# Input by the UNECE Population Unit
# to the 9ᵗʰ session of the Open-ended Working Group on Ageing

The Synthesis Report on the implementation of the Madrid International Plan of Action on Ageing in the ECE region between 2012 and 2017 reported on progress in implementing the objectives of the 2012 Vienna Declaration in which ECE member States had set the priorities for the implementation of the Madrid International Plan for the period 2012-2017. 45 national reports informed the report. This document presents relevant sections as an input to the two focus areas "autonomy and independence" and "long-term care and palliative care".

The full document is available on the UNECE website at this link:
http://www.unece.org/fileadmin/DAM/pau/age/Ministerial_Conference_Lisbon/Practical_infos/Synthesis_report_MIPAA15_Room_Document_with_Annex.pdf

The national reports which informed the synthesis report can be downloaded at:
http://www.unece.org/pau/mipaareports2017.html

# Autonomy and independence

**Extracted from Synthesis Report 2017:**

**(d) Respecting self-determination and dignity as core values through the end of life of an individual. This in particular should be the principal attitude in nursing and medical practice, including long-term and palliative care.**

ECE member States reported on diverse measures to enable people to approach the end of their lives with more self-determination and in dignity.

Ukraine is working on developing a palliative care strategy focusing on palliative care at home and local social service provision. Israel launched a *National Program for People in End-of-Life Situations and for Palliative Care* in June 2016. It aims to allow patients and families to live independently, in dignity, and to receive care suited to their preferences and values. The focus lies on the development of palliative services in hospitals and institutions of long-term care, in an effort to ensure continuity of care. The program emphasizes education, training and research.

Another measure taken by Israel to respect self-determination and dignity of older people was to amend the *Legal capacity and Guardianship Law* in 2015 to allow people with declined functioning to preserve their autonomy and maximal independence in managing their lives by reducing the amount of cases in which a guardian is appointed. Under the amended legislation, the appointment of a guardian is to be a last resort.

In Finland, the *Advanced Healthcare Directive* allows older persons to decide on their care when they are no longer able to make decisions for themselves due to illness or incapacity. The directive is the person's will on medical and care measures expressed in written or oral form. It can include the person's will on resuscitation, treatment or medical examinations, and whether the treatment should prioritize quality of life or longevity. The treating personnel should be informed about the existence of the patient's advance healthcare directive and they should respect the patient's will when making treatment

plans. The directive should be updated regularly to keep it up-to-date with the patient's current will and wishes.

Canada has invested significantly in the past eight years in the area of palliative care research. In 2013, the Government committed funding to support training in palliative care to front-line health care providers. The training is provided through *Pallium Canada*, a national organization created to improve the quality of hospice and palliative care services through the development and dissemination of peer-reviewed education, resources and clinical decision-making tools for inter-professional health care providers. In addition, the Canadian government worked with the Canadian Hospice Palliative Care Association to provide home support workers serving First Nations communities with appropriate tools and resources to support palliative care needs with the overall goal to improve end-of-life care in First Nation communities. Provincial end-of-life-care action plans and related measures were put in place in the Canadian provinces Alberta and British Columbia.

A small number of countries reported on legislation to regulate euthanasia and assisted suicide to regulate the conditions and procedures under which a person may choose their death (e.g. CAN, LUX). New legislation passed in Canada in 2016 enables safe and consistent access across Canada to medical assistance in dying. The legislation balances personal autonomy for those seeking access to medically assisted dying while protecting vulnerable Canadians. The legislation revises the Criminal Code to exempt health care practitioners who provide, or help to provide, medical assistance in dying from otherwise applicable criminal offences.

Austria has pooled federal, regional and local budgets to fund hospice care and a hospice and palliative care forum was set up in 2015 to implement measures to ensure dignity at the end of life. Further steps have been made to facilitate mobile hospice and palliative care by making funds from the Long-term care fund available for this purpose (2013) and increasing the number of mobile teams. Recent years have also seen an increase in the provision of in-patient hospices in Lower and Upper Austria.

### (g) Developing innovative methods and technologies for reliable, affordable and safe support and care of older persons at home.

Technology opens up new possibilities for assisted-living that enables *ageing in place* and provides support for family members and professional care providers. More than one in four countries reported investments in research and the development of products and services that increase the safety and security of older persons, support their independent living and enhance their social participation (e.g. AUT, CAN, CYP, DNK, EST, FIN, HUN, IRL, ISR, LUX, SWE, RUS).

