing staff to pay more attention to care users; and
- Improvement of data quality.

As a result, the average waiting time decreased by 36 days in 2021, 77 days in 2022 and 10 days in 2023 (until April). This is a reduction from 457 to 334 days. The time from application to needs assessment decreased by 83 days between 2020 and 2023. This is a reduction from 287 to 205 days. There is also an increase in people who require care, so the reduction of waiting time was not as significant as expected, but the system now covers more people in need of care.

Source: Institute for Older Persons and Social Services (IMSERSO), Ministry of Social Rights, Consumer Affairs and 2030 Agenda

Participants agreed that the most effective way to ensure the timeliness of long-term care needs assessment was to introduce a legal requirement. In Germany, the long-term care insurance system distinguishes five grades of needs for care. Applications for needs assessment should receive a decision on the grade level within 25 days. If the deadline is not respected without any valid reason, there is a penalty of 70 EUR per week paid by the long-term care insurance fund to the applicants. The measure is an effective incentive.

Participants stressed that timeliness should take into account urgency situations and not only the average waiting time. In Poland, waiting time for needs assessment is set at thirty days, but a fast-track procedure also exists for urgent situations. Municipalities assess situations and may exempt applicants of needs assessment, facilitating a direct provision of care. In Bulgaria as well, services are provided immediately in case of urgency and the needs assessment is bypassed.

To ensure timeliness in terms of service provision, also sufficient resources to provide the services, such as care workers and managers, need to be available. To relieve the workforce, the process for needs assessment should be simplified to help reduce the workload of care professionals and the average waiting time. Digital solutions such as algorithms or AI could facilitate a pre-selection and/or other administrative tasks. For instance, in Cyprus ICT statistical tools are used for risk assessment of care needs to prioritise applicants with higher needs, based on different criteria such as age, location or disability status. In Croatia, access to social protection is simplified, as single older people have access to a partly pre-filled application. Moreover, participants stressed that the more important issue when it comes to timeliness of long-term care is not to assess needs, but to provide long-term care services. Several innovative ways (e.g. working across services, outreach and prevention through GPs) to ensure the timely provision of adequate long-term care services were therefore mentioned.

Member States carry out multiple attempts to reach out to people with home visits, such as in Austria, Denmark, Italy and Slovenia. In Austria, the Recovery and Resilience Facility fund is used to develop community nursing via pilot projects, with the objectives of preventing the need for long-term care, supporting people in remaining at home and relieving informal caregivers. In a broader sense, health, quality of life, well-being, empowerment, independence and autonomy of the target group(s) are to be promoted. By 2024, 150 Community Nursing projects are to be piloted. At the moment of writing this report, around 130 projects have been realised and an evaluation will share results by 2024.

Outreach services, such as in the Danish example, are an additional approach which is relevant for timeliness of services: providing support as early as possible so that it can postpone care needs.

Box 4: Denmark's outreach services

Denmark has developed outreach services where each municipality is in charge of organising at least two preventive home visits per year to all citizens of 75 years old and more. The visits do not only focus on providing health checks, but also performing assessment on a broader perspective, which allows for primary, secondary and tertiary prevention of diseases as well as offering life-style advice and promoting health habits. Older persons have to actively renounce the visit if they do not wish it to take place. The visits are carried out by district nurses with the support of other primary care professionals. These preventive visits have positive results, as it was observed the persons accepting the visits saw improvement in their functional abilities. The measures are cost neutral as they allow to identify people with needs before they face health deteriorations which are more costly to cope with.

In Italy, there is a plan to introduce dedicated teams of community nurses (employed by local health authorities) and social operators (employed by municipalities) to perform preliminary assessment in two steps to assess persons with the most complex needs and provide timely response thanks to multidisciplinary teams. Another example was mentioned by Slovenia where volunteers of the Pensioners' association which is represented throughout the country visit older people in their homes.

Other policies focus on innovation to improve the timeliness of service delivery without increasing human resources in service provision per se. In France and the Netherlands,

there is a shift of paradigm to encourage ageing at home. Municipalities provide funds to adapt houses and allow care users to stay at home as long as possible..

Awareness of care entitlement is also a challenge in some Member States, and communication is important. Cyprus developed one-stop shops to assist persons in need of care with their application, including in rural areas, to reduce urban-rural disparities and witnessed a decrease in non-take-up of care services entitlement. In Sweden, municipalities organise health talks where NGOs are also present and show what they can offer to citizens in need of care.

