



POLICY PAPER

DEMOGRAPHIC CHANGE: AGEING AND LONG-TERM CARE

“We’ve put more effort into helping folks reach old age than into helping them enjoy it”. Frank A. Clark¹

Summary of Eurodiaconia Recommendations

Healthy, active ageing

Preventive care

- Public authorities must think long term, making good commitments to invest more in preventive care
- More research to prove cost effectiveness of preventive care should be carried out, and member states should share initiatives in this area, to enable more and better spending in this area

Tackling isolation and poverty

- Public authorities must invest in services for older people as well as for children in order to foster economic growth, create jobs, ensure quality of life as well as help people.
- Social services that seek to reach the most marginalised older people, including experimental pilot projects, should be financed
- Where social services are provided for remuneration they must be affordable to all
- All stakeholders should develop and reinforce participatory structures and methodologies, in addition to volunteering opportunities, which develop supportive communities.
- National governments must work towards adequate minimum income schemes. The European Commission should intensify support to Member States, facilitating policy and practical exchange

Independent living, Assistive Technologies (AT) and Ambient Assisted Living (AAL)

- Public authorities should provide persons in need with devices regardless of costs, focusing on increasing the capacity of people to make decisions for themselves
- The EU should promote the access and the right to technical devices and solutions not just for people with disabilities (as in the EU disability strategy 2020) but also for older people
- Research into technological solutions must incorporate service users’ perspectives and research projects in this field must involve long-term care service providers
- Calls for proposals under EU Research programmes relating to long-term care and ambient assisted living should ensure the engagement of service providers

¹ American journalist writing in the 20th Century



Ensuring a supportive framework for long-term care

Comprehensive, accessible, integrated care systems

- Public authorities must examine the different options for financing long-term care in the context of guaranteeing access to quality care to all who need it
- National legislation introducing mandatory schemes to ensure access to quality care services in old age should be introduced (for example, care insurance ensuring comprehensive coverage)
- Public authorities should develop integrated health and social care systems, to reduce barriers to effective service provision as well as promote an exchange of knowledge throughout the so called cure and care sectors
- Public authorities should take an integrated, multidisciplinary approach to policy and planning of social services, including, for example, ensuring transport links to services (of particular importance to older people)
- Public authorities should pursue increased cooperation between health and social sector staff, including interdisciplinary work and networking for mutual learning.
- The relevant funding, supervising, and legislating authorities and institutions at all levels must ensure that the financial, social and regulatory environments are such that social service providers are able to fulfil their missions
 - Stable funding, including funding for investments to enable sustainable provision is essential
- When tendering for social services, contracting authorities must award contracts to provide social services based on the “best quality for money”; best value rather than the cheapest offer
 - Such tendering must include consideration of independently verified quality criteria
 - Alternative financing and contractual arrangements to tendering should be considered, such as the Swedish and German models, which may be more appropriate for certain social services
- The EU and member states should develop more (specific) data on long-term care, in order to inform analysis and planning

Understanding the needs of older people and personalised care

- Varied and flexible forms of residential, community, respite and home care should be promoted, aided by investment and research into new ways of providing services
- Public authorities should ensure services in the field of palliative care, counselling for relatives and grief counselling are supported
- Public authorities and the European Commission should promote academic research on old age and needs in terms of long-term care, including dementia, as well as careers in geriatrics and age-related disorders and specialisms
- Training for treating medical conditions and addictions should include the specificities of working with older people, the socially excluded, mental health and people with a migration background
- Training and education in long-term care should include diagnosis of dementia and medical and non-medical treatments for dementia

Building inclusive, age-friendly societies

- Public authorities should ensure housing and other buildings are physically accessible and safe for the elderly when built, dispensing with the need for retrofitting
- Public authorities should support services which promote participation in all areas of life
- Public authorities should promote inclusive societies and age-friendly environments through campaigns and a holistic and participatory approach to urban planning
- The European Commission should work with Member States to implement a European-wide awareness raising campaign on the topic of people with dementia



Intergenerational understanding and solidarity

- Initiatives during the 2012 European Year, including campaigns to build intergenerational understanding and appreciation, should be built upon to continue making a positive impact
- The EU and national governments should ensure that active ageing and intergenerational solidarity remains on the political agenda
- Public authorities and the EU should promote and support projects financially that facilitate exchanges between generations, such as intergenerational houses and meeting places and those that link schools with homes for older people