Austria has been exploring ICT-based solutions for smart homes and smart services. Denmark has supported several research- and test processes towards integrating tools of ambient living in both nursing homes and senior social housing. In Sweden, the Agency for Participation has collaborated with several agencies and actors on a government inquiry on assistive technology and coordinated a support initiative to speed up the introduction of digital services in the municipalities such as personal emergency alarms.

The Canadian Government has funded research in technology and ageing through the AGE-WELL Networks Centre of Excellence which is a national research network in technology and ageing. Between 2014 and 2019 36.6 million Canadian Dollars are invested between industry partners, not-for-profit organizations and researchers. In 2014, the *CanStay Home* programme by *CanAssist* (a University of Columbia organization dedicated to helping people with disabilities improve their quality of life) developed a

suite of innovative technologies that support vulnerable older people and others to stay in their homes longer. One example is the *Wandering Deterrent System* that uses computer screens that flash personalized messages to discourage a person from leaving the house late at night (which is a current occurrence among people with dementia). Another example is the VIDATRACK service developed by the Cyprus Telecommunications Agency. It is an emergency signal transmission and detection management system that enhances the feeling of security of older persons and their families. The University of Luxemburg conducts research on the interaction of older persons with new technologies to use the knowledge gained in the development of new tools that assist independent living at home.

The Belgian region Wallonia introduced a new software in the home care sector that permitted to simplify administrative processes such as billing of services and allocation of subsidies that led to annual savings of over 4.5 million Euros. Ireland is introducing a *Single Assessment Tool* to implement a standardized IT-enabled health and social care assessment for older people nationally. This approach to care needs assessment, it is hoped, will facilitate a reduction of fragmentation so that assessment, care planning, and policy decision-making are effective, coordinated, and provide maximum value for money. Estonia restructured the organization of assistive technologies from a county-based into a national system in 2016 to simplify and improve the availability of assistive technologies.

An example of international cooperation in this field is the Active & Assisted Living Program (previously called Ambient Assisted Living Programme), a joint program of 20 European Union countries and Canada (since 2016). This program fosters the development and market entry of ICT-based solutions with the aim of facilitating older persons to live longer at home and as independently as possible. It is an investment with two goals, one is to improve the quality of life of older persons and support their self-management, and the second is to simultaneously, improve the effectiveness and efficiency of professional care.

**(h) Ensuring 'ageing in place' by promoting services and support to the individual and the family to enable older persons to continue living for as long as possible in their own environment and community. These services should take into account the special needs of women, in particular those who are living alone.**

Many countries have oriented their ageing policies to enable older people to remain in their own homes for as long as possible and in as good health as possible. The emphasis is put on independent living and deinstitutionalization by building and strengthening a comprehensive and integrated care and support infrastructure at local level supporting older people and their family caregivers in the community.

Support for "ageing in place" starts with providing information that help people plan ahead for their later years, to prepare before need arises. In Canada, the Forum of Federal/Provincial/Territorial Ministers responsible for Seniors published the guide *Thinking about Aging in Place* for older adults wishing to plan their future. In Austria, the website www.pflegedaheim.at provides targeted information to persons in need of care and family carers.

Social care and support is essential in helping older people to remain living in their homes when they no longer are able to take care of their everyday needs fully independently. A helping hand with running errands, gardening, and other chores of everyday life can make the difference as to whether an older person can remain living in their own homes. A diversity of home services have been implemented in the region (e.g. EST, ITA). The *Better at Home* non-medical home support programme in British Columbia, Canada, provides simple, non-medical services such as light housekeeping and grocery shopping,

to help older people remain in their own homes longer. In Uzbekistan, territorial programmes between 2015 and 2017 were developed to improve the housing conditions for older people and people with disabilities. These include annual repairs and yard maintenance that are actively supported by civil society organizations, local residents, youth and charity organizations. In Israel, the *Repair Commando*, a group of volunteers made up of electricians, plumbers, carpenters, technicians etc. carry out light repairs for older people. In the United Kingdom, an Hourly Service Centre for the provision of community-based or home-based social inclusion services has been established to provide a comprehensive service for people over the age of 65 who need help or are unable to look after themselves.

In many countries, social support and care are organized and delivered by municipalities at local level. In Finland, the *Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons* requires municipalities to draw up plans on measures to support the wellbeing, health, functional capacity and independent living of the older population and to organize and develop the services and informal care needed by older persons. By 2014, 80 per cent of municipalities had drafted such a plan.

