AGE member survey on the EU Care Strategy

National priorities to implement the Council recommendation on long-term care

With contributions from Belgium, Cyprus, Czechia, France, Germany, Italy, Malta, the Netherlands, Norway and Poland

AGE Platform Europe
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Executive Summary

The EU Council Recommendation on access to affordable, quality long-term care is an important milestone for the European Union, as it includes a person-centred and rights-based approach to long-term care based on quality principles such as 'respect'. Against the backdrop of increasing longevity and the likely increase of long-term care needs, and the renewed pressure to reduce public deficits and budgets, it is important for the EU and Member States to reaffirm the ambition to which they committed in the Recommendation. The Council recommendation requires Member States to publish the national implementation measures that they intend to take to transpose the principles to which they committed.

AGE has collected views from its members on national level to define which pieces of the long-term care system in their country need the most urgent attention. Looking at the different contributions, AGE puts forward the following recommendations to implement the ambition included in the EU Care Strategy:

- Social and health ambitions should be part of the next Council Strategic Agenda for 2024-2029.
- It is time for a European Care Platform as part of the European Pillar of Social Rights Action Plan.
- Member States must show political will for establishing rights-based long-term care systems.
- Member States must pursue dialogue with civil society representing persons in need of care, persons with disabilities and their families.
- Workforce shortages seem the most common barrier to the success of the Council recommendation.
- Member States must develop sustainable funding mechanisms for long-term care services.
- To achieve autonomy and independence, all kinds of health and long-term care policies need to be developed to ensure an available spectrum of care that suits all needs: health promotion, prevention, curative generalist and specialist care, home and community-based care, support to informal carers, palliative and end-of-life care, housing adaptation and accessibility of environments, mental and physical health care.
- Long-term care must meet the reality of free movement within the EU.

About AGE Platform Europe

AGE Platform Europe is the largest European network of non-profit organizations of and for older people. We elevate older people's voice, bringing their experience and aspirations to the table to celebrate ageing and fight for equality at all ages.

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Introduction

We all want to age in good health and maintaining our independence. Yet, older age is often associated with the idea of increasing frailty, reduced independence, disability and/or sickness and moving into residential care. This mental model however does not fit the reality: residential care is far from being the standard model, as 80% of care is estimated to be provided by informal carers, often female relatives who reduce their own opportunities for employment, income, social inclusion to provide care to their loved ones. Also, developing a care need is not a fatality: many people do age without major health issues, and there is a range of conditions and disabilities that have only a progressive onset, against which preventive, curative or rehabilitative treatments are effective. With the advancement of the rights of persons with disabilities, not the least the UN Convention on the Rights of Persons with Disabilities, alternative forms of care such as home care, community-based care, personal assistance, and the development of adaptable and accessible housing and environments, including technical assistance become more available and known.

Overall, we are observing a shift from paternalistic models that 'care for' 'dependent' persons to models that empower persons in need for care to maintain their independence – aiming at the enjoyment of the same rights and opportunities as other persons.

The EU Care Strategy of September 2022, and the Council recommendation on access to affordable, quality long-term care of December 2022, include these considerations by encouraging Member States to develop person-centred approaches to long-term care. This new framework resonates well with AGE's vision of care: that it empowers us throughout our lives. These principles also find themselves in the WHO Framework for countries to achieve an integrated continuum of care, developed as part of the UN Decade on Healthy Ageing.

The Council recommendation therefore holds the potential for reform of our long-term care systems, depending on the starting point of each Member State and/or region.

However, it is vital for the success of the EU Care Strategy, and in a wider sense for the harnessing the potential of longevity in Europe, to sustain the momentum of the Council recommendation on national, regional and local level. While the European Commission is organising helpful mutual learning exercises, advice on reforms funded by the Recovery and Resilience Programme, the Technical Support Instrument, the European Social Fund Plus and other funds, the actual uptake of the Strategy lies with the national level. Therefore, AGE has surveyed its members to bring in their local and national experiences, setting the priorities that should be addressed most urgently to implement the Council Recommendation.

AGE hopes to positively contribute to the drafting and refinement of national plans of implementing measures of Member States, to be released in June 2024, with the present contribution.

AGE recommendations: using the EU Care Strategy and Council recommendation as a lever for change

The national contribution outlined below highlight common aspects that should be taken into account for the entire European Union. Also, in our exchanges on the EU Care Strategy we realise how important it is that the European institutions continue to promote its implementation.

To keep the momentum of the EU Care Strategy, AGE has co-signed two important common appeals towards the Member States as a whole:

Social and Health ambitions should be part of the next Strategic Agenda 2024-2029

Facilitated by the European Social Insurance Platform, AGE Platform Europe has co-signed a statement to the European Council to ensure that health and social ambitions are part of the next five-year Strategic Agenda which the Council will adopt in view of the upcoming legislature. This was issued relative to the concern that leaked version of the leaders' discussions did not include social policies as an important priority.

The reform of the Economic Governance Framework on public spending and public debt allows for some more flexibility for Member States on public spending, including when implementing European priorities such as the European Pillar of Social Rights. However, the return to the fiscal software governing the austerity policies of the 2010s, connected with the high public debt levels made necessary by the effective and coordinated European response to COVID-19 and high inflation in the wake of Russia's aggression against Ukraine, does not bode well for the importance of social policies. Increasing longevity and the already unsustainable shortages of quality services as well as care workforce command durable investment into care services, but also into social benefits and services which support health promotion and prevention, make environments accessible to persons with disabilities, provide rehabilitation and reintegration and support people in their independence and autonomy. Therefore, the next Strategic Agenda should be unequivocal that social investment is necessary to turn longevity into a success story for the EU.