Informal and family carers and jobs in the care sector

- Increase the recognition of informal and family carers, for instance ensure health insurance, the right to a pension, recognise informal qualifications and where necessary provide financial support
- Promote flexible working arrangements to enable informal carers to care for family members
- Public authorities should support people re-entering the job market after periods of informal or family care
- Public authorities should carry out awareness-raising activities in order to change attitudes towards informal care and support special services for relatives, such as respite care, Alzheimer Cafés or self-help groups
- Public authorities should ensure a financial framework in which social service providers can pay decent, competitive wages and provide training and lifelong learning
- Providers should develop care workers' roles, giving more responsibility and widening their skills and knowledge base
- National information campaigns to promote working in the social sector should be initiated

Introduction

By 2050 more than a quarter of Europeans will be over 65 and the proportion of those over the age of 85 is expected to be 6%². Despite the fact that the average health of the EU population has increased in recent years, as disability and chronic illness increase with age more people will need more complex social and health services. By 2030 the number of people with dementia globally is expected to double and more than triple by 2050³. These trends require adaptation of the types of services and activities service providers provide. Many Eurodiaconia members report a lack of capacity in care homes and some organisations have had to refuse users because of this.

There will also inevitably be more pressure on families as increasing numbers of older family members will have higher and consequently more expensive social and health care needs, and as a result the provision of informal care by family members may increase. Alternatively, given pressures on family members to be active in the labour market, demand for formal care may increase⁴. Although both scenarios might coexist, due to decreased fertility rates in the last years (at least Western European) families tend to have one or maximum two children and generations increasingly live apart from one another. This also means that the burden of informal care cannot be distributed amongst relatives compared with former generations. In addition, a marked decrease in the working age population is predicted⁵. Incomes from social security contributions will therefore be in decline, and in addition public finances suffered from the counterproductive austerity measures during financial crisis of recent years. How can the increase in care needs be met in this climate?

² Eurostat, own calculations

³ World Alzheimer Report 2013

⁴ European Commission Second Biennial Report on social services of general interest

⁵ European Commission 2009 Ageing Report



Despite an increase in demand for services, Eurodiaconia's member organisations experience falling income and therefore increased difficulties in providing their services. Those with care needs are often seen as a burden by society, and the "challenge" of ageing in economic terms is often referred to. They are demanding a change of attitudes – away from seeing older persons as a burden and with incapacities, towards seeing their capabilities and possibilities. Ageing can bring positive developments, including allowing us to positively re-adjust the work-life balance and to experience new stages of life.

Investing in medical research and technology has led to increased life expectancy and increased autonomy for older people with care needs, but what investment do we put into ensuring older people live in dignity, free from poverty and social exclusion? How can we ensure all older people can live "active" lives?

Ministers from all EU countries agreed that it is essential to involve civil society in the work to promote healthy ageing.⁶ Many proposals to tackle demographic change have been endorsed by EU heads of state and government but it appears that little action has been taken.

This paper does not aim to deal with all issues relevant for ageing and long-term care, but focuses on Eurodiaconia's members' key concerns and recommendations in these fields in relation to social and health services and social inclusion.

Healthy, active ageing

Tackling isolation and poverty

*"Poverty adds to the isolation of older people and their isolation in turn exacerbates their poverty"*⁷

Ensuring older people can live in dignity must be a policy priority. Eurodiaconia members see that problems of loneliness and isolation are increasingly prevalent among older people and an increasing number of older people living in poverty. People aged between 75-85 often suffer from decreased physical mobility and autonomy and if family cannot afford non-essential care services or visits there is a risk of isolation which in turn can lead to a decline in living conditions. With increasing mobility, children are less likely to be living near elderly parents. Human contact with care providers is essential and home care services can also be proactive in reaching out to the elderly not living in a residential setting.

It is essential that pensioners are entitled to an adequate minimum income sufficient to live in dignity, lifting them above the poverty line, as agreed by EU governments in the 1992 Recommendation on minimum income and reiterated in the 2008 Active Inclusion Recommendation.

Changing public perceptions of older people so that society better values their contribution will help build support for actions to tackle poverty and exclusion and to guarantee access to quality social services so that older people can live in dignity. Investing in quality curative and preventive social and health services is essential to enable active ageing for older people, particularly those with care needs.

