

Dignity first – priorities in reform of care services (Sweden, 26-27 September 2013)

For a holistic approach to wellbeing and active ageing in care services¹

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Introduction

AGE welcomes this Peer Review and thanks again Sweden for hosting this debate. In the context of the current crisis, protecting dignity in care services is a challenge in all EU countries. The topic of the Peer Review 'Dignity first' sets up the right priorities.

Our members report that the current crisis has an impact on older persons' access to care services. While new technologies can help tackle this challenge, technology acceptance, availability and affordability are the main barriers for scaling up such solutions. Care reforms have to include the development of outcome oriented quality systems developed on a multidisciplinary and participatory basis.

Over the last years, several reforms on long-term care services for older people were introduced in different member states. While some reforms unfortunately tend to focus exclusively at reducing costs, AGE welcomes other reforms aiming at improving quality and efficiency in care delivery. Age friendly environments and support to preventive and rehabilitative initiatives, together with the development of an appropriate choice of care services and targeted support to frail older persons in need of care is the way to go to support older people as they age.

1. What are the current situation and the recent trends in the countries of your members in relation to home care? Are innovative approaches similar to the Swedish case already applied (e.g. free choice systems, person-centred approach)?

The current crisis has an impact on older persons' access to care services

AGE members report that the current crisis has an impact on the availability, accessibility and affordability of care services and on older persons' free choice, as well as on the long-term sustainability of the care systems. Our Dutch members reported that cuts in pensions and healthcare coverage are creating barriers for older persons with low income who can no longer afford the care services they need. In Czech Republic, responsibilities for care rely increasingly on older persons and their families with a risk to limit access to care services only to those who can afford it and let families cover to a large part the care costs of their dependent relatives. In the UK, increasing expenses by older persons on energy and food, together with reduction of social care budgets impacted on accessibility and

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availability of care services. Some EU countries are clearly in a very difficult situation compared to others (such as Greece, Spain, Portugal or Italy) and there is an increasing concern of the impact inequalities may have on older persons in the EU.

While these measures may impact quality care and quality of life of older persons, they also may impact informal carers, whose majority are women. Without an adequate support, informal carers are at a high risk of social isolation and burnout. A sustainable long-term care system cannot rely exclusively on informal carers. Our Dutch members are particularly worried about the increasing support asked from families to cover the need for care, cuts in professional care and the impact it will have in the longer term on the quality of life of older persons and of their informal carers and on the overall sustainability of the care systems. This is true especially if nothing is done to develop rehabilitative programmes and age-friendly environments.

Our members report also that home care is the preferred option of most persons in need of care mainly because they can keep a social network (family, friends, neighbours, local shops) and control over their life. Understanding this increasing demand to age at home, some local and regional authorities have developed very valuable initiatives to promote age-friendly inclusive environments. These include a more person-centred care, intermediate housing or improved choice for older persons, but also initiatives aiming to limit the impact of the crisis and create new opportunities for older persons in need of care to live autonomously. In Denmark in particular, a free choice system and support to rehabilitative programmes were developed and proved to be very effective so far in reducing the need for care. Initiatives to support informal carers and targeted support and training on dementia care for professional carers and volunteers were also developed in some countries. However there is still a lack of holistic approach to care services in many EU countries which limits the impact of some targeted and local policies on the overall care system. More examples of good practices can be found on the WeDO partnership website².

2. What is the experience of your member countries regarding the use of technology in home care?

ICT can support better care services but technology acceptance and affordability remain the main barriers

AGE members were involved in different European research projects with pilot sites aiming to test ICT for care solutions in different geographical and care settings³. Results turned to be generally positive and showed that ICT can help anyone to live more independently especially as they support preventive and rehabilitative processes. They also showed that older persons need to experience technology to concretely see how it can improve their daily life. These experiences also enable to draw some lessons on the development of ICT in care.

EU countries have very different experiences regarding the use of new technologies in home care as we could see from the different feedbacks we received from our members. According to AGE members, the main issue for older persons in need of care and their family is ICT acceptance. In some countries they identify in particular a lack of awareness and experience on how ICT can concretely help them keep control over their care and life.

