Investing
in later life
A toolkit for social services providing care for older people

Supporting older people and carers

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Investing
in later life

A toolkit for social services
providing care for older people

Providing
person-centred
care

Better ageing

About this toolkit

This toolkit is the result of the European Social Network's (ESN) work on ageing and care between 2014 and 2016, mainly through its working group on ageing and care, its crosscutting work on integrated social services, and the work on the social services workforce in the framework of its 2014-2017 strategy.

About the European Social Network

ESN is the independent network for local public social services in Europe. It brings together the organisations that plan, finance, research, manage, regulate and deliver local public social services, including health, social welfare, employment, education and housing. We support the development of effective social policy and social care practice through the exchange of knowledge and experience.

European funding

Country abbreviations	
AT	Austria
BE	Belgium
BG	Bulgaria
CY	Cyprus
CZ	Czech Republic
DE	Germany
DK	Denmark
EE	Estonia
ES	Spain
FI	Finland
FR	France
GR	Greece
HR	Croatia
HU	Hungary
IE	Ireland
IT	Italy
LT	Lithuania
LUX	Luxembourg
LV	Latvia
NL	The Netherlands
NO	Norway
PL	Poland
PT	Portugal
RO	Romania
SE	Sweden
SK	Slovakia
SI	Slovenia
UK	United Kingdom

Executive summary

The objective of this toolkit is to provide recommendations and examples of innovative practice for senior professionals working in social services providing care for older people. The toolkit is mainly based on desktop literature research, material from European projects in which ESN participates in an advisory role, ESN reports and the results of the ageing and care working group meetings. ESN's working group on ageing and care met five times between 2014 and 2016. Professionals who plan, coordinate and manage social services for older people shared knowledge and best practice around different issues such as initiatives to promote active ageing, carers support, improving the coordination of health and social care services, and support for people with disabilities growing older.

The first chapter of the toolkit focuses on the promotion of active ageing as a way of overcoming challenges derived from an increasingly older population. Active ageing is the process of optimising opportunities for health, participation and security for older people while providing adequate protection and care when they require assistance. A review of the legal and policy frameworks points out key developments in the area of active ageing. Moreover, the chapter describes some of the best initiatives across Europe aimed at enhancing the independence of older people as well as specific recommendations for professionals working in this area.

The second chapter tackles the necessity to improve support for formal and informal care givers. Most countries in Europe are experiencing challenges in recruiting sufficient qualified staff in the social services sector, particularly in the provision of long-term care. Rising demand for social services and demographic changes are major contributors to these challenges, as well as the low status of the profession, which leads to a high staff turnover. The review of the legal and policy framework around these issues points to, amongst other elements, the recent European Commission initiative on work-life balance under the Pillar of Social Rights. As for chapter one, examples of practice implementation from different countries and recommendations for senior professionals are provided.

The need to better integrate social services is discussed in chapter three. Although there is a trend towards care models with more integrated person-centred services, most countries continue to provide health and social care services for older people in silos rather than in an integrated way. In this chapter, cooperation and integration opportunities and the challenges of integrated services are analysed at three different levels: macro-level, meso-level and micro-level. As part of the analysis, concrete examples of implementation and specific recommendations are provided for each level to showcase how social services can successfully be integrated.

Finally, the last chapter explores how people with multiple conditions can be supported most effectively in a person-centred way. Indeed, older people with multiple and complex conditions, such as dementia, tend to require health and social care services on a larger scale. This chapter provides an overview of how health and social care services are supporting people with dementia and Alzheimer's disease as well as their families. It also explores how to best support people with learning disabilities growing older with the aim to reduce preventable ill health and premature deaths.

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Introduction

Care and support for older people is a significant challenge for public social services in light of the demographic changes taking place across Europe. The promotion of autonomy and inclusion of older people has to be balanced against the sector's challenges related to funding, quality and the mixed market economy of care services, as well as workforce training and sustainability.

Methodology

This toolkit is mainly based on desktop literature research, material from European projects in which ESN participates in an advisory role, ESN reports and the results of the ageing and care working group meetings. In particular, most practice examples used in this toolkit to illustrate the challenges and opportunities within each topic come from the working group.

ESN's working group on ageing and care was set up in 2014 to explore how to increase the capacity of public authorities to plan and manage older people's services in a sustainable and person-centred way. It consisted of a core group of members and thematic contributors, all senior professionals who plan, coordinate and manage social services for older people.

Professor Jenny Billings from the University of Kent helped the group to analyse national, regional and local policies and practices, on the basis of which recommendations for sustainable, person-centred services were developed. With this toolkit, the group contributes to the implementation of the Social Protection Committee (SPC) report 'Adequate social protection for long-term care needs in an ageing society' (Social Protection Committee, 2014) and wider EU policy developments in the field of long-term care.

The group met five times between 2014 and 2016 and looked at issues around service planning and contracting, cooperation between health and social care, active ageing, the social care workforce, quality assurance and technological innovation.

The first meeting took place in Brighton, UK, in September 2014. Participants discussed the European recommendations on long-term care from the SPC report, as well as local practices from the Municipality of Östersund in Sweden and Barcelona County Council, amongst others.

At the second meeting, also in Brighton, UK, in February 2015, participants examined European, national, regional and local initiatives to promote the integration of health and social care services for older people. Working group members discussed how the policy context influences service integration, and analysed various practice examples. Issues raised included the scope of integration, the social aspect of care, information sharing across sectors and evaluation of integration.

The third meeting in September 2015 took place in Seville, Spain. It explored European, national, regional and local initiatives for active ageing measures. The working group also collected examples of local and regional practice that support older people's participation in society as well as independent, healthy and secure living and enabling environments for active ageing for people who are 65+ and need some form of support. Members of the working group had the opportunity to visit active participation centres in Seville, and a video was recorded with a comparative overview of active ageing services in Spain, Belgium, Sweden and the UK.

The fourth meeting took place in Mechelen, Belgium in February 2016. It considered policies and practices aimed at supporting training and development of formal and informal caregivers working with older people.

The fifth and final meeting took place in Brighton, UK, in October 2016. It focussed on quality of services for older people and the role of technological solutions in tackling challenges in social care. In a joint session with ESN's disability working group, participants discussed how services for people growing older with learning disabilities should be provided.

Chapter 1:
Promoting active ageing

Volunteering

Prevention and rehabilitation

Background

Increased longevity is often mentioned in the same breath as fears of increased demand for care services with an associated explosion of costs and demand for care workers. Yet, research shows that we are not only living longer, but also that we are less likely to experience long periods of ill health or a disability in older age than we were two decades ago (Tesauro and Pianelli, 2010). This means that the potential of increasing healthy life expectancy and delaying the onset of age-related conditions is already evident.

According to the WHO's Active Ageing Policy Framework (2002), which is widely recognised as the most important guideline in this area, active ageing allows people to realise their potential for physical, social and mental wellbeing throughout life. It focusses on opportunities for health, participation and security to enhance quality of life in older age, while providing people with adequate protection and care when they require assistance. The overall goal of initiatives that promote active ageing is to extend healthy life expectancy and improve quality of life, including for those who are frail, disabled or in need of care.

The Active Ageing Index (AAI) is a tool to measure the extent to which older people can realise their full potential in terms of employment, participation in social and cultural life, and independent living. Whilst currently it is only used to measure progress on these indicators at national level, its potential use at regional and local levels was discussed by ESN's ageing and care working group in 2015. Subsequently, it was discussed at a European peer review in Berlin in 2016, to which ESN contributed a comments paper (2016).

Based on the analysis of a pilot in Germany where the AAI was applied at the local level, the peer review concluded that a local level AAI is feasible and could be a helpful tool in measuring progress on key active ageing indicators, such as political participation, the employment rate and independent living (European Commission, 2016). ESN members emphasised that the local implementation of the AAI could contribute to an evidence base for active ageing policies and practices that could help local and regional authorities to introduce new policies in this area. Existing evaluation of policies and practices is predominantly qualitative and often difficult to compare or generalise, not least because the indicators used are often very situation specific.

Several European initiatives promote different aspects of active ageing, including the European Innovation Partnership on Active and Health Ageing (EIP AHA) and ICT-AGE, a research project that encourages the use of technology-based solutions to enable older people to continue living at home. The role of local and regional authorities has been emphasised by several projects, like the WHO initiative on age-friendly environments and the AFE-INNOVNET project on age-friendly environments[1].

Extending working lives is often a priority for policy-makers, but other aspects of active ageing also benefit society greatly and often require legislative provisions to enable them.

Local public social services play a key role in implementing active ageing measures that support older people who are already in need of care to be socially included and to maintain their quality of life. This chapter focusses on some of these initiatives, specifically in realising the potential of volunteering, prevention and rehabilitation measures.

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[1] AFE-INNOVNET was a consortium of 29 stakeholder from 16 countries whose overarching goal was to set up a large EU-wide community of local and regional authorities and other relevant stakeholders across the EU to find smart and innovative evidence based solutions to support active and healthy ageing and develop age-friendly environments across the EU.