- Public authorities must invest in services for older people as well as for children in order to foster economic growth, create jobs, ensure quality of life as well as help people.
- Social services that seek to reach the most marginalised older people, including experimental pilot projects, should be financed
- Where social services are provided for remuneration they must be affordable to all
- All stakeholders should develop and reinforce participatory structures and methodologies, in addition to volunteering opportunities, which develop supportive communities.
- National governments must work towards adequate minimum income schemes. The European Commission should intensify support to Member States, facilitating policy and practical exchange

⁶ Council Conclusions on Healthy and Dignified ageing, November 2009

⁷ «La pauvreté renforce les processus d'isolement des personnes âgées et leur isolement renforce leur pauvreté» Etienne Martin in Proteste, March 2010



Preventive care

EU employment, social policy and health ministers have stressed the importance of preventive measures, calling on Member States to “to adopt an approach that shifts the focus towards preventive measures as a strategy to improve quality of life and reduce the burden of chronic diseases, frailty and disability”⁸. “Primary” preventive measures are particularly important, in terms of promoting healthy lifestyles, as well as secondary prevention, for early disease detection.

The Marmot Review on health inequalities in the UK stated that “*Services that promote the health, well being and independence of older people and, in so doing, prevent or delay the need for more intensive or institutional care, make a significant contribution to ameliorating health inequalities*”⁹.

- Public authorities must think long term, making good their commitments to invest more in preventive care
- More research to prove cost effectiveness of preventive care should be carried out, and member states should share initiatives in this area, to enable more and better spending in this area

Independent living, Assistive Technologies (AT) and Ambient Assisted Living (AAL)

The European Commission noted in 2009 “Dependent people prefer long-term care in a residential or community setting rather than institutional care, but in many countries institutional care still accounts for more than half of public expenditure”¹⁰. Eurodiaconia would make the same call to policy makers as the Commission did in the 2010 Demography report, “to develop policies aimed at preserving...financial autonomy as well as physical autonomy thanks to adapted housing, transport and access to services that allow older people to stay in their own homes for as long as possible.”¹¹ Enabling older people to maintain their autonomy necessitates a holistic policy approach.

The rising importance of AT and AAL must be addressed. Any form of device, from walking sticks to self-regulating cooking plates and voice-operated smart home options can be helpful for people in need of support. A growing share of older people are interested in new forms of support and, but stress the importance of human contact and quality interaction for well-being and to prevent social isolation and exclusion. Providing people with devices can allow them to live in dignity, increasing their capacity to decide and act on their own. In addition, it might be a cheaper solution for public authorities compared to residential care, although this should not be the driving force. Public authorities or social security agencies consider and mostly only fund conventional rehabilitation equipment, yet technical progress providing user-oriented solutions is evolving fast which means that many may miss out on opportunities offered by new solutions.

Discussions concentrate on privacy protection as well as affordability, regarding high costs for technical devices, but should also consider ethical issues as well as usability. We recognise the enabling role that technology can play in assuring independent living but losing human contact because of advanced technology in the home is a serious threat. Technical design has also to be oriented to human needs – and not the other way round. Technology must be developed with service users as an empowering tool that helps improve their quality of life and that of their carers.

- Public authorities should provide persons in need with devices regardless of costs, focusing on increasing the capacity of people to make decisions for themselves
- The EU should promote the access and the right to technical devices and solutions not just for people with disabilities (as in the EU disability strategy 2020) but also for older people
- Research into technological solutions must incorporate service users’ perspectives and research projects in this field must involve long-term care service providers
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⁸ Council Conclusions on Healthy and Dignified ageing, 2980th EPSCO Council meeting, November 2009 p5

⁹ *Fair Society, Healthy Lives*, Marmot Review, February 2010

¹⁰ Joint Report on Social Protection and Social Inclusion (2009) (European Council and European Commission)

¹¹ European Commission second European Demography Report 2008



Ensuring a supportive framework for long-term care

Comprehensive, accessible, integrated care systems

The integrated delivery of social and health services is essential to the future of elderly care. Taking into account complex living situations as well as ongoing individualised needs and a stronger focus of older people on right of self-decision making, comprehensive care systems could provide solutions. Regarding comprehensive care systems, barriers between professional, financial and legal matters must be overcome. This is particularly an issue where care services are organised at the regional and local level. Integrated care needs to ensure high quality service delivery, and coordinating and planning with different stakeholders is essential and must include prevention and rehabilitation and independent living.