Time for a European Care Platform as part of the European Pillar of Social Rights Action Plan

Ahead of the La Hulpe summit on the European Pillar of Social Rights (EPSR), AGE co-signed a declaration of a number of European NGOs calling for a European Care Platform as part of the EPSR Action Plan. The La Hulpe conference reconfirmed the institutions' commitment to the Pillar of Social Rights in the next legislature, but the Declaration suffers from important weaknesses: on one hand, Austria and Sweden have not supported the Declaration. On the other hand, long-term care does not enjoy a very prominent part in the declaration, despite being subject of Principle 18 of the European Pillar of Social Rights. The Declaration does not even name the EU Care

Strategy or the Council Recommendation, nor does it remind Member States of their commitment to implement the Recommendation. Care is mainly seen from a lens of 'increasing needs' and labour market integration of persons with responsibility for people in need of care, not as an own right in the spirit of the EPSR.

The EU Care Strategy and the fruitful exchange between the Member States, the Commission and relevant civil society organisations should be pursued and made permanent by the creation of a European Care Platform.

Political will for change as the basis for establishing the long-term care sector.

Across Europe, long-term care systems suffer from fragmentation of competences between authorities and a lack of political attention to the needs of the sector. For instance, very often responsibilities for long-term care are divided between the ministry of health, the ministry for social affairs, the national social protection institution, regional and local governance levels. The division of competencies might not be the same whether care is provided in residential settings or at home. This leads also to a lack of clarity for persons in need of care and their families, differences in the accessibility of residential and home care and between urban and rural territories.

Where care services exist, they may still follow a functioning where persons in need of care have to conform to the services' logic, rather than benefitting from services adapted to their needs and wishes.

To change this situation, political steering and attention is needed. Some examples such as the reflection process initiated on regional level in the Biscay province, or the Brussels region show that it is possible to change the mentalities, and this does not necessarily mean to massively increase spending on long-term care.

AGE welcomes the nomination of national care coordinators and the enthusiasm in changing long-term care for the better during the mutual learning exercises. It is important that long-term care coordinators are empowered with a mandate and effective tools to trigger change in a country's long-term care system. Where a care coordination is formed instead of a single coordinator, it is important that the responsibilities are clearly defined around a common vision.

Necessary dialogue with civil society organisations representative of persons in need of care and persons with disabilities

Our members in general formulate difficulties to contact the national long-term care coordinators and engage a discussion on the implementation of the Council recommendation. AGE reminds that the recommendation contains the requirement to consult with all relevant stakeholders, namely social partners, civil society and the social economy. However, requests for meetings or to be associated with the elaboration of national implementation measures have been frequently not responded to. AGE welcomes the association by the European Commission of relevant

stakeholders in the EU-level mutual learning workshops, however. Regarding the elaboration of an indicator framework by the SPC Indicators subgroup, we point however to the fact that there is no information about the indicators under discussion and the state of the work.

Workforce shortages put the success of the Council recommendation at risk.

Throughout the Member States, it seems that mainly the lack of qualified workforce is hindering the expansion of quality long-term care services. This holds true for most professions related to long-term care, but is particularly the case for some specific professions, such as geriatricians or medical professionals with a geriatric specialisation.

By and large, it is acknowledged that workforce shortages are due to a lack of attractiveness of the sector for new professionals. A large share of the current workforce is approaching retirement age and not enough younger people decide to embrace care as a career. In addition, working conditions are leading to a significant staff turnover, many care professionals leaving the sector to pursue other careers. It seems vital that care professions must be made more attractive by improving working conditions, increasing available time for human interaction, attractive salaries and career pathways. Therefore, Member States should strengthen sectoral social dialogue to improve these items. It can be argued that better pay and working conditions might also introduce a better gender balance in the composition of the care workforce.

The fact that long-term care is relying a lot on informal care a as a default choice (by the absence of affordable, quality formal services) and often untrained live-in care workers further shows that public policies do not see it as a serious career, despite the potential for job growth and economic value for the sector.

Develop sustainable funding and social protection for long-term care.

Even if changing care services towards a person-centred, rights-based approach might not need additional funding, the inaccessibility of care services shows that there needs to be investment into the expansion of quality services. The 2024 Pension Adequacy Report confirms that care needs remain an important financial risk and that the inability to fund out-of pocket costs for long-term care remain one of the main reasons not to access care.

There are positive examples of levying funds for long-term care, such as the progressive introduction of a social protection-based long-term care insurance in Slovenia. Against the backdrop of return to the EU's fiscal framework, the European Commission and Member States should ensure that enough fiscal space is left to allow for better availability, deinstitutionalisation and person-centredness of care to realise. As Member States have more flexibility in public spending when implementing EU funds and the European Semester's Country-Specific Recommendations, it must be ensured that more Member States received targeted recommendations on long-term

care. The European Commission has already started to lay the groundwork for this regarding four member States in the 2023 European Semester, these efforts should be continued.

To achieve autonomy and independence, all kinds of health and long-term care policies need to be developed.

All kinds of health and long-term care policies need to be expanded in most Member States to ensure an available spectrum of care that suits all needs: health promotion, prevention, curative generalist and specialist care, home and community-based care, support to informal carers, palliative and end-of-life care, housing adaptation and accessibility of environments, mental and physical health care.