1.1. Legal and policy framework

In 2014, the SPC, consisting of national government representatives from social policy ministries and the European Commission, published a report on long-term care (Council of the European Union, 2014), which focuses on prevention and rehabilitation, independent living and productivity of care delivery. It outlines how rising life expectancy is expected to increase the demand for long-term care whilst an insufficient supply of carers may threaten the quality of care older people can expect to receive in the future. The report describes the imperative for Member States to move from reactive to proactive policies in order to delay or reduce the need for long-term care.

Many countries have started to make important changes to support various aspects of active ageing. In Iceland, a national report by the government puts an emphasis on prevention, health promotion and on the potential for older people to stay active for longer; for example, by remaining longer in employment. In Latvia, according to the White Book of the Social Assistance Reform and the Social Services Law, municipalities are expected to develop alternatives to residential institutions. In England, the Care Act gives local authorities a new legal responsibility to provide care and support services that focus on service user empowerment, choice and control.

Prevention in later life is one aspect that has been widely addressed in various European countries. For instance, the Danish law on preventative home visits, introduced in 1998, was the basis for the implementation of home visits to older people across the country including an overarching social, mental and physical assessment as well as a follow-up by a multi-disciplinary group of professionals. One study showed that older people living in municipalities that had implemented preventative home visits had better functional ability, less fatigue and fewer nursing home admissions than those living in the control municipalities (University of Copenhagen, 2012).

The Care Act in the UK places a responsibility on local authorities to provide services that help prevent or delay care and support needs by working with communities to identify the support and resources locally available. Regarding rehabilitation, the Act also obliges local authorities to "provide or arrange a range of services which are aimed at reducing needs and helping people regain skills, for instance after a spell in hospital" (Department of Health, 2016).

Austria is developing rehabilitation care *(Remobilisierungs- und Rehabilitationspflege)* according to national quality guidelines in order to prevent or delay in-patient or long-term care. Rehabilitation care was developed following an official 2012 report that criticised the gaps in support after hospital stays and patchy access to assistive home-care devices leading to inadequate care and sometimes early admissions to residential care facilities (Bundesministerium für Arbeit, Soziales und Konsumentenschutz, 2012).

Swedish municipalities are required to ensure that planning for new housing and residential areas is done taking into account the needs of older people and people with disabilities. With a focus on enabling people to live in their own homes for as long as possible, Swedish municipalities provide extensive home-help services through multi-professional teams, daytime activities for people with dementia and learning disabilities, and technological support (Swedish Institute, 2016).

There are also numerous regional and local examples of legal frameworks and policies that support active ageing. For example, in Andalucía (Spain), active ageing is embedded in the legislation as a right including four pillars: participation, healthy living, security and long-life learning. Throughout the region, 168 active participation centers have been set up reaching out to over 600,000 older people. In Flanders (Belgium), the aim of the Flemish care policy is stimulation, support and rehabilitation in order to help people in need of care to stay in their homes for as long as possible.

1.2. Supporting volunteering

Members of the working group on Ageing and Care emphasised that volunteers are playing a vital role in Europe's social care systems by providing support and activities beyond statutory care and supporting vulnerable older people who may lack family support or who are socio-economically disadvantaged. As the WHO (2002) points out, volunteering increases older people's social contacts and improves their psychological wellbeing while making an important economic and social contribution to society. However, as Table 1 shows, there are challenges that need to be addressed in order to ensure that volunteering is a positive experience for everyone involved. Volunteer coordinators are often needed to guarantee a reliable service, to deal with problems and to advise volunteers and service users. Moreover, volunteers should not be used to provide statutory services for free in order to reduce costs – they should rather be seen as providing additional activities and support in line with their knowledge and abilities.

ESN members from Germany and Austria explained that volunteers in their local areas visit older people to support the assessment of care needs, provide support with daily tasks and talk to older people who are socially isolated. In both countries, the volunteers – in many cases older people themselves – receive training and a small financial compensation for their work.

Citizen advice bureaus have been set up in many European countries, such as Austria, Germany, Iceland and Spain, to provide information and advice to older people about services and support available for them, including voluntary activities, computer training and legal advice. Many of them also offer advice on specific health concerns, such as dementia, for older people and their relatives and carers. In addition, information is given on community colleges, voluntary work and activities aimed at all age groups to increase social inclusion and participation of older people in the community.

In line with this, Germany has promoted the concept of intergenerational houses *(Mehrgenerationenhäuser)*, centres where people of all ages and abilities can meet and support each other through various activities. The objective is to facilitate a dialogue between the generations promoting civic participation in an informal setting. In 2016, the federal government approved financial support for 550 houses all over the country for the next four years (Bundesministerium für Familie, Senioren, Frauen and Jugend, 2016). The houses are co-financed by the municipalities and the regions *(Länder).* The houses offer activities provided by volunteers, for instance child-minding, creative activities for children and young people, further education courses, language courses, support for people with care needs and their carers, and computer workshops. Each house works closely with the municipality and is expected to adjust the activities and programmes offered to local needs and assets[2].

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[2] For further information, please visit (in German): www.mehrgenerationenhaeuser.de

Table 1: Opportunities and challenges for social services in supporting volunteering among older people

Opportunities	Challenges
Many (younger) older people want to help others and contribute to their community.	Investment is required to pay professional volunteer coordinators and supervisors who need to be adequately trained.
Advice and activities beyond statutory duties are provided.	Recruiting and training volunteers requires time and a good outreach campaign.
Community and intergenerational relationships are strengthened.	Informing potential beneficiaries of volunteer services about its availability requires good networks and a communication plan.
Quality indicators are established to assess the service regularly, which leads to the profile of volunteering being raised and partners being more likely to get involved and support the initiative.	It can be difficult to measure the benefits of volunteering independently of other factors.
Volunteers have access to training, experience and qualifications that can help them to improve their employability.	Ensuring sustainable funding for volunteering initiatives requires time and patience to build.
A focus on the competencies and assets of older people rather than on their 'deficits' allows for better use of resources and a positive approach.	Ensuring the sustainability of volunteering requires reliable partners in politics, administration, NGOs and private organisations.
Involving older people actively in the planning, implementation and evaluation of voluntary activities and putting their preferences at the heart of initiatives ensures better targeting of resources, participation and trust.	It may be challenging securing human and financial resources to enable the transition from a voluntary project to becoming part of the community infrastructure.

Implementation in practice
Local volunteering centres for older people in Dortmund, Germany

Local advice centres promote active ageing, volunteering and community relationships

This initiative takes place in all districts of the city of Dortmund and consists of a network of about 200 volunteers who provide social support for older people organised through 12 'Seniorenbüros' (seniors' offices).

Older volunteers over the age of 50 visit isolated older people living alone to support them in their day-to-day activities, for instance going for a walk, shopping, or attending medical appointments. Apart from general help, an additional and important function involves interaction and communication with the older person. One group of volunteers specialises in supporting older people with dementia.

Dortmund's services for older people manage the initiative and cover its annual cost of about EUR 200,000. Social workers employed by the city manage and supervise the volunteers and the experience of the service user and their families. The volunteering positions are advertised online on the council's website and in local newspapers.

The service is advertised at targeted promotional events in homes for older people, through flyers and at the University of the Third Age at the University of Dortmund. A specialist service for older people in Dortmund provides 30 hours of basic training for the volunteers, who assist up to two times a week in households with lonely older people or in households with people with dementia.

The initiative has already shown progress towards achieving its main objectives:

- Prevent early nursing home admissions;
- Enable older people to feel more self-confident and to participate more in community life;
- Provide some relief for informal carers from their caring responsibilities and help them to continue living with the older person with dementia;
- Provide older persons with the opportunity to help others and contribute to community relationships through volunteering;
- Promote active ageing and greater independence.

The full practice example is available here:
www.esn-eu.org/raw.php?page=files&id=1978

Reinhard Pohlman
City of Dortmund

"For over 25 years, the City of Dortmund has been supporting the local volunteer service which brings together more than 200 volunteers, mostly aged between 60-70. The volunteers visit older people with complex needs and dementia for several hours per day, helping them with their daily care activities. This is an indispensable service for our city".

1.3. Prevention and early intervention

The shift of health and social care systems' focus from reaction to prevention of ill health and early detection of risk factors is still ongoing. The benefits for this shift to prevent and delay ill health, thereby promoting and enabling older people to live a healthier, independent life for longer, and to reduce demand for expensive health and social care, have been widely documented. However, prevention is often seen through the medical lens, which can neglect important social, behavioural and environmental aspects of prevention (Kümpers et al., 2010).

Aspects of prevention that have been of particular benefit include (Kümpers et al., 2010):

- Measures preventing falls;
- Trialled and tested geriatric assessment tools;
- Preventive home visits;
- Multidisciplinary teams working with older people with complex needs or dementia;
- E-health solutions;
- Self-management.

Members of ESN's working group on ageing and care provided practice examples aimed at either maintaining good health generally, including promoting physical exercise, preventing social isolation, and weight management. Other initiatives provided by the members of the group had as their objective supporting people in coping with specific issues and risk factors, such as hearing and sight problems, loss of a spouse, memory loss, and reducing the risk of a fall.

Prevention is not only about changing the behaviour and the environment of an individual; it also concerns communities' environments. The WHO's Global Network of Age-Friendly Cities and Communities encourages the exchange of experience and mutual learning between cities and communities that are committed to promote active and healthy ageing and a good quality of life for their older residents (WHO, 2017).