Participants also stressed the importance of monitoring the long-term care systems to identify issues. Systems are usually managed at different governance levels which poses a challenge for the coordination. For instance, in France various stakeholders collect data which are difficult to harmonise and compare. In the Netherlands, care needs assessment is performed at regional level. If health insurance providers do not have an agreement with health providers, applicants are put on a waiting list until a health provider is identified. Administrative centres have access to the waiting lists and can act if the waiting time is too long. In Sweden, a monitoring system 'Open Comparison' was developed based on a set of indicators covering several aspects of quality, such as waiting time. An additional service 'Older people's guide' enables care seeking people to get information about available caregivers. However, data protection can also be a challenge to monitoring, for instance in Estonia possibilities to use data are very limited.

5 Affordability

Affordability is a critical aspect of long-term care, as care recipients and their families often contribute via co-payments. If care services are unaffordable, people with long-term care needs would face either a lack of help, or families would have to step in by providing informal care. Financial considerations often deter the utilisation of (home) care services, with households running the risk of economic impoverishment due to out-of-pocket costs associated with long-term care[3]. In order to enhance households' access to sufficient care, most Member States have some form of minimal public and non-profit long-term care support for people with needs who cannot access family support and have insufficient income and assets to fund their care. In most Member States accessing services involves, to different extents, a co-payment of fees.

Box 5: Affordability of long-term care in the Dutch healthcare system

The Netherlands operates under two key legislative acts: the Health Insurance Act (2006), which regulates curative care and the Long-Term Care (LTC) Act (2015), which regulates heavy, intensive care for vulnerable elderly people, people with a disability and people with a mental illness. Additionally, the Social Support Act (2015), which aims at stimulating self-sufficiency and participation of all inhabitants and to promote social cohesion in society, mandates that municipalities provide non-medical support to enable individuals to age at home.

The aim of the **Health Insurance Act** (Zvw) is to ensure the quality, efficiency, and accessibility of healthcare services. This legislation mandates that anyone residing or working in the country must have a basic health insurance package, beginning from the age of 18, with individuals paying both premiums and deductibles. The delivery of care is entrusted to healthcare providers, and the insurance coverage is provided by private health insurers. The system encourages competition among insurers, fostering the purchase of accessible, high-quality, and effective healthcare services. Key points within

[3] OECD (2023) Public social protection reduces poverty risks, but gaps remain OECD Policy Brief, OECD Publishing, Paris

the Health Insurance Act include the acceptance obligation, ensuring that insurers cannot discriminate based on premiums, and a duty of care, emphasising the commitment to providing comprehensive and accessible healthcare for all individuals covered under the legislation. These components collectively contribute to the overarching goal of maintaining a robust and equitable healthcare system in the Netherlands.

The **Long-Term Care Act** provides for high-level care for vulnerable older people or people with severe mental or physical disabilities. There are different kinds of residential care provided, like nursing homes, care facilities for people with disabilities and mental healthcare centres. There, people who have a long-term care needs assessment get personal care and nursing. Service provision through the long-term care act is based on a statutory social insurance. The social insurance is dedicated to providing comprehensive care for vulnerable older individuals or people with severe mental or physical disabilities. People pay an income-dependent premium through their payroll tax. The amount of the premium is based on a fixed percentage (9.65%) of the income tax, on a maximum amount of EUR 35 129 (2021). In addition, adults who wish to make use of healthcare services under the Long-Term Care Act pay a co-payment which is also income-dependent. In this case it matters whether the client lives at home or in a care facility, is younger or older than 65, and is single, married or has a domestic partner. All contributions are deposited into the Long-Term Care Fund, which is managed by the National Health Care Institute. The central government tops up the fund using public money if these funds are too low.

The **care needs assessment**, conducted by an independent national institute, the Care Needs Assessment Centre CIZ (*Centrum Indicatiestelling Zorg*) involves collecting information on individual health and other objective criteria (while the social context of the service user is not part of the assessment) placing individuals into care profiles to determine the type of care needed. The profiles include: older people; people with intellectual disabilities; people with physical disabilities; people with sensory disabilities; people with long-term psychiatric disorders.