In many Member States, reliance on informal care by absence or inaccessibility of formal services is the most common care 'policy' developed. Informal care, however, is not sufficiently supported as many informal carers – mainly women – need to reduce their availability for employment to provide care without compensation in terms of income support, accrual of pension rights or otherwise. Supporting informal carers would mean to allow for better financial support, more time and supporting services than the minimum standards of the EU's Work-Life Balance Directive. Supporting services, such as day care, respite care, peer exchange, training and counselling are vital given informal carer's risk of poverty and social exclusion, physical or mental health issues. Such support also contributes to harmonious relationships between informal carer and the person in need of care. In general, informal care should be a choice and not a necessity deriving from the inaccessibility of other quality services.

Where care is provided by live-in carers or other types of domestic workers, a proper employment status for these workers is often lacking. However, to provide quality care, these workers need adequate training, be part of a system that allows for life-long learning, exchange and some degree of oversight, protection from abuse and harassment and a system allowing them to take leave and respect sustainable working times, i.e. a system allowing for temporary or permanent replacement.

Beyond informal care, the care sector is still marked by a prevalence of residential care. Often, residential care is chosen above home care for reasons of availability or affordability (e.g. when residential care is funded by health insurance while home care is more funded by out-of pocket payments). Yet, most persons would prefer staying at home and maintaining their independence. Large institutions carry the risks of placing the institutional logic above individual needs and aspirations of the persons in need of care. Therefore, the development of home care and community-based care is important to expand the continuum of available options to persons in need of care.

The focus of the Council recommendation on long-term care services does not preclude an emphasis on prevention. The best care service is the one that is not needed. However, little seems to be done in terms of strengthening health prevention

in general and in particular of people with needs of care or with conditions that are likely to lead to the development of a care need.

It is also reported by AGE members that there is little availability of palliative care in the Member States. In many cases, palliative care is restricted to the end of life, rather than alleviating suffering over the longer and medium term of chronic and potentially degenerating conditions. Offsetting the onset of a care need through prevention, rehabilitation and other interventions would however be the best way to uphold the right to independence. In a similar way, strengthening the accessibility of public, private and online environments to persons with disability upholds people's autonomy while they face a potentially disabling health condition. Long-term care interventions should therefore also be available to adapt peoples' homes to keep them accessible in light of their changing needs.

Long-term care must meet the realities of freedom of movement.

The EU is built on the fundamental principle of freedom of movement. It is often highlighted that this means that potential long-term care workers and informal carers from Eastern or Southern Member States leave to work in Northern or Western Member States. However, beyond this reality, there also is the effect that many persons retire and may require care services in another Member State than the one responsible for their pension payments or health insurance. There is a risk that different philosophies of national systems might put these people at risk of not accessing the support they need: for example, if a person is insured in a Member State that relies on long-term care services provided in-kind for free or low co-payments and they reside in a Member State relying on an insurance model that provides cash benefits for care. The reform of the Directive on the Coordination of Social Security starts clarifying the competencies, but not all Member States have long-term care an established branch of social security. In the next long-term care report, it would be worthwhile to look at potential gaps derived from labour mobility in the access to care.

In the longer run, it might also be worthwhile to develop a long-term care reinsurance system, based on the model of the pandemic-era SURE reinsurance scheme for short-term unemployment. Such a reinsurance scheme would allow for solidarity between Member States who are net recipients of internal migration and those who have a net migratory deficit.

Long term care: National urgencies and priorities for reform

In the following sections, we summarise the contributions received from our members on the specific priorities included in the Council recommendation on long-term care that should be implemented in their national context. National long-term care coordinators are encouraged to contact the organisations having contributed to this section directly or contact AGE to have the contact of AGE members in their Member State. AGE reiterates that the consultation process on national implementing measures seems to not have been sufficiently accessible to national civil society.

Belgium (Flanders)

Comments provided by Vlaamse Ouderenraad

Main priorities for reform: development of formal care services, staff shortages, privatisation of care, affordability

Affordability

The government should urgently address the very high cost of a stay in a residential care centre and the rapid increase in that price (an increase of 10 percent in one year). The average daily price in 2022 is 64 euros, plus the cost of specific services, such as hairdresser, pedicure, laundry service, etc. These costs may vary depending on the resident's needs. The result is that the majority of residents cannot pay the cost with their pension. That is why an increase in the healthcare budget is necessary, as it has not been indexed in the last ten years. The monthly price is 2,039 € in public institutions, 2,111 € in non-profit institutions and 2,274 € in commercial institutions. As a comparison, the average employee pension in 2022 was 1,255.45 €. So, the cost of a residential care centre is double the monthly average pension.

There is a tendency to encourage older people to stay at home, even if they are requiring care, in their own community and as little as possible in residential care centres. The government expects that the family and the neighbours will help the older people when they need care. This seems good in theory, but in practice many older people appear to have no network that can help them. Moreover, they can rely less on informal care from their own children because they first these have to work longer (up to the age of 67) and often both partners are working.

The encouragement to have older persons stay at home is motivated by the desire from the government to make savings and reflects a strong neoliberal view in which the government is increasingly withdrawing and leaving care to private commercial institutions, which of course have a for-profit motive. The result of this policy is a strong sense of loneliness, with many people not receiving quality care because they cannot afford it.

Adequacy/Quality

There is a major shortage of professional healthcare providers.

There is generally still too little attention paid to the application of human rights, not even in healthcare training.

In Flanders, a research project is currently underway to investigate the quality of residential care centres from the perspective of the residents. the intention is to make recommendations for policy on the basis of these results. Currently, government control is still too focused on efficiency and economics and not enough on quality as experienced by the residents.