Figure 1: Global age-friendly Cities: A Guide, by the World Health Organisation, 2007

In Europe, the EU Covenant on Demographic Change engages local and regional authorities in developing environments for active and healthy ageing that increase healthy life expectancy, enhance opportunities for independent living for older people, and support a society for all ages. The Basque Government (Spain), has developed a plan to support its municipalities in becoming age-friendly environments (Basque Government, 2015). They have used the following tools to assess how age-friendly their communities are and what elements should be improved:

Table 2: Assessment tools for age-friendly municipalities

Secondary sources	Social meetings and focus groups	Questionnaires
Data on topography, population size and density, neighbourhoods and districts, places for cultural and sports activities	Focus groups with 6–12 participants who are representative of the target population or important minorities within it	A 'friendliness questionnaire' can be used to collected the opinions of a larger number of citizens of all ages on issues, such as: – Parks and outdoors space – Streets and sidewalks – Public transport – Housing – Relationships with family members and neighbours – Participation in voluntary activities and associations – Leisure and cultural activities – Social inclusion and intergenerational relationships – Social and health services
Population projections by age and sex	Citizen meetings with at least 50 participants with the options of dividing participants up into groups to address one or more sub-topics during the meeting	
Data on the age and gender structure of older population in the municipality, on income and pension levels, on number of persons in their household and education level		
Age and gender structure of the population with care needs	In-depth interviews with experts or leaders in the field (if appropriate)	
Availability and accessibility of private and public services and activities for older people		
Mapping programmes and activities for older people offered by NGOs in the area		
Monitoring progress on implementation of plans for housing and accessibility		

Creating age-friendly environments requires a long-term joint effort between local authorities, social and health services, community organisations, local businesses and citizens. The potential benefits of this kind of comprehensive, inclusive strategy to proactively promote and facilitate active and healthy ageing is evident given that it accounts for the multidimensionality of active ageing and the interconnectedness of physical, mental, social and community wellbeing and inclusion (Boudiny, 2013).

Research and information about new technological products that can support active ageing, is collected and shared at European level through the Active and Assisted Living Programme (AAL). It focuses on developing ICT and other technologies to enhance the quality of life of older people, and to bridge the gap between research and markets to make new products commercially viable (AAL Programme, 2016). This kind of evidence-base can help local authorities and social services, who are often the ones buying, commissioning or procuring services that use these new technologies.

Table 3: Opportunities and challenges for social services in promoting prevention and early intervention

Opportunities	Challenges
Many physical activities that can help to prevent ill health and frailty already exist or are easy to set up.	Benefits from prevention measures often occur in different parts of the system, hence a whole system evidence base is required but difficult to provide.
Easy to use e-health interventions can help to improve people's health literacy and control over their physical activities, nutrition, vital statistics and other aspects of self-management.	The medical bias of health systems can make it harder for social and long-term care services to work with them on promoting a holistic approach to prevention.
Embedding prevention and early intervention in services' strategies, with clear objectives and implementation plans, can help to mainstream them.	People with lower levels of health literacy, people in rural areas, socially disadvantaged groups, migrants and people with disabilities or mental health issues are less likely to benefit from prevention and early intervention measures.
Ensuring access, affordability and quality of rehabilitative physiotherapy and occupational therapy can be very effective in supporting recovery after hospital discharge and regaining the ability to perform daily activities.	The benefits of preventative measures often only become apparent in the long-term, but the short-term political cycles demand results quickly.
Creating age-friendly environments can be an important public policy contribution to enabling older people to participate in community activities and remain autonomous for longer.	Establishing causality between a prevention measure and the prevention of a symptom or a condition is almost impossible given the variety of other factors that cannot be controlled for.
Apart from strength and balance training, measures preventing falls that address the potential fear of falling, are important tools to prevent serious incidents and hospital admissions.	Self-management or self-care should not simply be seen as a replacement of services in order to save costs.
In order to enable people to stay in their own homes for longer, professionals supporting them should schedule regular meetings with them and their carers to review whether additional adaptations could be made to maintain independence and quality of life to the greatest extent possible.	Changes to the built environment to remove barriers can be expensive, and therefore changes can be slow.
Removing barriers from buildings and streets improves the mobility and independence not just of older people but also for people with disabilities and temporary mobility constraints.	

Implementation in practice
Active participation centres in Andalusia, Spain

Local participation centres empower older people and promote active ageing

In this regional initiative from Andalusia (Spain), a series of centres were set up to support and boost active ageing policies at regional level. A legal modification that turned former 'day care centres' into 'active participation centres' made it possible.

With this network of almost 200 centres, the Regional Ministry for Social Policies and Equality of Andalusia aims to bring active ageing policies closer to older people, as well as enabling them to participate in the decision-making process. It has been implemented as a consequence of adapting previous structures to new needs, creating centres that are more democratic, increasing social participation, and widening dissemination of active and healthy ageing policies.

The active participation centres introduce the notion of healthy lifestyle improvements through activities open to everyone over the age of 60. They organise social, cultural, recreational, self-help, musical and sport activities, crafts and tourism. Activities are classified in three groups: mobility, handicraft and cognitive skills, and emotional skills. In addition to these workshops, the centres may also offer services such as legal advice, social services, podiatry and hairdressing as well as connect older people with other initiatives, for instance, in tourism. Finally, they organise activities around key dates such as the 'Older People's Day' or the 'Day of the Region'.

Older people are involved in the design of active ageing policies through a regional Older People's Council. They are also involved in managing the centres through the Participation Boards, whose members are elected in a General Assembly. Finally, older people also participate through committees in the organisation of specific programmes.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=2532

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Mercedes García Sáez
Agency of Social Services and Dependency of Andalusia

"Active Participation Centres aim to promote the wellbeing of older people, fostering integration, participation, solidarity and enhancing social relationships. Moreover, these centres support the provision of social and care services to other groups of the population".

1.4. Rehabilitation

Rehabilitation measures are another key aspect of active and healthy ageing that focus on helping people to regain or improve their ability to carry out daily activities. As the UK's Chartered Society of Physiotherapy points out: "rehabilitation should focus on changes to functional disability and lifestyle restrictions based on the patient's own goals for functional improvement".

Members of ESN's working group on ageing and care provided examples of rehabilitation measures in people's own homes to promote 'self-care'. Some initiatives focused on elements of rehabilitation for older people with specific conditions, such as hearing or sight problems or who are at risk of isolation. Further activities, such as arts, have been used to give older people, who suffer from specific conditions like dementia, the opportunity to express themselves through alternative means.

One of the most significant impediments to successful rehabilitation often occurs when an older person is discharged from hospital and follow-up support in the community is insufficient. Ideally, a pre- or post-discharge home assessment should be offered by an occupational therapist or another health and social care professional in order to identify necessary adjustments to reduce the risk of a fall, take into account the person's functional abilities and the support they may need in managing daily activities (UK's College of Occupational Therapists, 2015).

The potential for technological innovation to support rehabilitation and management of chronic conditions has increasingly been understood, particularly in the Nordic countries (Iceland, Denmark, Sweden, Norway and Finland). Denmark, for instance, has invested in several funds that support projects to gather evidence on the use of technologies (Nordic Centre for Welfare and Social Issues, 2010). Figure 2 gives an overview of the types of technological innovation used to support older people in their own homes.

Figure 2: Types of welfare technologies commonly used to support older people in their own homes

Telemedicine	Telehealth	Telecare
Remote information on diagnosis, treatment and prevention from a doctor given to a service user using phone, email, webcams and other technologies	Remote monitoring of blood pressure, body temperature or other vital signs	Home monitors of falls, movements, fire or gas
Remote information exchange between health professionals using ICT	Data on vital signs is transferred to a monitoring centre that alerts a clinician if appropriate	User-activated alarms that connect service users to a response centre
		Tele-consultations between service user and a doctor, nurse or support worker

Table 4: Opportunities and challenges for social services in facilitating effective rehabilitation

Opportunities	Challenges
Multidisciplinary, person-centred rehabilitation services can provide effective support and avoid care gaps.	Coordinating care between different organisations and ensuring smooth transitions between services, for instance from hospital to community and home care, is still a major challenge due to fragmented systems.
Home visits enable professionals to better understand service users' circumstances and discuss helpful adjustments at home.	A lack of incentives to ensure continuity of care after an older person has left a service can contribute to care gaps and discourage service coordination.
E-health interventions can support rehabilitation by enabling people to monitor their own health and keep track of their progress.	A narrow focus on functional abilities can neglect important issues around coping with disability, fears and perception of one's health, or obstacles to social participation.
Where possible and agreed to by the service user, family members or friends should be involved in the rehabilitation process in order to help support their loved one for as long as possible.	Technological solutions need to be shown and fully explained to the user and a professional should check regularly whether the device is used properly and if it works as expected, which requires the necessary technical knowledge.
Feedback from service users on their experience of a service and their wellbeing during rehabilitation should be incorporated into services' strategy. Pooled budgets can reduce disincentives to ensure that service transition is organised properly.	Professionals should be trained appropriately so they have all the necessary knowledge to communicate the benefits of technological solutions.