² www.wedo-partnership.eu

³ See www.age-platform.eu/age-projects/all-projects



Affordability is also a key issue. There are important discrepancies in the way health/social care systems support the costs for ICT, even with basic technologies like social alarms. In many countries, there is still a very low public support to the use of ICT for care. And even when renting a product is an option, the price per month remains sometimes too high for many older persons. Some efforts are made at local/regional level but too few countries actually developed supportive national-wide policies.

Technology reliability and the concrete usefulness of some technologies are still questioned by some older people. First because the market of technologies in care is mainly targeted at safety so far, i.e. to emergency situations and assistance in case a problem arise, so older persons may not feel attracted; second because older persons are normal users of technologies, i.e. they are interested in useful and attractive technologies where they concretely see the benefit they can gain. They favour the use of mainstream technologies (like tablets, smartphones with different apps, mainstream videoconference systems, etc.) and ICT targeted at relevant activities in their daily life. This ranges from accessing online public services, to meeting people, playing games, participating in activities, etc. They also recognise that assistive technologies can be useful to support them in specific situations. Supportive initiatives aiming to involve older users in testing and developing new technologies, as well as training both older persons in need of care and their carers to ICT skills appears to be an asset to support the use and diffusion of technologies in care. While ICT should not be seen as the single solution to support the coordination of care professionals, it can help exchange and sharing of information between them and improve information and advice in care for older persons. Training and investigating concrete experiences of supportive coordination ICT systems may help to improve our knowledge in that area⁴. User friendliness of the software and hardware is also important, like for any other age group.

Other issues are raised concerning ethics when using ICT for home care, such as data protection, or the importance to keep direct social contacts together with virtual contacts. The use of sensors or robots may create challenges in the future concerning the right to intimacy and the capacity of older persons to keep control of their life and care needs.

Last but not least, access to Internet remains a barrier if not the main barrier older persons experience. An ICT for care policy should go in hand with an investment strategy to ensure broadband coverage across the country like other commodities (water, electricity, etc.).

3. How is the quality in the provision of services monitored in the countries of your members (e.g. quality registers)? Which information/indicators are being used?

Lack of transparency on how quality is monitored and controlled in care services and the need to use more outcome oriented indicators

There is a great variability in the way quality of care services is monitored across the EU which makes it difficult for older persons to get transparent information on care services in their country and in other Member States. While in Sweden quality registers are set up at least regionally and complaints can be officially filled in, our members reported that in Slovenia there is no legal obligation for a care provider to follow a quality monitoring and control system.

⁴ See the recently launched SmartCare project on ICT for integrated care: <http://www.pilotsmartcare.eu/>



Our members reported in particular the lack of information and publication of quality controls and monitoring which is a barrier to older persons to make an informed decision when choosing for a service. Only in a few countries like Ireland and Germany, results from inspections are publicly available. Few external quality controls of professional home care services are made⁵.

In most countries, quality indicators are focused on quantitative measures (i.e. number of beds, number of carers, etc.). Results from the WeDO Project showed that outcome-oriented and evidenced based quality LTC monitoring and control needs to be developed, highlighting that the ultimate goal is to improve the wellbeing and autonomy of the person. Few countries have developed such system⁶. The WeDO European Quality framework for long-term care services could support such initiatives at EU level by providing general outcomes to achieve from the service users' point of view⁷. The WeDO partner Austrian Red Cross is currently preparing a checklist for service providers of care services based on the quality principles and areas of action of the European quality framework for long-term care services.

4. What kind of impact have the related policies on the different actors involved in the care process – users, carers, health professionals – for example in terms of independent living, quality of life or work-time savings? In which ways can quality and accessibility of care services be balanced with sustainable finances?

Person-centred preventive and rehabilitative approaches proved to have a positive impact on independency, quality of life and cost efficiency

Our members (following the conclusions of the previous Peer Review) highlighted the very positive impact preventive and rehabilitative initiatives have on the quality of life of older persons and especially on their capacity to empower older people to remain autonomous for much longer⁸. Personal targeted training proved to be a good option to reduce the need for care, together with accompanying care reforms with adequate training to care professionals. Denmark is a good example as from 2008 to 2012, the number of people that are older than 65 years has increased by

⁵ For example: started from a system applied exclusively to care homes, the Eqlin system now includes a quality monitoring system with outcome oriented indicators for home care services which are at the moment used in Austria and in Germany.