Workforce/professionalisation

There are major staff shortages in both home care and residential care. The healthcare profession appears to have become less attractive to young people. That is why attempts are made to attract foreign carers (from Eastern European countries, from India, from Africa). The problem with this is first and foremost a language problem. The foreign professionals usually do not speak Dutch or speak Dutch with difficulty, which makes communication with people in need of care very difficult. That seems to lead to friction and lower quality than people expect. Moreover, many of those foreign healthcare providers have a completely different work ethic than we expect here (for example, only the agreed hours and no extra availability). They often lack a human rights perspective. Moreover, the legal minimum standard for healthcare personnel is too low to provide the required quality.

Facilities

A serious problem is the privatization of healthcare. We have three types of residential care centres in Belgium: the public ones that are financed by public authorities (26% of all healthcare institutions), the strictly private ones that are managed by commercial organizations (32%) and which are therefore aimed at making a profit and thirdly the private institutions (non-profit institutions) (40%) that are not aimed at making a profit and are managed by charitable organizations such as religious organizations.

The problem is that private commercial institutions, aimed at making a profit and benefiting their shareholders, make a profit by using fewer staff and by curtailing the quality of care. In many of these types of institutions there is also an outflow of staff because the work pressure is very heavy. More and more of those institutions are in the news because of abuse and bad treatment. Much stricter government control over quality and humane care is needed. Moreover, the accounting of commercial institutions often appears to be not transparent.

Cyprus

Comments provided by PA.SY.DY

Main priorities for reform: availability and affordability of palliative care, fragmentation between public authorities and care providers

Affordability:

Social protection for long-term care in Cyprus is adequate, since the government provides financial support, preventing poverty. Financial support is provided to persons that choose to live (i) in community care centres (ii) in private long term care facilities or (iii) stay at home. Financial support is provided for people at pension age and as long as is needed (end of life). Support covers the additional cost for long-term care. In home care, this cost covers a domestic live-in carer. This is particularly the preferred option in rural areas.

The issue of affordability of palliative care derives from the fact that palliative care is only publicly supported for the short-term in hospitals. Private palliative care units exist but are prohibitively expensive.

Comprehensiveness:

The system of palliative care is not existent. In the hospital there is some short-term medical treatment, but this works with not with assistance at home.

In cases of severe care need, such as advanced dementia, you need to go to a private clinic which is very expensive. There is no public care for persons with dementia.

Quality and adequacy:

Support is provided relative to the needs and wishes of the person. Quality criteria apply to municipal and private long-term care centres, there are however no criteria for live-in carers, and no training requirements.

Professionalisation:

Remuneration of care professionals seems not to be an issue, but there is a need for better training and professionalisation.

A change in the law has made it easy for public authorities to transfer the institutions under their management to private commercial companies. They do this to pass on the costs of their own residential care centres. The effect is usually a reduction in the quality of care and, importantly, a serious price increase for residents. The difference between public and private commercial institutions in the monthly cost for a resident is on average 200 euros, while the services provided are less.

Governance

Responsibility for long-term care is fragmented between public authorities (ministry of health, ministry of the interior), agencies (state health services organisation, health insurance organisation) and providers (social welfare services, private care providers, non-governmental organisations, patient associations). A better coordination seems important to achieve a more effective long-term care system.

Czechia

Comments provided by Zivot 90

Main priorities for reform: development of alternatives to residential care, integration, support for informal carers

Availability:

The concept of long-term care in the Czech Republic is still predominantly associated with (and carried out by) medical institutions, i.e. hospitals, subsequent post-hospitalization institutions and residential care homes, sometimes with special regimes for dementia, etc. Therefore, it has an institutionalised ethos. The reality is that individuals, who underwent medical treatment and need further care, remain in an institutional setting for much longer than necessary, with few chances to make other choices. The perception is that the traditional model of institutional care provision forms the basis of long-term care at present. Outreach services, where they are available, are often not adequately staffed, and are unevenly available in terms of geographical distribution.

Zivot 90 calls for a shift towards home care, where an individual would be able to choose a mix of services if and when he or she needs them. Home care should be developed as a viable option, and be fully supported both financially as well as with a respite service for informal carers. We also call for coordination between sectors + greater emphasis on prevention as well as active participation of those in need.

Integration

There is inadequate cooperation between the medical and social sectors, though at present, new legislation was put on the table this year to interconnect the services between the two, and by 2027, it is expected that there will be a new type of profession that covers socio-medical service. No case management is in place (or it is completely inadequate) and there is not sufficient trained staff.

Informal carers

At the moment home care is carried out exclusively by informal carers and/or family (with an estimated 1 million of carers in a population of 10 million!), and supporting provisions are not easily accessible. The key problem is the lack of proper information,

and lack of coordination. There is a financial benefit that can be drawn by a caring family member, but this is limited to 90 days.

Information

Zivot 90 has introduced electronic and telephone service with which an individual can access help 24 hours per day. This has proven very successful, yet it is a service fully provided by an NGO and should be supported by the government.

France

Comments provided by: Confédération française des retraités, Anciens de BP France

Priorities for reform: workforce, quality in residential and home care

Availability:

In France, doctors, nurses and all other social and medical professionals are dramatically missing. As a consequence, people often do not receive care as soon and as long as they need with the expected level of quality, i.e. with the provision of what is needed to respect people in need, sometimes even their basic needs. Beyond trained human resources, sometimes equipment and consideration are lacking as well.