Implementation in practice
Personal hygiene independence for older people in Östersund, Sweden

Home-based rehabilitation after hospital discharge

The Municipality of Östersund in Sweden has introduced an initiative to support older people to improve their functional skills related to personal care and hygiene, particularly bathing and showering. The initiative specifically targets older people who are discharged from hospital as they often do not receive an assessment of their needs in their own homes. This can mean that the help and support they receive at home does not always meet their needs and requirements.

In this initiative, care managers and occupational therapists work together to provide home-based rehabilitation to older people. Care managers process the applications for home help and conduct an individual assessment in the person's own home, often together with other professionals. The occupational therapists provide the support services and supervise home support workers.

All the professionals involved work for the municipality of Östersund. The mix of professionals and the extent of collaboration may differ between teams in the municipality. For example, if an occupational therapist identifies a balance problem, a physiotherapist may be asked to assess and implement an intervention. Problems with participation in social activities outside the home might also be identified and addressed with another intervention.

The costs of the initiative – mainly staff costs – are covered within the municipality's care budget. The initiative is cost-effective as the overall service costs are only 40% of the total costs in the control group that did not receive the intervention. Therefore, the initiative has continued and been transferred to several other Swedish municipalities since it was first introduced in 2002.

> The full practice example is available here:
> http://www.esn-eu.org/raw.php?page=files&id=2046

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Lars Liljedahl
Östersund Municipality

"Östersund municipality believes that citizens need to be given the opportunity to maintain their abilities, independence and wellbeing. Therefore, and for a couple of decades, the municipality has adopted a 'rehabilitative approach' when providing support to our citizens".

Chapter 2:
Supporting formal and informal carers

Mutual recognition of qualifications

Social services workforce

Background

Throughout 2016 and 2017, ESN explored planning and managing the social services workforce in a research project, the findings of which are presented in the report 'Investing in the social services workforce' (Baltruks et al., 2017). This overarching theme around the social services workforce was also addressed by ESN in its publication 'Investing in children's services, improving outcomes' (Lara Montero et al., 2016), which was the result of the project 'Investing in children's services', and in the working groups on disability and ageing and care.

The formal social care workforce, i.e. those who are providing care in a formalised, paid position, is as diverse as the settings and contexts in which they work. A country's degree of 'formalisation of care' can be measured by the size of the long-term care workforce in relation to the older population, which indicates the coverage of care services (Rodrigues et al., 2012). European countries vary markedly in the extent to which they provide community and residential care services as well as the mix between public, private not-for-profit and private for-profit providers. This impacts on staff working conditions and the environments where care workers work, as well as on the extent to which care professions are regulated and formally recognised.

ESN's work reflected what has been widely documented in the literature. Almost all European countries struggle to attract enough social care workers, not only due to the low status and image of the profession, but also because of the growing pressure on the workforce. Projections on how this situation could worsen in the future are difficult to make due to a number of factors impacting on it.

On the other hand, high turnover rates, part-time work or high sickness rates can contribute to the need for more care workers than demographic projections alone might suggest. Moreover, with the rising prevalence of multi-morbidity, dementia and other complex care needs, more staff working time may be required per person on average than was the case in the past. For example, in Germany between 1999 and 2013 the number of care workers employed in residential and community care services increased by 70 per cent, whilst the number of users of these services only increased by 30 per cent over the same time period (Bundesministerium für Gesundheit, 2016). Recruitment and retention are therefore closely interlinked. The first part of this chapter will look closely at how these challenges can be addressed by social services.

As many countries increasingly provide long-term care in people's own homes, the second part of this chapter will discuss some of the challenges connected with this, both for service users and the professionals supporting them. The vast majority of care and support older people receive is provided by informal, i.e. unpaid, mostly family caregivers. Therefore, this chapter will also explore how social services can support informal carers and value the immense contribution they make to older people's lives and to care systems.

2.1. Legal and policy framework

In 2013, the European Commission adopted the Social Investment Package (SIP), which stresses the role of high quality, integrated and personalised services in developing people's skills and capabilities, improving their opportunities and helping them to make the most of their potential throughout their lives. The Communication from the Commission: 'Towards Social Investment for Growth and Cohesion' (European Commission, 2013) mentions in particular shortages in the long-term care workforce. It says these should be addressed by promoting employment in this area, although no legislative measures followed any of these recommendations.

In 2014, the SPC warned of a "threat to the supply of long-term carers from the decline in the number of people of working age and social changes" but saw an opportunity for better collaboration between ministers of health and social affairs on developing solutions for the social and employment challenges posed by the growing demand for long-term care.

Regarding the mutual recognition of qualifications within the EU, the Directive 2005/36/EC on the recognition of professional qualifications, amended by the Directive 2013/55/EU covers doctors, nurses in general care, physiotherapists and others. This means that members of these professions are automatically allowed to work in another Member State. However, qualifications in the area of social work and social care are not covered. The recognition of qualifications in this field is therefore up to the Members States. An overview of qualifications in the field of social work and social care in various EU countries can be found in ESN's report on the social services workforce, which also highlights the different degrees of formalisation of the social care workforce.

As part of the European Pillar of Social Rights, the European Commission recently published a proposal for a new work-life balance directive (European Commission, 2017), which would give informal care-givers caring for a seriously ill or dependent relative the right to take up to five days of care leave per year compensated at least at sick pay level. It also proposes the right for working carers with dependent relatives to request reduced working hours, flexible working hours and flexibility at work.

The Commission envisages monitoring flexible working arrangements as part of the European Semester and sharing best practices on flexible working arrangements and initiatives such as labels and certifications for employers with a good work-life balance. However, the proposal does not address the problem that in many countries the care responsibility lies solely with the – mostly female – family members due to a lack of community care options. Therefore, calls for clear proposals to improve the provision of community care and respite care options are needed to bring about meaningful improvement. Without affordable, accessible respite care options, many carers will not be able to take out time for themselves, and these recommendations will not be implemented.

In most European countries, national laws govern employment in social care services, either through national guidelines for the qualifications and training of workers or through general legislation such as national minimum wage laws. Whilst most long-term care is provided by care workers who receive varying degrees of formal or on-the-job training, there are also other professions involved in caring for older people, including physicians, nurses, occupational therapists, physiotherapists, social workers, psychologists, or mental health specialists. Most of these professions are regulated at national or regional levels by professional bodies or regulatory agencies. However, social care workers include 'unskilled' jobs that are mostly not regulated with the proportion of these in the social care workforce differing significantly from country to country.

Several countries have also strengthened the rights of informal carers. For instance, France's 2016 Law on Adapting Society to Ageing [Loi d'adaptation de la société au vieillissement), recognises the important role informal carers play in caring for older relatives, and gives them the right to take a break from their caring responsibilities through an annual lump sum of EUR 500 to finance day care or temporary accommodation. The law also gives carers the right to take unpaid care leave in flexible ways, including the possibility of working part-time (European Social Policy Network, 2016).

In Italy, informal carers are entitled to up to three days of paid care leave each month, which is fully funded by the National Institute of Social Security. In addition, carers can take up to two years' unpaid leave and have the right to return to their job afterwards. Carers can also receive a monthly cash benefit of about EUR 500 (*Indennità di Accompagnamento*) and they are free to spend this as they want, for instance on employing a low-cost migrant worker at home or subsidising their own income. Whilst these payments have increased over time, national funding for social services for dependent older people and people with disabilities was cut by 60 per cent between 2008 and 2013, even though the country already relied to a greater extent on family care than other Western European countries (Centre for Policy on Ageing, 2016).

In the personal and home care sector, undeclared work is common to the detriment of workers, who cannot benefit from work protection legislation, minimum wage, working time regulations and insurance tied to employment status. The International Labour Organisation (ILO) Convention No 189 on decent work for domestic workers sets out standards and approaches for ensuring fair terms of employment and decent working conditions as well as promoting formalisation of employment relationships. However, it has so far been ratified only by six EU Member States.

2.2. Recruitment and retention of social care staff

Most countries have a variety of roles in formal social care requiring varying degrees of formal training. In Austria, Denmark and Germany for instance, there are specific training routes in the form of apprenticeships or training courses, the length and content of which are regulated nationally or regionally. In the UK, by contrast, training for social care roles is predominantly provided after recruitment in the form of on-the-job training, supervised placements, or through short-term courses. In some countries in Central and Eastern Europe, such as Bulgaria or Poland, care workers in residential institutions tend to be 'medical assistants' or similar healthcare professionals (Alzheimer Europe, 2013; Ministerstwo Pracy i Polityki Społecznej, undated). In all countries, there are also social care jobs, such as social care assistants or home care assistants that require no formal training and are not regulated by a national or regional agency.

Many European countries already have high vacancy rates in the long-term care sector, which can be attributed to the low pay, unattractive working conditions, including shift work, high turnover rates, rising demand as well as the lack of men in the workforce. These recruitment problems are expected to intensify in the future, which risks putting more pressure on the existing workforce and making it harder to provide quality care (Lipszyc et al., 2012).

The literature suggests different ways of addressing recruitment and retention challenges. Reducing the threshold of skills and initial training requirements while providing tailored training schemes after recruitment is one way to attract people to the social care sector (European Centre for the Development of Vocational Training, 2010). Another strategy concentrates on valuing the role of current workers; for instance, by appointing them to become 'care ambassadors' to attract new workers by sharing their experience (Skills for Care, 2015).