⁶ A few examples: the German initiative heimverzeichnis.de is a quality monitoring system delivered by trained volunteers⁶. This initiative takes stock of the European Charter of the rights and responsibilities of older people in need of care and the WeDO project. The Irish National Quality Standards for Residential Care Settings for Older People are also outcome oriented⁶ and evidenced based (i.e. standards are developed thanks to proved successful practices and peer reviewed by experts).

⁷ See www.wedo-partnership.eu

⁸ For example:

In the WeDO project, a concrete example of a small project on improving resident's bladder continence proved to show concrete outcomes in terms of independent living, quality of work for carers and costs savings (cf. p13 of the European quality framework for LTC services).

In the UK, the POPPS Programme (Partnership for Older People's Projects) proved to be very useful to foster prevention initiatives. The programme was funded by the Department of Health to develop services for older people, aimed at promoting their health, well-being and independence and preventing or delaying their need for higher intensity or institutional care. The evaluation found that a wide range of projects resulted in improved quality of life for participants and considerable savings, as well as better local working relationships.



13% but the number of people that receive homecare has decreased by 14%. Denmark is focusing on developing a more active care rather than a passive support, through rehabilitation, preventive action, the use of technology and the opportunity to involve volunteers. Our Danish members however highlighted that person-centred care is very important to adapt the rehabilitative programmes to the needs and expectations of older persons and not force people to use a standard model of care. Finally, as mentioned in the discussion paper, age friendly environments already proved to be efficient in improving older persons' quality of life and wellbeing in many cities and regions in Europe. A network should be launched next year to support a wide exchange of knowledge and practices in this field. This will be done thanks to a call for proposals issued by DG CONNECT to set up a thematic network on age-friendly environments, launch a European Covenant on Demographic Change and support work done in the European Innovation Partnership on Active and Healthy Ageing on age-friendly environments.

Such examples show that it is possible to reach a balance between sustainable finances and quality and accessibility. But it is very important to continue to guarantee access to health and LTC to all based on their needs rather than on their contributions to the health insurance or personal income. Women are particularly exposed to higher risks of poverty because of lower pensions in general, as well as housing difficulties. Attention must also be paid to the needs of the most vulnerable (older people with low income, polymorbidity and complex needs, persons in end of life care, persons with dementia) keeping in mind that even an average pension may not be sufficient to cover all the additional costs that such health condition brings to the individual's budget – costs of long-term care can indeed lead to poverty considering the high level of costs incurred.

More globally, a life-cycle approach is needed to ensure that expenses are targeted and implemented at the right time to ensure the optimum added value. Such approach implies a close examination of the impact of all policies on health, more investment into health promotion, a focus on health and safety at work and the avoidance of limited and less effective ad-hoc vertical approaches.

The organisation of health and social care systems needs to be better coordinated to deliver a more effective task sharing between informal and formal carers and to optimise the complementarity between different structures and/or professions. Initiatives that proved to work in that area were the ones targeted at improving the recognition and value of care work, thus improving the image of the carer, and enabling care workers and assistants to work in a more holistic and flexible approach. The Buurtzorg example in Netherlands goes in that direction⁹.

Conclusions and recommendations

In AGE last General Assembly declaration, we call for a holistic approach to wellbeing and active ageing and a better coordination of actions between the various health and social services. We also call on the EU and member states to take action to combat elder abuse and ensure a dignified end-of-life for all. Finally, we want to raise awareness of individual and collective responsibility in accompanying each one of us in the final stages of our life.

It has to be reminded that better quality life of life means that the person will keep on doing more things on its own when possible. A quality service with outcome oriented indicators is expected to save public and private money on care services on a longer term thanks to a good balance between prevention, interventions and rehabilitation activities. Improving quality of end-of-life care services and fighting

⁹ <http://www.buurtzorgnederland.com/>



against elder abuse are also specific areas where more needs to be done to guarantee dignity in care.

Finally, cuts in LTC will have a detrimental impact on the employability of informal carers, mainly women and older workers but also on the number of professional carers available. An adequate provision of LTC complemented with efficient support measures to individual older persons in need of care and their informal carers is needed. This means that a holistic approach to long-term care and a comprehensive vision of older persons' care needs is the best way to respond to the expected increase in the demand for care, protecting dignity and preventing a rise in inequalities in Europe.