A good practice should be highlighted, the 'medicobus' that exists in some départements. This is a mobile medical clinic which allows medical teams to visit people in need of care who suffer from chronic diseases following a fixed calendar and itinerary.

Coordination is difficult because of the lack of professionals and because of the complexity of the French health system.

Palliative care is inexistent in more than 20 French "départements" (roughly 1/5 of France) and most often is insufficient in the other "départements".

Affordability

Care is less and less affordable because manly medicines are no longer or less and less refunded by the health insurance, because more and more professionals ask for extra financial contribution, because often necessary care can only be available far away from the patient home.

Adequacy

It seems that home and community-based care have developed during the past years despite the difficult working conditions for the professionals. Older people in need of care prefer living at home than moving to a dedicated institution. But here is a financial barrier. If you need only a little help, it is cheaper to stay at home than moving to an

institution, but if you need much help, it becomes too expensive and also difficult to manage by the family, especially is the family lives far away.

Technology and digital solutions in the provision of care services are not developed. Human presence and care are more important for the older persons and their family, but maybe digitalisation could help to increase coordination of professionals and the link between professional and informal carers and doctors.

Quality:

There is a policy for people to stay at home, but there is no control about the quality of care. There is the question of the prevalence of abuse, no one knows if the job is done well there. It is much better for the people to stay at home than to go into an institution, but there are not enough people caring.

We need not only nurses, but also training for managers. The quality of the nursing home can dramatically change between one home and another.

A director a nursing home must be a person who has the charisma necessary for this home to have a soul, for the well-being of the resident to be at the centre of the organisation and functioning of the teams, who listens to staff members and families with a view to continuous improvement and personalized adaptation to the needs of each of the residents and not just an administrative manager. However, in France, more and more managers are appointed in charge of several establishments and not managers who meet the above criteria, while the lack of staff, or even training of this staff, is sometimes glaringly absent.

EU Quality principles

- **Respect**: Most carers respect the older people they care for, but their job is difficult, they must work in a limited span of time, because sometimes they need a long time to drive from one place to another, their patient's home is not always very easy and organized for such care, and therefore the patient may feel disrespected. Administrative processes are desperately complicated and here again, patients may feel disrespected. Also, given the shortage in care opportunities and forms of care, older people's freedom and rights are not always respected.
  There is little control if any of the professionalism and ethics of carers, whether they are professionals or family carers.

- **Prevention:** Not much is done to develop prevention. Free preventive check-ups are available only until people get 75. In some regions, when an older person would need physical re-education after a vascular cerebral accident for instance, there are no longer physiotherapists available in the hospital, it is very difficult to get appointments with such a specialist down-town, and they do not visit people at home any longer because they have no time to go there. As a

consequence, these people develop a much stronger need for support. However, a positive development regarding prevention is the increasing number of walking and gymnastic clubs in the communities, as well as other kinds of physical or intellectual activities.

- **Person-centredness**: This is more or less respected thanks to the humanity and sense of ethics of the professionals.

- **Comprehensiveness and continuity**: Given the lack of means, this is far from being assured, even though professionals do their best.

- **Focus on outcomes**: There is little cultural support for evaluating in order to improve. The focus is mainly directed on saving short-term costs without taking into consideration the fact that prevention and early palliative care would at the end reduce costs. As an example, institution managers now often manage 2 or 3 homes, being in charge of administrative and financial objectives with no more time to devote to the residents and their family and even to the professionals as human beings and not only as numbers and status.

- **Transparency:** It is sometimes challenging to find the right person with the right information. But efforts have been made lately to provide central contact points for administrative information and help, in most place, even in very little towns.

Workforce:

This should be the first priority. In 2023, a host of meetings concluded that there was a financial argument to put this priority high up the agenda. We need to increase the quality of work in the sector. Professionals receive very low salaries and indecent reimbursements for their moving/travelling costs. They start work very early in the morning and end their work very late at evening. Care must be ensured 7 days a week. They have little opportunities to get continuous learning and are not efficiently trained for palliative care. Their work can be physically very hard despite improvements in medical equipment technology. Many have problems with their back.

There are more and more foreign people recruited as carers. This can create a problem when these carers do not speak French easily, having in mind the fact that older people often have difficulties to hear and most of them like and need to exchange with their visitors.

Informal carers

For a long time, no real attention had been paid to informal carers. Nowadays the situation is slightly improving. Some facilities are possible at work in a few firms, and

carers have the possibility to organize their work according to their family duties, colleagues can transfer part of their free time (RTT) to a family carer in their firm, time spent as informal carers can be taken into account for pension credits.
It is possible for older people in need of care to access institutions during the day, which makes it possible for informal carers to keep their job.
Some associations organize training for informal carers.
We must underline the fact that most informal carers do a wonderful job and really care for their relative, often in difficult conditions and to the detriment of their own life, their career, their physical and psychological health and their family life. However, we must also be aware that problems may exist within families: abuse, harassment, neglect, sometimes because the situation has become too difficult, sometimes because of a lack of empathy and respect.

Governance

The present French government's key objective is to have the Parliament vote the authorization of "active help to die", which clearly means to authorize both euthanasia and assisted suicide, although a law does exist (Loi Claeys Léonetti – February 2016), which allows for deep sedation until death in case of strong suffering of the patient. There is a risk that such a law is cynically adopted to save costs, to compensate for the lack of medical and social professionals and for the lack of places into hospitals and institutions dedicated to people in need of care. The promotion of assisted suicide has been a heavy discussion for years, but reduced to the choice between dying with terrible suffering or dying when we want without suffering. However, palliative care has not been part of this discussion although it has been proven than less people with a will to undergo euthanasia to a large extent do not maintain that wish when they have effective access to quality palliative care. Long-term care and palliative care in general have not been an important issue for the government despite very ambitious and very sensible plans, which largely remain wishful thinking since the necessary means are not allocated.