Figure 3: Key drivers for recruiting social care staff, adapted from ESN publication 'Investing in the social services workforce'

Clear team and management structures

Clear career pathways

Role clarity

Key recruitment drivers

Job security

Support mechanisms for staff

Training programmes
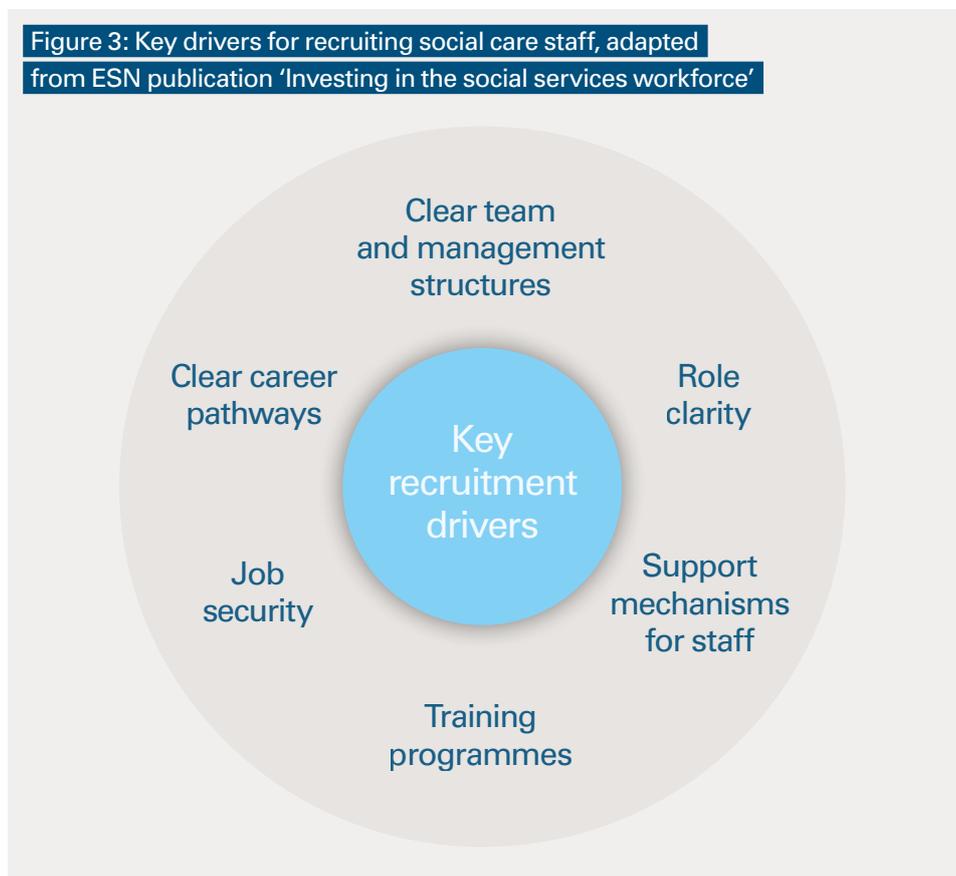
Many European countries have increasingly tried to fill vacancies with migrant care workers, who make up more than half of the social care workforce in some large cities like London (Hussein and Christensen, 2016). Migrant care workers are recruited through formal 'managed-migration' schemes or by relying on free labour mobility within the EU. Yet, many migrant care workers – mainly women from less-well off countries – work under poorer conditions, for less pay, longer hours and more night shifts than native workers (van Hooren, 2012).

A 2013 peer review on long-term professional care and the role of migration policy highlighted the effects that migrant care work has on migrants' countries of origin as well as the countries they work in (European Commission, 2013). The Romanian contribution emphasised the personal impact on migrants and their families and children, who often stay behind in Romania. Both the migrant care workers, who might be isolated and socially excluded in the destination country, and the children who are separated from their parents and often raised by their grandparents, can develop mental health conditions. Moreover, the cost to the country of losing a large number of young skilled people leaves Romania with a shrinking, older population and a loss in potential development, which is also expected to make it more difficult to develop an adequate long-term care system itself (Rusandu and Predescu, 2013).

This difficult situation, where vulnerable migrant workers are needed to fill vacancies in the care sector, puts social care employers in a difficult position as financial constraints do not allow them to raise wages, improve working conditions and develop opportunities. However, where migrant care workers' training or language skills are insufficient, the quality and safety of the care provided can be at risk (Stone, 2016).

It is not only the recruitment of professionals that is an issue. The social services sector also has difficulty holding on to staff. With poor rates of retention and high rates of staff turnover, it is important to look at the reasons behind these and ways to improve them.

Job satisfaction can be increased by involving care workers in decision-making, teamwork and mentoring. An organisation's retention strategy should be built on regular staff feedback on job satisfaction, workload levels, and how well supported they feel by colleagues, managers and supervisors (Webb and Carpenter, 2012). Providing adequate support to employees so that they can better manage the demands of their work can play a key role in keeping them in the organisation.

Mutual psycho-social support can be very helpful, for instance for residential care workers having to deal with older service users' deaths, or for home care workers who usually work alone and have few opportunities to talk to colleagues about their work. Staff retention can be encouraged by good management skills. The supervisor, who can be a social worker, a senior care worker or a manager, highlights solutions, good examples and opportunities, fosters team building, and ensures that complaints or potential risks to safety and quality are reported (Burack-Weiss and Brennan, 2008).

The general image of care work being unattractive does not necessarily reflect the perception of those working in the profession. Many enjoy working with older people and value the challenges and variety of tasks as well as the long-term job security a career in this field brings with it. This does not deny the concerns about working conditions and remuneration, but it shows that care work under good conditions can indeed be an attractive career choice for many people (Sozialverband Deutschland, 2015).

Table 5: Opportunities and challenges for social services in recruiting and retaining staff

Opportunities	Challenges
Training and work placements can enable trainees to learn about best practice, address potential concerns or difficulties, and learn about strategies to cope with stress, conflicts with service users and the physical burden of care work.	Staff shortages in social care are often addressed by employing agency workers on demand, frequently at high cost and risk to quality and continuity of care.
Individual inductions for new recruits should take into consideration their strengths and experience to help them feel confident in the work they do.	'Unskilled' social care positions are especially likely to be filled ad hoc with little or no training or formal induction.
Recruitment campaigns targeting unemployed people and men can improve recruitment considerably.	The lack of men in the social care workforce makes it more difficult to recruit enough staff.
Involving service users and informal carers in recruitment processes recognises their expertise.	Local issues, such as high living costs in urban areas, or remoteness in rural areas, can be major recruitment obstacles.
Digital documentation can help reduce the time spent on bureaucratic tasks and free up more time to spend with service users.	Overly dense regulation can put an additional burden on care workers and risk them feeling they have to prioritise targets and guidelines over service users' wellbeing.
Recruiting migrant care workers can help reduce vacancies and enable workers from worse-off countries to find rewarding employment if the working conditions and remuneration are decent.	Due to their often more vulnerable situation, migrant care workers tend to accept lower pay and poorer working conditions.
Workloads should be kept at sustainable levels through robust planning, time-based staff allocation, stress management and prevention measures.	Vacancies and high absence rates can lead to overburdening existing staff, which can lead to a vicious circle of more absences, which in turn increases the pressure on the workforce.
Regular performance reviews, where potential development opportunities are discussed, can make staff feel more valued and in control of their work situation, which may incentivise them to stay in the job for longer.	Unfair treatment and discrimination of some employees can create a negative work atmosphere, which can lower the quality of care and add to retention problems.

Implementation in practice
School holiday placements in the social care sector in Riga, Latvia

Secondary school students get work experience in residential care

This initiative started as a programme of work placements for 21 secondary school students aged 15 to 18 at Gaiļezers, which provides residential care for older people in Riga. Over three months, the 21 students were given an introduction to the work of Gaiļezers, its clients and their needs.

The students accompanied and assisted clients in activities such as going for walks, using technical aids, shopping, library visits, specialist appointments, as well as leisure activities such as crafts, reading, singing, playing board games and musical instruments, and physical exercise. The work placement at GaiĐezers, which lasted for a month, was a good opportunity for each student to get to know the clients, care staff and their duties, as well as aspects of social service provision and administration.

The students showed interest in working with older people and some said they preferred this placement to other opportunities, such as placements in supermarkets. The practical experience of seeing and responding to older people's needs raised students' awareness of older people's everyday lives and some of them said that it made them think about their parents' and their own old age.

Gailezers' clients appreciated having new people in the residential facility and said that it had a positive effect on their mood and their mental engagement. The students could pay more attention and devote more time to individual clients than care professionals who are subject to time and work constraints.

The students received a small payment of €360 for their placement and the supervisors received a small remuneration proportionate to the number of students that they supervised. The total costs for the project over the three months was €10,997.26 of which the State Employment Agency (SEA) contributed €4,471.20 and Riga City Council's Education, Culture and Sports Department €6,526.06.

The initiative has been running for two years and similar schemes have been established in two other residential care facilities in Riga.