We recognise that action needs to be taken in many member states to ensure that funding for quality long-term care (LTC) for all remains sustainable. However, any “re-balancing” of financial responsibility for LTC must be carefully considered and planned in consultation with all stakeholders (including older people and their carers) in order to address potential collateral impact on some groups of users and carers (for example women aged 50+) and to ensure that older people in need of care and their carers have access to the support they need for a dignified life. The involvement of private insurance in funding LTC must not detract from public responsibility to ensure ALL older people have access to quality care. Private funds therefore cannot be the only source of financing for LTC.

LTC still lacks data and academic research compared to other areas of social welfare and therefore comparative statistics on the number of people in need of care or assistance, staff, services, and quality management are not available. Meeting the needs of people and designing systems, however, should be based on valid data from across Europe.

- Public authorities must examine the different options for financing long-term care in the context of guaranteeing access to quality care to all who need it
- National legislation introducing mandatory schemes to ensure access to quality care services in old age should be introduced (for example, care insurance ensuring comprehensive coverage)
- Public authorities should develop integrated health and social care systems, to reduce barriers to effective service provision as well as promote an exchange of knowledge throughout the so called cure and care sectors
- Public authorities should take an integrated, multidisciplinary approach to policy and planning of social services, including, for example, ensuring transport links to services (of particular importance to older people)
- Public authorities should pursue increased cooperation between health and social sector staff, including interdisciplinary work and networking for mutual learning.
- The relevant funding, supervising, and legislating authorities and institutions at all levels must ensure that the financial, social and regulatory environments are such that social service providers are able to fulfil their missions
 - Stable funding, including funding for investments to enable sustainable provision is essential
- When tendering for social services, contracting authorities must award contracts to provide social services based on the “best quality for money”; best value rather than the cheapest offer
 - Such tendering must include consideration of independently verified quality criteria
 - Alternative financing and contractual arrangements to tendering should be considered, such as the Swedish and German models, which may be more appropriate for certain social services
- The EU and member states should develop more (specific) data on long-term care, in order to inform analysis and planning

Building inclusive, age-friendly societies

To ensure quality of life for older persons, particularly those with dementia, it is not only about caring from a medical perspective, but about assistance and support services to allow people to take part in daily life despite their condition. Societies and communities must become inclusive and age-friendly in all aspects, including for older people with dementia. Examples of inclusively designed communities are sports clubs open for people with



dementia, or cashiers in supermarkets and police trained in the area of dementia. The built environment can often contain barriers to older people participating in society and urban planning must take into account older persons and others with reduced mobility. Public authorities and service providers should work towards building acceptance and understanding of dementia in society, including through publicising experiences of people with dementia.

- Public authorities should ensure housing and other buildings are physically accessible and safe for the elderly when built, dispensing with the need for retrofitting
- Public authorities should support services which promote participation in all areas of life
- Public authorities should promote inclusive societies and age-friendly environments through campaigns and a holistic and participatory approach to urban planning
- The European Commission should work with Member States to implement a European-wide awareness raising campaign on the topic of people with dementia

Understanding the needs of older people and personalised care

Eurodiaconia has developed a detailed document on quality in social services which stresses the importance of integrated, flexible, continuous care, and lays down quality principles that service providers and their staff should follow¹². Service user involvement and empowerment is a key element. Service providers should see users as equal partners in creating their service plan and users should be involved in carrying out the service they receive, as well as its evaluation as they are able and wish to.

Service users' quality of life increases as services take into account their wishes and as users gain ownership over the process of service delivery. Service quality also improves as a better understanding of the users' wishes, capabilities and needs is gained and services are more tailor-made to the individual.

Eurodiaconia members witness that home care and support is increasingly in demand, as well as a broad range of flexible care services, such as day-care centres, semi-residential care settings and mobile services. Such flexible care based on the individuals needs is still often missing, but urgently needed in all member states. Some Eurodiaconia members note an increase in need for care of very excluded people for whom care homes are not adapted. Awareness of specific issues, an understanding of and tailor-made solutions to help people such as those with a migrant background and people living in poverty can help.