Effective strategies to make long-term care services more affordable for users involve adjusting cash allowance regulations, harnessing social assistance programmes, and allocating additional public financial resources to alleviate co-payment fees. Several countries have taken steps in that direction. In Austria, since 2020, there has been an annual indexing of the federal long-term care allowance. Belgium and Germany have witnessed an increase in the long-term care compulsory social contribution. Bulgaria has allocated new funds, with a substantial 45% increase in 2023 compared to 2020. France has undertaken an expansion of resources within its primary long-term care programme (the APA) with the goal of reducing the number of individuals subject to co-payment fees. Slovenia has introduced a compulsory long-term care insurance and is actively working to enhance affordability in its long-term care system.

In Estonia (see box 6), the Care Reform in 2023 is designed to assist individuals requiring support in covering residential care costs.

Box 6: The Care Reform in 2023 in Estonia

The objective of the 2023 Care Reform in Estonia is to make 24-hour care financially accessible, relieving the families from the burden of caregiving and improving the availability of home-based care. The reform introduces a change in the 24-hour care service funding schemes, making parts of its cost covered by the public sector, regardless of the service recipients' income or the economic capacity of their family members. According to the new system, municipalities cover care costs (including labour, work clothes, personal protective equipment, health check-ups, vaccinations and training). On

the other hand, care recipients pay for other expenses, including meals, administration, support personnel, technical aids, transportation, and other associated costs.

Moreover, care recipients with lower income receive additional support from the municipality. An impact assessment of the reform is foreseen in 2026.

Efficiently targeting those most in need and ensuring fairness

Participants discussed how the financial burden of long-term care can be shared in a fair way: across generations and between public and private spenders. How the financial burden is distributed depends on the organisation of the welfare regime and if access and eligibility to long-term care is universal, means-tested or relies mainly on informal care.

In terms of sharing costs across generations, a long-term care social insurance-based system, such as in the Netherlands, Germany, Luxembourg and part of Belgium (the Flemish region) that relies on social contributions levied on wages during one's working life, can be considered as model to promote fairness across generations. However, countries with such a model also face the issue of levying costs on a shrinking workforce.

Moreover, all types of long-term care systems seldom cover the full costs of long-term care, which means that the scope of coverage (what type of needs or services are financed) and the depth of coverage (what share of costs are publicly financed) varies. Therefore, adequacy of long-term care depends still highly on individual means and the family's ability to provide care.

It is challenging to assess affordability of long-term care and therefore cost-sharing, as comparison of private expenditure (co-payments to services, top-up payments which are an addition to a service and out-of-pocket payments to fully fund a service by private funds) of users and their family is difficult across the EU. There are (self-) reporting issues and private payments depend on several factors, such as means-testing, the relation to other public payments (for example pensions) and the presence of a ceiling or a cap for public financing of care. Nonetheless, research carried out by the OECD[4] provides a comparison across countries based on typical cases, highlighting how public support reduces poverty risks, but not necessarily as much as needed.

Recent reforms aim to decrease costs for service users, in particular in countries where expenditure on long-term care has been low. For example, in Estonia, a country with a low public expenditure on long-term care in comparison with other European countries, the new care reform implemented in 2023 described above (see Box 6) aimed to increase public funds for home and residential care. In addition, care recipients with lower incomes now receive additional financial support from local authorities. If before the reform, service users covered the total costs for residential care, since 2023, the municipality contributes to around half of the care costs, depending on needs.

For residential care, which usually implies higher public and individual costs, out-of-pocket payments are often dependent on financial resources of the wider family. Some countries like Austria, Germany and Estonia aim to reduce private expenditure for residential care. In Austria, since 2018, only the income but not the assets of the person living in residential care are used to cover the costs of care. In Germany, the long-term care insurance funds have been paying subsidies for residential care recipients since 2022 and the amount will further increase from 2024 onwards. In Ireland, there is an additional fund for social activities in residential care.

In order to efficiently target those most in need of long-term care while ensuring financial sustainability, many Member States use means-testing for accessing long-term care. This

[4] OECD (2023) Public social protection reduces poverty risks, but gaps remain OECD Policy Brief, OECD Publishing, Paris

approach aims to steer funding to those who can least afford to pay for it, so the level of support depends on the income and/or assets of the recipient of care. In some countries, the spouse and children have a duty to support financially the use of long-term care services. However, there are also concerns that means-testing alone may result in a significant level of unmet needs, increase stigma and administrative costs[5].