> The full practice example is available here:
> www.esn-eu.org/raw.php?page=files&id=2043

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Mārtiņš Moors
Riga City Council, Department of Welfare

"Long-term care facilities in Riga are running school holiday placements for secondary level students in order to introduce them to social care professions. This is part of the programme organised by the State Employment Agency in order to guide youngsters in choosing a profession".

2.3. Supporting care workers who care for people in their own homes

In the context of a shift from residential to more community-based services, demand for professionals working in this field has increased, although differences between European countries are still significant. For example, whilst employment in the non-residential adult social services sector made up 5.3 per cent of the total share of employment in Finland in 2014, it accounted for only 0.6 per cent in the Czech Republic (For Quality![3], 2016).

Workers' representation in social care generally tends to be underdeveloped given the diversity of jobs in the area and the lack of regulation. In particular, home care workers are seldom organised in unions or professional associations, which may lead to difficulties in enforcing workers' rights, including minimum wage laws, or opportunities to access training, or to report incidents and complaints (For Quality!, 2016).

Registering the social care workforce is an effective first step in professionalising social care and home care workers, and gives public authorities and regulators contact with an often 'hidden' workforce. Registration can be connected to advice on workers' rights and available training courses. In the long run, this can improve working conditions with the potential to reduce turnover, and improve the quality of care provided.

An example of such an endeavour is taking place in Northern Ireland, where the Northern Ireland Social Care Council (NISCC) is in the process of registering all social care workers in an effort to professionalise the workforce. This will bind social care workers to the NISCC's standard of practice and will in return protect social care workers legally and regulate the training available, which must be acquired by anyone being employed in this profession.

Many countries have extended cash-for care or personal budgets to older people. Personal budgets enable older people to buy services directly and employ personal assistants directly in their own homes. This can empower service users and allow them to tailor the care they receive to their needs, while flexible employment contracts can be an advantage for care workers who have children or are studying.

Age UK (2013) provides a comprehensive guide on how to make personal budgets work for older people in order for them to have meaningful choice and control over their care. Their report emphasises that personal budgets should not be regarded simply as handing over money to service users, and that they require continuous support, good information about care options and support in crisis situations. In most countries, local authorities are responsible for these tasks and for ensuring that care assistants employed by service users are treated well, paid on time and have the skills required to provide care safely.

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[3] The For Quality! European project on quality of jobs and services in the personal and household services sector was funded by the PROGRESS Programme. Between 2014 and 2016, a network of nine European stakeholders, including ESN, exchanged best practices, mapped developments in 11 countries and developed a general report, a toolkit and a set of European recommendations.

Table 6: Opportunities and challenges for social services in supporting social care workers who work in older people's own homes

Opportunities	Challenges
Giving home care workers access to the same training opportunities as residential and community care workers is important to ensure quality of care.	It is difficult to monitor and assess working conditions and hours in someone's own home, therefore information campaigns targeted at home care workers and their employers are important to inform workers about their rights and where to seek support in case of abuse.
Personal care budgets can empower service users if they have good information and advice on how to best use their money to choose and employ staff and manage risks.	Employing someone in their own home, for instance through a personal budget, is usually a new experience for service users and their families, therefore information and advice on expectations and boundaries is recommended.
Allocating enough time for home care visits allows workers to provide compassionate, adequate care.	Time and financial pressures may take priority over service users' preferences and wishes.
Telecare and telehealth solutions can relieve care workers of some of the unpleasant aspects of bodily care (e.g. intelligent toilets), improve efficiency of documentation, and ensure reliable, seamless health monitoring.	As the Nordic Think tank for Welfare Technology (2014) found, working with new technologies requires care workers, who are often not used to such tools, to be willing to adapt to changes that affect their work environment.
Specific training courses or workshops can help workers to adapt to new technologies and feel confident to use them in their daily work.	In many countries, home care workers have no access to formal training due to a lack of resources and regulation of the workforce.
Home care workers should benefit from meetings with colleagues.	Many home care workers can feel isolated due to a lack of contact with colleagues.
Robust policies and procedures to deal with verbal or physical abuse against care workers can prevent situations from escalating, and make workers feel safer.	Migrants and unregistered care workers are more likely to tolerate abuse due to their vulnerable position and a lack of knowledge about available support, their rights and who they should go to in order to address the situation.

Implementation in practice
Re-ablement and Community Home Support in the North of England, UK

Interdisciplinary community support teams

enable people to die in their own homes

Stockport Council's in-house Re-ablement and Community Home Support (REaCH) works with district nursing teams to enhance and combine social care and clinical support offered to people at the end of their life. This approach has enabled more people to die at home, and has reduced the number of hospital admissions at times of crisis.

REaCH offers a person-centred integrated clinical and social care support plan. The plan aims to protect people's dignity and treat them with respect during a difficult time as well as making sure their wishes are met and are at the heart of decision-making.

REaCH aims to increase the capacity of the district nursing service by employing REaCH assistant practitioners who are experienced and able to provide additional support with the same skill level as district nurses. These assistant practitioners are trained and have end-of-life care skills. The district nursing service provides clinical supervision and certifies the competencies of REaCH assistant practitioners. Staff from both services are integrated and located together. The district nursing service receives the referral, assesses users and allocates cases to the REaCH staff. REaCH staff attend all district nursing meetings to discuss cases and agree on the level of support.

Prompt access to aids and adaptations as well as reordering medication and pain relief by working with the GP and community nurses are key aspects of the support provided. The integrated service is underpinned by the principle of interdisciplinary working and understanding how different roles can best match the rapidly changing support needs for the individual. The interdisciplinary team is brought together to meet all the needs and choices of the individual, with the aim to enable people to die in their place of choice, typically their own home.

Stockport Council conducted a pilot project, which demonstrated that 92 per cent of people on the pilot (56) were able to die at home. Prior to the pilot commencing, 70 per cent of people died in hospital. This demonstrates that the project has made a significant impact in enabling people to choose to die at home.

The project received funding largely from two sources, Stockport Council (GBP 400,000) and the Better Care Fund (GBP 100,000), which contributes funding to integrated care projects.

The full practice example is available at:
www.esn-eu.org/raw.php?page=files&id=2275

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Jim Thomas
Skills for care UK

"Integrated working isn't about who employs the workforce. It's about how the workforce use the different skills and knowledge they have to deliver the most person-centred care they can".

2.4. Supporting informal carers

As European care systems are increasingly focussing on enabling older people to stay in their own homes for as long as possible, this implies a greater reliance on informal carers, especially in countries that have not developed adequate community services that are affordable and accessible. Whilst some countries have introduced provisions to formally support informal carers, for instance by introducing care allowances, paid or unpaid care leave, caring for a dependent relative still puts many carers in a situation where they have to balance their work and care responsibilities, deal with the physical and emotional challenges of caring, and address financial difficulties that may arise from meeting their relatives' care needs (Eurocarers, 2016a).

Eurocarers, the European association representing informal carers, estimates that informal carers provide about 80 per cent of long-term care in Europe (Eurocarers, 2016b). Caring for a family member can be a rewarding experience but at the same time, many informal carers have to deal with the challenges associated with their care responsibilities. For example, they are 20 per cent more likely to have mental health problems, such as depression or anxiety, than the general population.

Figure 4: Useful skills for informal carers, adapted from 'Informal carers' skills and training – a tool for recognition and empowerment (Eurocarers, 2016c)

Disease-specific knowledge

Skills to maintain health and facilitate rehabilitation

Skills to manage sysmptoms

Informal carers' skills

Skills related to ADLs (personal hygiene, feeding, dressing, etc.)

Management of emergency situations

Manage stress and protect one's own health
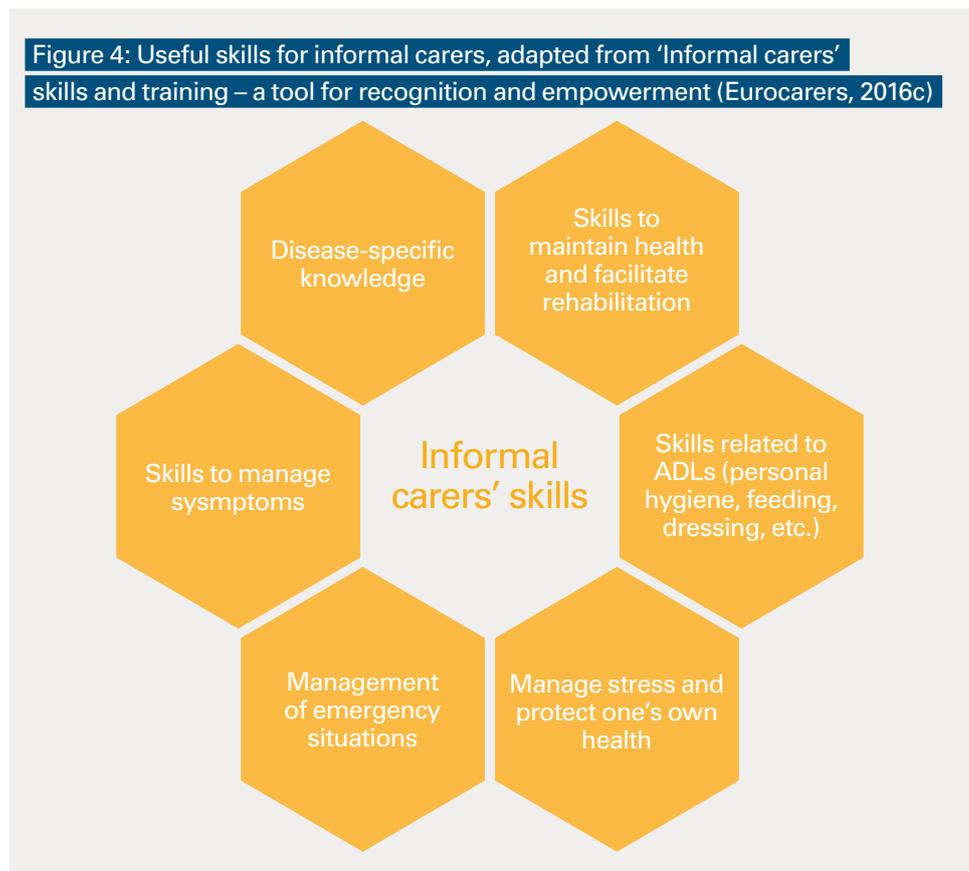
Members of ESN's working group on ageing and care saw a clear role for social services to support informal carers. For instance, in the Netherlands and in the UK, there is an explicit expectation from the national government that local authorities provide sufficient support to informal carers and account for this in their annual progress reports. Beyond financial support, the most important forms of assistance identified were the provision of information; assessment of the financial, social, health and living situation of carers; support including respite and emergency care; and peer support groups to foster the emotional and social wellbeing of carers.