There is a need for more staff with specialist training in areas such as gerontology and dementia. Dementia and Alzheimers are increasingly common conditions in Europe and members of Eurodiaconia experience growing needs because of this, and calling for very different forms of long-term care. As numbers of elderly increase the occurrence of diseases prevalent in old age will also, as will mental health problems due to an increase in related risk factors. Tackling mental health problems in the elderly also needs a specific approach, but taking action in the areas of inclusion, access to services, health promotion and preventive measures will also contribute to better mental health. Addressing the stigma attached to mental health problems should also be a priority.

Overmedication in older ages is a challenge. On the one hand, numerous medicines are prescribed due to multi-morbidities, yet on the other hand mutual reactions often are not considered because of changes in health personnel or missing documentation. In addition, dementia is sometimes mis-diagnosed and often non-medical solutions for persons with dementia, particularly in the early stages, are more suitable.

Needs for palliative care are increasing due to complex medical indications and severe illnesses. Accompanying people at the end of their life as well as counselling for relatives, including dealing with grief, helps ensure that people can die in dignity and promote the well-being of all those affected.

- Varied and flexible forms of residential, community, respite and home care should be promoted, aided by investment and research into new ways of providing services
- Public authorities should ensure services in the field of palliative care, counselling for relatives and grief counselling are supported
- Public authorities and the European Commission should promote academic research on old age and needs in terms of long-term care, including dementia, as well as careers in geriatrics and age-related disorders and specialisms

¹² Principles for quality diaconal social services <http://eurodiaconia.org/our-work/policy-areas/social-services>



- Training for treating medical conditions and addictions should include the specificities of working with older people, the socially excluded, mental health and people with a migration background
- Training and education in long-term care should include diagnosis of dementia and medical and non-medical treatments for dementia

Informal and family carers and jobs in the care sector

Our members believe that informal carers are often not sufficiently supported in their role, both in terms of respite care or psychological support and in terms of benefits or pensions or entering or re-entering the labour market if their care responsibilities stop, for example, if a relative goes into formal care.

Many countries experience a shortage of workers in the care sector¹³. Jobs in the care sector are often not valued by society which means that the sector does not attract the workers needed. Irregular working hours, physical and mental burdens as well as increasing time pressure are discourage people to start their career in the care sector and it is a challenge for providers to ensure decent working conditions due to pressure on costs. Quality staff are essential for effective social services and service providers will need even more in the future due to the increasing demand for the services. Improving working conditions in the sector and promoting the image of care work would prevent some of the black and “grey” market work and abuses of migrant workers.

- Increase the recognition of informal and family carers, for instance ensure health insurance, the right to a pension, recognise informal qualifications and where necessary provide financial support
- Promote flexible working arrangements to enable informal carers to care for family members
- Public authorities should support people re-entering the job market after periods of informal or family care
- Public authorities should carry out awareness-raising activities in order to change attitudes towards informal care and support special services for relatives, such as respite care, Alzheimer Cafés or self-help groups
- Public authorities should ensure a financial framework in which social service providers can pay decent, competitive wages and provide training and lifelong learning
- Providers should develop care workers’ roles, giving more responsibility and widening their skills and knowledge base
- National information campaigns to promote working in the social sector should be initiated

Intergenerational understanding and solidarity

“To remain young while growing old is the highest blessing” (German proverb)

Eurodiaconia members observe a gap in intergenerational dialogue and perceive a risk of conflict between generations for economic resources. They members stress the importance of increased interaction and understanding between generations to build solidarity and maintain a willingness to contribute to financial solidarity mechanisms. Volunteering by all ages can help build intergenerational solidarity by creating links between young, middle and older generations and promoting mutual cooperation and interchanges between the generations. Ideas for mixing of generations should be promoted but be careful to take into account the wishes of older people, not forcing them to live in environments that they may not have chosen otherwise.

- Initiatives during the 2012 European Year, including campaigns to build intergenerational understanding and appreciation, should be built upon to continue making a positive impact
- The EU and national governments should ensure that active ageing and intergenerational solidarity remains on the political agenda
- Public authorities and the EU should promote and support projects financially that facilitate exchanges between generations, such as intergenerational houses and meeting places and those that link schools with homes for older people

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¹³ Biennial Report on social services of general interest, Chapter 2