Germany

Comments provided by BAGSO

Main priorities for reform: compensation for informal carers, shifting the responsibility for ensuring care and choices in the care type to the municipalities

Adequacy and social protection:

Good care must be adequately and permanently financed. A need for nursing care and assuming the responsibility for providing it as an informal carer must not lead to dependence on social assistance or poverty.

A sustainable limitation on co-payments must be implemented urgently, e.g. by the way of turning the reimbursement system around: there would be a need for an upper

limit of co-payments and responsibility of the care insurance for the remaining (variable) costs. Co-payments could also be reduced by having investment costs covered in full by the federal states and the costs for medical treatment in in-patient nursing facilities by the health insurance companies.

Care has developed into a lucrative market in which profitability aspects play an increasingly important role. However, the quality of care and contributions to long-term care insurance must not be dominated by the expectations of return on investment of service providers and investors; at the very least, there is a need to define limits for profit-making.

Care service offer and care needs:

BAGSO calls for the mandatory introduction of a case and care management system coordinated by the municipalities. This should include regular and needs-based preventive home visits to older people in order to determine the need for support, directly and precisely *in situ* and to develop individual assistance plans based on this. These serve as the basis for individual benefit arrangements with the involvement of professional service providers, family support and civil society services. The counselling centres should be tasked with reporting to the municipality any additional needs that cannot be covered by the existing services.

Employment and working conditions:

The roles of the actors in the health and care sector must be designed in such a way that they better meet the needs of people in need for care and their relatives and conserve the human resources that are generally in decline. To this end, the roles of medical and social care must be changed, and their interaction optimised. Since social and health care are equally responsible for quality of life, health care must no longer take precedence or sovereignty over social/long-term care. The appropriate structures for training and professional development must be created in long-term care, while the work and remuneration conditions in the care sector must ultimately be designed in such a way that people can be employed in the long term in his field too.

Informal carers:

BAGSO calls for the introduction of a wage replacement for informal carers up to three years. The Independent Advisory Board on Work-Care Reconciliation set up by the Federal Government presented a detailed concept for this in 2022, which must now be implemented. Moreover, any disadvantages suffered in career or pension must be compensated.

Governance:

In view of BAGSO, it is necessary to assign the responsibility for the management and design of long-term care services to municipalities, and to provide them with sufficient

funding. With its call for new structures for care under municipal responsibility, BAGSO takes up a central point of the Federal Government's Seventh Report on Older People (2016), which has shown what role municipalities can and must play in shaping life in old age. To ensure equal care structures that take account of local structural characteristics (e.g. large cities, rural areas), municipalities must be obliged to collect data on population and care needs on a regular and territorial basis and, based on this, develop a needs planning for all areas that have influence on the lives of older people. This can be embedded in an overall concept for ageing policy.

For more details:
https://www.bagso.de/publikationen/positionspapier/positionspapier-sorge-und-pflege/

Italy

Contribution submitted by Older Women's Network Europe (Italy)

Priorities for reform: non-regulated privatisation, financing of the reform carried by law 33, need for specialist skills

In 2023 Italy issued Law 33[1] on Delegation to government on policies in favour of older people, both self-sufficient (on development of healthy ageing policies) and in need of care. In some respects, it resembles the EU Care Strategy. Lately (19/03/2024) a regulatory Legislative Decree came into force[2]

Adequacy and social protection:

Law 33 states that the sustainability of long-term care will be assured by the "Universal Performance" (max 850 euros per month) in the form of a financial allowance, or equivalent services identified upon the care needs of the patient. Under Legislative Decree no 29, the measure will be experimental for the coming two years. The Universal Performance enhances the previous "Accompanying allowance" only for very few people (annual income not above 6.000,00 euros)

Care service offer and care needs:

Art 4 of the Law 33 defines the Essential Levels of Health Care for people in need of care and a more simple and efficient assessment of needs and access to services at

[1] Full text on Gazzetta Ufficiale

[2] See the complete text on Gazzetta Ufficiale

home or in hospitals. The adoption of a monitoring phase regarding the way in which the ELHC are performed is also mentioned. The Legislative Decree, however, only postpones the adoption of a monitoring framework to a future decree.

In some regions, a financial choice seems to have been made to rather develop residential care than home care, following a budget review.

Quality

There is not sufficient control for private care facilities, quality is lower.

Employment and working conditions:

Art 5-point b3 refers to the identification of Region's professional requirements in the field of psycho-social health.

Non-regulated privatisation is a big issue for us all, professionals evade the public and go private and charge higher prices, creating labour shortages for public and not-for profit providers.

Art. 5 points b1 and b2 of the Law 33 refer to training and training standards. In the implementation of Law 33/2023, Legislative Decree no. 29/2024 establishes that National, Regional and Local authorities have the responsibility in defining the training paths to which the Regions CAN attain to develop nationally homogeneous training standards for professionals assisting older people in need of care, and in order to obtain the 'family assistant' qualification. There is however no mention of continuous training and regularization of undeclared work.

The geriatric specialisation has been abolished in Italy some years ago, because it was considered not necessary anymore. Older people with specific needs (cardiovascular, etc.) go into the generalist department in hospitals, but the numbers show that there is a big share of older persons in generalist services. It might be better to re-develop geriatric specialisation to provide adequate care for them.