Moreover, there have been efforts to increase the provision of long-term care for those living within rural areas. Some countries target funds to increase the availability and range of care across the country. For instance, in Poland, municipalities receive additional funding to contract long-term care services in rural areas. In Cyprus, rural local authorities get extra funding to contract long-term care services. Nevertheless, most countries face challenges in recruiting, training, and retaining long-term care workforce, particularly in rural areas. Digital technologies, services tailored to those with particularly complex needs, outreach, prevention and rehabilitation as well as integration of health and care systems can all contribute to better targeting support for those most in need.

In general, the role of long-term care as complex set of support structures for people with multiple and changing needs, could benefit from a re-definition. Participants debated questions around the definition of care and which service is responsible for which type of needs. Often health care needs are publicly covered, but not support with cognitive impairments or social participation. For instance, it may be the case that someone with diabetes is covered by the health care system, while someone with dementia has limited access to public support. Participants also discussed whether personal lifestyle and risks leading to higher care needs should result in higher contributions to health and social care funds.

6 Main takeaways and recommendations

This section describes the main findings how social protection for LTC can be strengthened from the workshop in five key points:

1. Ensuring comprehensiveness through inclusive needs assessments

The development of needs assessment processes demonstrates a trend to include more than functional limitations in activities of daily living, namely more attention to cognitive decline and limitations, as well as social participation. Moreover, comprehensiveness can be increased by also strengthening the role of prevention of future care needs in the needs assessment process. Needs assessment processes are reformed in some countries to address both health and broader care needs.

2. Reforming care delivery models towards integrated care

Horizontal and vertical fragmentation constitute obstacles for comprehensiveness of service provision. These relate for example to the way in which the long-term care is often fragmented across different governance levels, across different professions and providers, and to fragmentation of data collection. Tools and procedures need to be able to bring staff from different professions together to provide comprehensive and person-centred care, and to balance the need for standardisation with the necessary flexibility to adapt the care to the

[5] Colombo, F., Llena-Nozal, A., Mercier, J., Tjadens, F., 2011. Help wanted? Providing and paying for long-term care. Paris: OECD Publishing. Fernández, J.L., Forder, J., Trukeschitz, B., et al., 2009. How can European states design efficient, equitable and sustainable funding systems for long-term care for older people? Copenhagen: WHO Health Systems and Policy Analysis - Policy Brief 11. Rothgang, H. & Engelke, K., 2009. EU Peer Review -Long-term care : How to organise affordable , sustainable long-term care given the constraints of collective versus individual arrangements and responsibilities - Discussion Paper.

needs of the individual person. Care plans can be a useful tool to improve integration of care. Adapting care better to the needs of the care recipient and thus improving person-centred care could also make a reconceptualisation of care necessary, for example by involving care recipients more in the planning of care, providing one-stop shops for information, expanding coverage for care at home to enable individuals to age in place, diversifying the offer of care services and ensuring a continuum of care settings.

3. Developing digital technology to increase comprehensiveness and timeliness

Digital technologies can be used to further develop the integration of care and person-centredness. However, such technologies should be co-designed with those who will use them, which is currently often not the case. In addition, digital tools, such as video calls, should also be combined with face-to-face contact. ICTs can contribute to timeliness of services (e.g. reducing travel time). Furthermore, digital technologies enable data collection which can inform the development of policies in long-term care. However, data collection is currently often not harmonised across different funders or providers.

4. Improving timeliness through legislation, outreach services and monitoring

Timeliness of needs assessment can be ensured through maximum waiting times enshrined in law and penalties for delays. It is important to also have procedures for urgent service provision besides the standard procedure of waiting for a needs assessment. However, timely service delivery highly depends on sufficient financial resources and availability of trained staff. Outreach services, facilitating ageing in place, raising awareness about services and monitoring of long-term care systems (e.g. monitoring of waiting lists and gaps in provision) are additional options for improving timeliness of service provision.

5. Addressing affordability

The affordability of long-term care can be ensured by providing a sufficient level of cash or in-kind benefits to cover a comprehensive set of needs. Strategies to improve affordability of long-term care include cash-allowances, social assistance programmes or services in kind. While means-testing is a key strategy for targeting those most in need, this can lead to substantial unmet needs. Recent trends also include reforms to reduce private expenditure on residential care.

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