However, they also pointed out that it is often difficult to reach informal carers as their role is rarely recorded anywhere and many do not seek support or advice. As highlighted by a migrant informal carer when the group members visited services in Mechelen (Belgium), migrant communities often tend to be more reluctant to seek help because there is an expectation in the community that families would care for each other rather than involving someone external. Moreover, the carer highlighted that migrant communities were often badly informed about care options. The language barrier can contribute to this lack of information, although working group members emphasised that in many countries public authorities provide information in different languages.

Table 7: Opportunities and challenges for social services supporting informal carers

Opportunities	Challenges
Improving the quality of care provided by informal carers through flexible training related to general care skills (personal hygiene, manual handling) and specific aspects of medical care (administering medication, home-based dialysis, colostomy bag management, monitoring of blood and insulin levels) can improve care.	Many informal carers do not see themselves as such, which can make it harder to reach them.
Supporting informal carers own wellbeing through peer support groups, respite care or counselling can benefit those they assist.	Resources need to be made available for professionals to organise and manage support groups and services for informal carers.
Involving informal carers in team meetings acknowledges their expertise and can improve the overall care provided due to their intimate knowledge of the service user.	In countries with underdeveloped long-term care systems, there is often a lack of professional support and advice available for informal carers, which can result in avoidable and expensive in-patient or residential care admissions.
Ensuring that adequate, friendly support is available in emergency situations reduces the risk of admissions to in-patient care and can help the informal carer to feel able to fulfil their care responsibilities for longer.	A lack of respite care can stop informal carers from taking up training and support opportunities if they have nobody to care for their loved ones while they are away.
Clear information and advice about the specific conditions as well as general health and care issues, can go a long way to help informal carers feel more confident in the care they provide and to seek help when necessary.	Language barriers can make it difficult for older migrants and/or their carers to access information.
Information material targeted at informal carers – in various languages - should contain advice on financial support and other services available for them.	
Telecare, telehealth and teleconsultation solutions can support informal carers if they are equipped with the skills and confidence to use them.	
Co-designing support services with informal carers can empower them and contribute to designing more targeted services.	

Implementation in practice
Emotional support groups for informal carers in Barcelona, Spain

Support groups help informal carers to avoid isolation and improve care given to dependent people

Carer support groups were first established in 2009 after the signing of an agreement between the Catalan Department of Employment, Social Welfare and Families, the La Pedrera Foundation, and the Barcelona County Council (BCC). The overall objective is to improve the quality of life of non-professional primary carers of dependent people through a programme that facilitates emotional support and social interaction between caregivers in similar situations. The carer support groups, currently led by the BCC, constitute a model of care for caregivers based on psychosocial interventions that address the challenges associated with caring for someone. Between 2009 and 2015, the total number of groups established reached 297, spread over 118 municipalities.

Municipal officers who are responsible for social services provision identify eligible people to participate in the groups. The local council also manages and coordinates logistical organisation, the implementation and the evaluation of the groups in each municipality. The methodology underpinning the support groups is based on group dynamics, meaning that the interaction between the members and the issues discussed is based on participants' experiences, interests, needs, feelings and fears.

Feedback indicates that the support group has improved participating carers' self-esteem and quality of life. Just to give a few examples, the support group has helped carers reduce feelings of anxiety, verbalise problems and concerns, reduce behavioural problems, such as eating or sleeping disorders, and regain control over their lives as well as developing strategies to cope with feelings of social isolation.

BPC is responsible for designing, planning, implementing and funding the programme together with the participating municipalities. In 2015, the overall costs were EUR 119,830. Increasing demand for the service, high satisfaction of carers attending the groups and the inclusion of the initiative within the service portfolio of the BCC indicate that the project can be sustained in the long-term.

The full practice example is available here:
wwww.esn-eu.org/raw.php?page=files&id=2274

Luis Berrios Novoa
Barcelona County Council

"The Emotional Support Groups for Informal Carers organise meetings so that caregivers can share their needs and concerns, as well as their experiences and knowledge. The aim is to reduce the negative impact of care that sometimes can be experienced by caregivers and non-professional carers, and to improve the quality of life of dependent people".

Chapter 3: Services cooperation

Integrated social and health care

Person-centred care

Background

Although there is a trend towards models of care with more integrated, person-centred services, most countries continue to provide health and social care services for older people in silos (Harding et al., 2015). There is currently no EU guidance in this area. However, the WHO Global Strategy on people-centred and integrated health services (WHO, 2015) provides a comprehensive overview of the principles, benefits and possible paths to person-centred health and social care.

> "Integrated care includes initiatives seeking to improve outcomes of care by overcoming issues of fragmentation through linkage or co-ordination of services of providers along the continuum of care" (European Commission 2017b).

In 2015, ESN carried out a comprehensive study on integrated social services in Europe together with Vilans, the National Centre of Expertise for Long-term Care in the Netherlands. The final report (Lara Montero et al., 2016), which includes an assessment of 44 practice examples from 17 European countries, demonstrated the multidimensional benefits of integrated care for people, their families and carers, and for public services.

In the same year, ESN's working groups on ageing and care also looked at forms of cooperation and integration of health and social care services for older people. It compared policy frameworks of integrated social and health care services and analysed twenty practice examples from Belgium, the Czech Republic, Finland, France, Latvia, Spain, Sweden and the UK. All these practice examples have now been uploaded to ESN's online practice library.

As a member of the EIP AHA's Action Group on Integrated Care, ESN has been able to exchange experiences and information about health and social care integration with about 120 public and private partner organisations in Europe. The EIP AHA Group provides a platform to exchange and analyse activities at local, regional or national level implemented by stakeholders who are committed to promote innovative and concrete actions to improve older people's health and quality of life.

This chapter looks at cooperation and integration opportunities and challenges at three levels:

- Macro-level cooperation and integration between systems or between providers and commissioners involving large population groups;
- Meso-level cooperation and integration of services and care pathways for people with the same conditions involving organisations and communities;
- Micro-level cooperation and integration of care provided at the local level to individual service users and their carers.

For all three categories, it is important to note that there is no single model, as different circumstances require different solutions. Full integration is not always the best solution and should not be regarded as a goal in itself but rather a way to achieve better care (Goodwin et al., 2014).

3.1. Legal and policy framework

At European level, the SPC has called for "fully integrating the health and social elements of long-term care provision" (Council of the European Union, 2014). Whilst the European Commission and the Council of the European Union are advocating the transition to more integrated models of care, legislative and policy frameworks in this area come from national, regional and local levels.

A detailed overview of policy frameworks for integrated health and social care can be found in ESN's integrated services report (Lara Montero et al., 2016). Some examples of key developments in recent legislative changes are outlined below.

Cooperation between health and social care differs in every country. For instance, in the Czech Republic, the health and social components of long-term care are provided by two different systems with various levels of cooperation. In France, services cooperation is promoted by the 13 Regional Health Agencies *(Agence Régionale de Santé, ARS)* that are tasked with bridging the gap between healthcare and long-term care. Similarly, in England the 2012 Health and Social Care Act established groups of healthcare professionals, local authorities and communities (*Clinical Commissioning Groups – CCGs*) that commission health and social care services and have a duty to seek improvement of services, reduce inequalities, promote service user involvement and choice, innovation and integration (NHS Commissioning Board, 2013).

Several European countries have implemented specific policies that seek integration between the health and social care sectors. In Sweden, the 'Ädel reform' *(Ädelreformen)* of 1992 made municipalities responsible for care of older and disabled people as well as for people who are discharged from hospital. The responsible municipality has to pay a fee if a patient stays longer than needed in hospital.

In Italy, the Legislative Decree No. 229/1999 strengthened the role of municipalities and promoted local partnerships for health and community care. It created an integrated framework of health and social care services provided for older and dependent people as well as other disadvantaged groups (Lo Scalzo et al., 2009).