Informal carers:

Art. 5-point c2 states that informal caregivers will be awarded with certifications for competences and skills acquired in the caring process. The Legislative Decree no. 29 recognize the value of informal caregivers and involve them in the definition of the caring process. Non-economic support is also mentioned.

Governance:

Under Law 33, the governance was accorded to a new institution, namely the National Caring System for People in Need of Care (an intergovernmental pool of experts, regional and local authorities with the active participation of civil society). In spite of

this provision, under Legislative Decree the Ministry of Labour and social Affair will be in charge of the governance the coordination, organization and governance.

Law 33 has been drafted with the essential contribution of *Patto Per la Non Autosufficienza*. However, the Legislative Decree has been approved by the government regardless of the many amendments requested by the Parliament and the civil society, leaving civil society organisations disillusioned[3].

Malta

Comments provided by National Association of Pensioners

Main priority for reform: attractiveness of the long-term care sector for employment, develop the sector in view of increased demand

Adequacy

It bears pointing out that like most other EU countries, Malta has an ageing population and therefore the demand for long-term care, whether in the community or in elderly homes, will continue to increase in time. Malta also has one of the lowest, if not the lowest in fact, fertility rates which according to latest EUROSTAT data, in 2022, stood at only1.08 and this will likely add to the problem in the long run.

Workforce

There is a need for attracting more Maltese youth to take up work in the long-term care sector. The present situation is that the country is becoming increasingly reliant on the importation of foreign workers, mainly from outside Europe, to compensate for the lack of Maltese workers employed in this sector. Such work has become unattractive and not much sought-after by Maltese youth.

The reasons are various, not least the relatively low pay and strenuous physical demands which care work with elderly people often necessitates. As is to be expected, when it comes to foreign workers, this situation is not fraught with difficulties, particularly insofar as the language barrier is concerned, and also the overall quality of long-term care service provided. It is pertinent to note that the Minister responsible for this sector in Malta has recently indicated that these workers will be required to have a basic knowledge of the Maltese language to work in long-term care provision.

In these circumstances, it is important that measures are introduced to encourage younger workers to move into the care work sector, as otherwise, the problem will become even greater and more foreign workers will have to be imported from abroad.

[3] Decreto Anziani: (dis)illusioni e possibili ripartenze per la non autosufficienza • Secondo Welfare

Netherlands

Comments provided by Oudere Vrouwen Netwerk Nederlands

Priorities for reform: Staff shortages, privatization, burden of administration, adequate housing

Availability

On paper, all forms of care are available, but in fact there is a shortage of services for people in need of care living at home. Another issue are people who are stuck in hospital because of the long waiting s in residential care.

Availability of services is fragmented, especially regarding home care, after the effect of liberalization of the care sector and public procurements procedures.

Quality principles

- Respect: the guidelines and regulations seem to guarantee 'respect', but the means allocated disprove this
- Prevention: after years of neglect for this topic, there is more awareness and attention to developing prevention, such as public awareness campaigns.
- Comprehensiveness and continuity: the stakeholders involved in care could work better together.
- Focus on outcomes: Carers have to spend too much time on administration and documentation.
- Facilities: residential care homes were closed, which forces people to stay home. However, there is not sufficient accessible and/or adaptable housing for older persons in need for care, so many are locked into inadequate housing.

Workforce and skills

- The liberalisation of the market led to the reduction of staff (not enough new was trained). Many people were trained in care institutions to build their career, but the number of institutions were reduced, they did not stay on.
- Salaries are less attractive than for other professions.
- There is a need for more in-service training.

Informal carers:

In many situations, the fact that there are informal carers mean the reduction of time formal carers.

Governance

There is a multiplicity of care need assessments that bring a lot of red tape. There are over 10.000 signatures for a petition to Parliament by formal carers, who spend more than 10 hours per week in administration of care. Informal carers face the same challenge.

Privatisation is an issue. Private equity companies are buying practices of doctors, dentists etc. and develop private care, where working hours are cut down and quality is reduced. Some doctors have only teleconsultations, which are less accessible to older persons and persons with disabilities.

Norway

Comments provided by the Norwegian Pensioners' Association

Priorities for reform: Staff shortages, development of home care and residential facilities

Availability of services:

A new reform in Norway has been launched about 'stay safe at home'. There is political will or wish for older persons to stay at home and need for a reform. Staff and housing are two main pillars of this reform. This year is the first that this reform is launched, we are expecting that the national assembly finishes the discussions next year.

Patients' organisations and carers' organisations ask for more residential facilities, because there is a lack of trust into home-based care. There is a feeling of safety connected to the fact of having staff available 24/7.

Workforce

Even as one of the richest countries, we face staff shortages, because of the massive needs related to ageing. The issue is not money but to find available health carers. This year, there was a dramatic decline in enrolment for nursing studies. In some rural areas, only 1/3 of the available student places are lacking students. As a rich country, we could import carers, but the official stance is that we shouldn't. But many people do come from Philippines and Eastern Europe to work as carers in Norway.

Governance

There are very few private nursing homes, and those which are private are mainly non-profit. Those who tried did not succeed because they did not deliver good quality.

Poland

Comments provided by Alzheimer Polska

Priorities for reform: staff shortages, quality of care, accessibility across the territory and of all forms of care

Affordability:

Long-term care provision relies heavily on informal (family) caregivers, mostly women. Most older adults have insufficient financial resources to self-finance their long-term care, especially for the costs of some residential LTC services for which they have to pay out of their pocket. Other services are co-financed at fixed rates that vary depending on the income (as they are means-tested).