One way of ensuring that the social care needs of older people are identified and recognized is through preventive house visits (e.g. AUT, DNK). In Denmark home visits have long been established to detect problems and create a dialogue with older persons about their life situation and need for assistance. In 2016, the Danish law on preventive home visits was revised to address several target groups. Home visits are paid to all older people over the age of 80 (previously 75) but also to vulnerable people between 65 and 80 who are in a difficult life situation and therefore considered at risk, for example after losing a spouse.

Concern about ensuring equity in access to services has been raised by a number of countries (e.g. FRA, FIN, GRC, SVN). Finland's key government project *equal, well-coordinated and cost-effective services for older persons and all aged informal carers* aims to develop home care and services accessible from home as the principle form of care provision while at the same time developing equal access to such services across the country and enhancing their coordination. In the Netherlands the policy "*Longer living independently*" introduced in 2014 aims to support municipalities by enhancing collaboration between municipalities, care providers and other stakeholders by sharing innovations, collectively identifying barriers and preventing mismatches. France reported financial support to home care service providers who are in economic difficulties and in the process of restructuring, in order to maintain service provision and save jobs in the care sector.

In the former Yugoslav Republic of Macedonia, the Red Cross of Skopje with the support of the Ministry of Labour and Social Policy and the City of Scopje have implemented a day-care centre for older persons and home assistance targeted at older people and people with disabilities who are in need of medical and psycho-social support and to those who are at risk of social isolation. In Greece the *Home Social Care* Programme, established in 2014 specifically targets uninsured older people, economically deprived individuals and those living with disabilities who are in need of social care and nursing services.

To make the administration and delivery of home care services more efficient and to enhance coordination centred around the needs of older persons, there have been increasing efforts to integrate social and nursing care services (e.g. FRA, LTU, MKD). In Lithuania, the *Integral Assistance Development Programme* was launched in 2013 to enable people to receive assistance at home and help family carers to remain in the labour market. Financed through the European Social Fund, the programme provides nursing and social services for people with disabilities and old people needing care, as well as

advice to their family care givers. During the implementation period 2013-2015, 1,500 people received assistance, and 1,400 family members consultations. As both beneficiaries and municipalities positively evaluated the programme, a new *Action Plan for Integral Assistance Development* was approved for 2016-2019, spreading the programme to almost all municipalities in Lithuania from 2016.

# Long-term care and palliative care

**Extracted from Synthesis Report 2017:**

**(k) Ensuring a continuum of affordable, high-quality care, ranging from arrangements for primary and community-based care to various forms of institutional care.**

In the context of population ageing, there continues to be growing demand for geriatric health care and long-term care services. In the region, these are provided through a broad infrastructure of formal health and care services provided in the community, at home, in day care centres, and nursing and residential care comes. The emphasis has been on supporting "ageing in place" as long as possible through mobile home nursing and support services and to provide residential long-term care for those who can no longer be cared for at home.

The provision of health care services in the home or community can help delay or prevent unnecessary hospitalisation or admission to nursing homes. Home nursing provides treatment and nursing at home for people who are temporarily or chronically ill or dying. In Denmark, all citizens in the municipalities are entitled to home nursing. When prescribed by a general practitioner, the municipalities must provide home nursing free of charge, including all necessary requisites. This entitlement is rooted in the aspiration of Danish ageing policy to provide help based on individual need rather than type of residence, to provide care at home for as long as this is possible and to secure access to nursing homes for those who can no longer be cared for at home. The Canadian province Saskatchwan runs *Home First/Quick Response* projects that target enhanced home care services for intense short-term needs or longer-term support service. It has the goal of sustaining older people in their homes for as long as possible in order to delay or prevent admission to long-term care, facilitate appropriate discharge from acute care to the community, prevent unnecessary admissions to emergency rooms and engage service providers in the system to support seniors in their own homes. Austria invested significantly in the extension of mobile services and technologies for supporting care at home.

Many countries have increased investments in the provision and quality of long-term care service to meet growing demand (for example AUT, DEU, EST, NLD, ROU, RUS). Estonia increased the funding for nursing care services by approx. 40 per cent between 2012 and 2015. The Russian Federation has widened the coverage of inpatient institutions for social services where older persons live on a permanent basis, including in rural areas where new nursing homes of 15-50 places have been built in addition to modernizing already existing institutions.

Affordability of care and access is another very important issue that has been addressed in different ways across the region. Cyprus runs a care services subsidy scheme to cover the costs of care services for those who meet certain conditions of the Guaranteed Minimum Income legislation and whose income is insufficient to cover the costs of their

care needs. Ireland has a *Nursing Homes Support Scheme* since 2009 that provides financial support to those in need of long-term nursing home care. The scheme aims to ensure that long-term nursing home care is accessible and affordable for everyone and that people are cared for in the most appropriate settings. The Scheme was reviewed in 2015 and recommendations are being implemented. In Austria, people in need of nursing are eligible for funding for 24-hour care if the general requirements for live-in care are met. The *Long-term Care Act 2015* in the Netherlands covers the persons in the most vulnerable categories, such as those requiring permanent supervision or 24-hour care nearby, providing a broadly defined set of services, including residential care.

New legislation in Germany comprehensively restructured social long-term care insurance and improved benefits by a total of 5 billion Euros per year. Changes to the needs assessment have improved access to long-term care for people with dementia. The reforms also expanded services for all those in need of long-term care, strengthening home care services as well as in-patient facilities. To finance these improvements, contributory payments to the long-term care insurance were increased by 0.5 contribution rate points.

The fragmentation of services needed by older people who may have multiple needs is a challenge, both in terms of efficient administration and cost effectiveness but also in terms of ensuring that older people receive the care they need, regardless of where they live and of their ability to bear the costs. Ireland's Health Service Executive is working on a Single Assessment Tool to implement a standardised IT-enabled health and social care needs assessment for older people nationally. This new approach holds the potential to reduce fragmentation so that assessment, care planning and policy decision-making are effective, co-ordinated and cost effective. Israel developed a pilot programme of individualized care management. The model is based on the local service system for diagnosis and referral to existing services and seeks to address the fragmentation of service providers.

Long-term care reforms that seek to deinstitutionalise care and place the emphasis on "ageing in place", such as for example in the Netherlands, have implied an increasing reliance on informal care in families and the community. To better integrate informal care within the broader landscape of care provision, some countries reported on measures that foster collaboration between formal and informal care providers. In Israel, MATAV – the largest NGO of home care workers, has begun to implement a programme to train the caregivers of older people to identify the needs of family members and set up effective cooperation for the benefit of the older person, their family members and the professional care givers.

In the Netherlands, recent government efforts have sought to enhance coordination between health care professionals and informal care providers. The project *Yes to Informal Care* (In voor Mantelzorg) facilitates better collaboration between informal caregivers and health care providers.

Ensuring the quality of care provided across a broad landscape of care providers and settings is a challenge. Providing a sufficient number of health care personnel that is adequately trained is one aspect that countries have been addressing, the introduction of quality standards and their enforcement another. The Swedish government earmarked over 100 million Euro in 2015 and a further 200 million in 2016 to increase staffing levels with the aim of raising the quality of care for older people, increasing reassurance for older people and improving conditions to ensure that the quality of care provided is equal across Sweden, including with respect to gender equality. Kazakhstan reported on increasing the number of nurses to improve the capacity to monitor older people with chronic diseases.

In order to ensure that care services provided are of adequate quality, countries advance regulation and controls in this area. Kazakhstan for example introduced standards for

gerontology and geriatric care services in 2015. In Cyprus, the Social Welfare Services are promoting the adoption of legislation and regulations for home care that will lay down conditions for the qualifications and suitability of carers and their responsibilities towards care receivers. In Austria, roughly 20,000 visits are paid to the homes of care allowance recipients to assure the quality of home care. Graduate nursing specialists examine the specific care situation on the basis of standardized protocols. Since 2015 it is also possible to request these home visits. The reform of social services in Albania includes a draft law on the regulation of provisions of services from third parties, introducing clear procurement procedures and quality standards.

With regard to the quality of care provided in nursing homes, the Netherlands launched a programme called *Dignity and Pride. Loving Care for our Elderly* that focuses on prioritizing the relationship between the client, their social support and healthcare professionals. By 2016, results of the programme included an increase in supervision of the Health Care Inspectorate on providers with high-risk profiles and reinforcement of good quality standards, structural implementation of 200 million Euros, providing additional resources for the education of nursing care. Another Dutch programme to enhance the quality of long-term care is the *Care reform agenda: Living dignity* with care which shifts attention from care provision as such to a broader perspective on the well-being of persons relying on long-term care by (1) giving people with severe limitations substantially more (financial) control to choose their support and care at their home or in other living arrangements, (2) encouraging more innovative health care providers in long-term care and (3) stimulating technological innovations in long-term care.

In Sweden, the National Board of Health and Welfare has worked with the Swedish Association of Local Authorities and Regions to develop a system of benchmarking to support national actors, service providers and practitioners to enhance the quality of care. The system of recurring indicator-based comparisons of quality and resource consumption in health and medical care, social services and public health reported at regional, county council, municipal or unit level aims to encourage these actors to analyze their operations, learn from each other, improve quality and efficiency.