One of the priorities for the government should be unification of the costs of LTC services, so that people in need of such care could afford them. Older people in need of LTC perceive the differences in the costs of staying in a residential nursing home (financed by local government vs. financed by the National Health Fund) as discrimination. They see no reason why they cannot be charged the same amount for LTC, regardless of the type of nursing facility.

Today, the cost of stay in a public welfare nursing home (DPS) is first charged to the beneficiary and their close family, and only when the person concerned is unable to pay does the local government step in. As for granting a place in the residential welfare nursing home, often the income threshold allowing the right to stay in such a nursing home is too low, and therefore becomes a barrier to even apply for such care. Co-financing of the care in such a nursing home by the family is highly challenging to them, which means informal, family carers have to carry on providing care on their own, often without public support.

On the other hand, residential LTC services offered by a healthcare nursing home are financed by the National Health Fund, with the beneficiary paying “an accommodation” fee amounting to 70 percent of their monthly income, which is much less than in a welfare nursing home. Therefore, the waiting time for a place in such a rehabilitation institution is much longer, and much more difficult to obtain.

Funding LTC is not necessarily the biggest challenge for the government, especially that underfunding is a problem, well known to current authorities.

Availability

Too often the services do not cover the potential users’ actual needs, as the services are either not available at all, or if they do exist, they do not address particular or changing needs as a person’s disease or disability develops. Access to care is limited by a long waiting time to get a care needs assessment, as well as by income threshold,

which entitles to certain services. If one's income is higher, care services cannot be granted, and one has to rely on private care services.

Care services are organized by both public and private sectors. As the private sector is mushrooming and the cost of stay in a private nursing home is similar to the cost in a welfare nursing home, waiting time is much shorter. There are a few very good, but very expensive private nursing homes which people with average income cannot afford. However, most private nursing homes offer lower quality care and untrained staff.

There are still significant regional differences in the provision of long-term residential care, day-care, as well as the number of well-trained staff. There is an issue with access to long-term care outside of bigger cities. Setting up more day care centres, offering respite care and granting hospice care in rural areas is needed. Access to palliative care is restricted to a set list of diseases, which excludes some conditions such as dementia and disregards actual needs.

The gaps are sometimes filled in through NGOs' support and initiatives who often lack financial resources to continue their care work. NGOs who offer care services should be recognized and helped by offering continuous government support.

There is a need to develop home care services, which are often cheaper and more welcome by persons in need of care, instead of living in an institution, as well as day care centres tailored to particular needs and wishes of the users. These should offer therapeutic and meaningful activities, diminishing social isolation, and in this way be a form of respite to informal carers and enabling them to continue working.

The biggest challenge in the access to facilities is our current law. People with long-term care needs should be able to decide and express their wishes. This is impossible today; it is the family who decides on their behalf, or the court. Incapacitation procedures are still in force in Poland but should be replaced by supported decision making.

Quality/Adequacy of care services

Quality often suffers because of poor recognition of older peoples' needs, and differs a lot in long-term care facilities, depending on the staff attitudes to the persons they care for, their training, the number of staff employed, and their working conditions.

Despite appropriate government regulations on those matters, often they are not followed for financial or other reasons, mostly attitude and inadequate training of the staff, as well as staff shortages.

Therefore, there are still cases of abuse of respect and dignity, improper staff attitude towards older people, cases of improper, discriminatory language used by the staff,

and neglect of their needs and human rights, often because of lack of understanding the needs or limitations of people who cannot express their will or are not even asked to express their wishes. Thus, the concept of person-centredness seems still one of the biggest challenges in the training programmes of people who are employed in LTC. However, the shortages in work staff form a serious challenge, which the government should deal with in planning the development of quality in long-term care facilities and in deinstitutionalization of care.

Workforce:

Staff shortages in LTC provision seems to be the primary issue to tackle in Poland. There is a decrease in the number of care workers, while at the same time there is an increase of the need to get quality care services at home or close to home, in the community. There are various reasons for the shortages: low wages, and thus lack of motivation, attractiveness, status, and recognition. Becoming a care worker, and especially to support the elderly people, is considered not an attractive job. The challenge is to motivate young people to take up such a job and see it as a career.

Government has recently promised a substantial pay rise for nurses employed as care workers, which is a positive signal, as the differences in payments between social/welfare and medical care facilities were discouraging nurses and other care staff from entering social care.

There is unequal access to geriatric care, as there are only 560 geriatricians, and some Polish regions have none. Experts believe there should be some 3,000 to adequately cater for the population, but few doctors want to choose this specialisation.

Poland needs also more well-trained staff in palliative and hospice care.

Informal carers

The family has traditionally been the main provider of LTC. Currently, there are mostly (80% and predominantly women) family members, like spouses or adult children of the person in need of care who carry the burden and responsibility for caring. Their needs are often ignored or not sufficiently understood and recognized. They should be helped with regular breaks, holidays, respite care, flexible working hours, if they combine care with work. They also expect information on available services, on how to get access to them, on their rights. Training should be granted to them on regular basis, including psychological education to avoid burnt-out. They constitute a large group of unpaid care workers which should be entitled to special benefits, as they pay financial, social and physical price for caring.

Governance

One of the biggest challenges for the governance of long-term care is collecting data on the health and care needs of older persons to be able to plan the development of care services. Another challenge is integration between the health and social sectors of care, both in terms of service provision and financing.

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