On the other hand, Finland is undergoing a 're-centralisation' process of its health and social care services. Previously provided at the local level, health and social care will become the responsibility of 18 counties, and will be organised through 12 hospitals and five collaborative areas. This reform has created tensions over competences between local and newly created regional authorities, while the central government takes increased financial and planning control over services (Doyen and Lara Montero, 2016).

At the regional level, the region of Catalonia in Spain has developed a plan *(PIAISS)* that aims to promote a model of health and social care integration that responds to people's needs in a person-centred way. Many of the challenges of integrating the two systems faced by Catalonia are due to the different resources and structures of the health and social services systems as outlined in table 8, which are similar in many other European countries.

Table 8: Social and healthcare services in Catalonia (Sarquella, E. 2015)

Social services	Healthcare services
Exclusive powers to regional government Run by local and regional authorities	Majority of powers for the regional governments according to Spanish law Run by regional government
Different maps of service delivery areas	
Universal coverage and free access to some services	Universal coverage and free access
Funded by taxes but with co-payment for some services	Funded by taxes. Co-payment in pharmaceutical products
Multi-provision model	
Wide range of services covered publicly by regional government and by local authorities, provided directly publicly or by third sector or private providers	Wide range of publicly covered services provided mainly in public facilities
Budget: €2,279 million €1,878.33 million: regional government €400.67 million: local authorities	Budget: €8,500 million

3.2. Macro-level cooperation and integration

Macro-level cooperation and integration programmes involve whole system change and are often initiated top-down by national, regional or local governments and/or health services. They are often motivated by an aim to address care gaps that result from fragmented systems.

Health and social care services can be integrated at macro-level through pooling funding, integrated commissioning or merging providers.

Pooled funding, where the partners involved are contributing to a common budget with which the initiative or service is funded, can be a driver of integrated care. Pooled budgets have been referred to as an option to overcome financing fragmentation, but concerns have also been raised regarding resource distribution between the organisations involved in the arrangement (Lara Montero et al., 2015).

Integrated or joint commissioning can refer to arrangements where commissioners from different sectors (e.g. health and social care) or between organisations in one geographical area commission a service together for a whole population, specific groups or individuals. Fully integrated commissioning is rare and often only used for specific services or for individuals with complex support needs (Humphries and Wenzel, 2015).

Where providers merge to create a single organisation or service, this is often referred to as 'organisational integration'. Alternatively, providers can bring their services together in 'collectives', virtually using digital tools, through provider networks or through contracts between different providers (Lewis et al., 2010).

As part of the EIP AHA's Action Group on Integrated Care, the Scirocco Project[4] has developed a Maturity model that helps organisations assess their readiness to change to an integrated care model using 12 indicators. It is a useful self-assessment tool that can help organisations to reflect on where they are, where they want to get to, and which areas need improving in order for a more integrated model of care to be enabled.

Members of ESN's working group on ageing and care who shared examples of macro-level integration, emphasised the role of one organisation taking leadership to ensure a clear vision and robust management of the organisational change.

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[4] The Scirocco Project aims to implement the Maturity Model for Integrated Care that was developed by the EIP AHA's Action Group on Integrated Care. Scirocco is developing a self-assessment tool to facilitate successful scaling up and transfer of good practice in integrated care across European regions.

Figure 5: Maturity model for integrated care, Scirocco Project

Figure 6: Using the Maturity Model – Experience of Scotland
(Pavlickova, 2017)
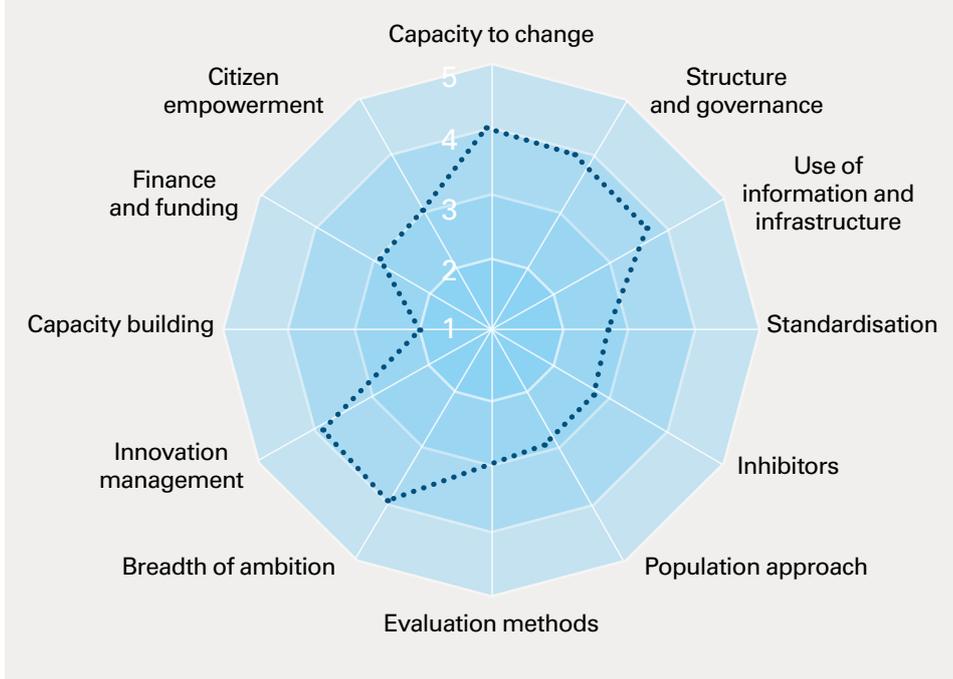
Table 9: Opportunities and challenges for health and social care integration at the macro-level

Opportunities	Challenges
Designing primary care integration that promotes the use of community resources can facilitate the transition to integrated community care models.	Many healthcare systems are fragmented with different parts financed and structured separately and with different priorities, which means that they require different incentives to move to an integrated care model.
Through integration, duplication of services and/or documentation can be reduced, thereby providing services more efficiently.	While governments advocate for more integrated care – which requires close cooperation – they are also introducing more competition between providers and this can represent conflicting incentives.
With macro-level integration, long-term funding beyond project stage is secured early on to ensure sustainability.	Funding is often fragmented or limited to a pilot stage, which can lead to projects being terminated even though they show promising results.
Initiatives evaluated as part of a systematic approach and evaluation outcomes can improve the service further.	Successful cooperation, integration projects and practices, even when shared online, often come to the attention of only a small number of people or after a period of time, so organisations end up 'reinventing the wheel' over and over again.
Involving research organisations in the process can provide thorough evaluation and contribute to the evidence-base on service integration.	Many organisations only employ informal evaluation methods or collect data without a clear strategy on how to analyse and evaluate it.
Legal, ethical, public and professional aspects of privacy and data protection are discussed and solved in order to enable the use of digital data sharing solutions.	Integrating digital care records can be a complex endeavour due to interoperability issues or information sharing concerns.
National or regional top-down strategies for integration can be important to guarantee political and resources backing.	Top-down organisational or structural mergers can be very disruptive and require a lot of resources whilst lacking evidence of clear benefits to care outcomes.
	National policies for health and social care integration that devolve responsibility to the regional or local level can be perceived as an obligation or an administrative burden rather than an opportunity if local stakeholders do not take ownership of the process.

Implementation in practice
Integration of Health and Social Care in Scotland

The legislative framework for the integration of health and social care services in Scotland aims to improve outcomes for service users

The challenge for all Western societies regarding how to cope with ageing populations is at its most acute in Scotland where, over the next 10 years, there will be a 25% increase in those aged over 75 – the highest users of health and social care services (Bruce and Parry 2015). Therefore, integration is seen as a way to make more efficient and effective use of limited resources and is believed to be central to improving outcomes for patients and service users.

The Public Bodies (Joint Working) (Scotland) Act 2014 is the legislative framework for the integration of health and social care services in Scotland. The Public Bodies (Joint Working) Act 2014 created a number of new public organisations, known as integration authorities, with a view to breaking down barriers to joint working between the national health boards and local authorities. It placed a requirement on the national health boards and local authorities to integrate health and social care budgets, put in place nationally agreed outcomes and a requirement on partnerships to strengthen the role of clinicians and care professionals, along with the third sectors, in the planning and delivery of services. Adult social care employees are still employed by local authorities but are now integrated in structures that are often led by health professionals. Moreover, health and social care professionals are now working under the supervision of the recently created Health and Care Partnership.

The 2014 Act requires national health boards, responsible for health services, and local authorities, responsible for social services, to jointly submit an integration scheme for each area setting out the detail of which functions will be delegated to the integration authority. These schemes are intended to achieve the National Health and Wellbeing Outcomes agreed by the Scottish government, and have to be approved by Scottish Ministers (Scottish Government, 2014). The Act allowed national health boards and local authorities to integrate health and social care services in two ways, the integrated joint board model or the lead agency model.

Under the integrated joint board model, an Integration Joint Board (IJB) is set up and the national health board and local authorities delegate the responsibility for planning and resourcing service provision for delegated adult health and social care services to the IJB. National health boards and local authorities delegate budgets to the IJB which then decides how to use the resources. Under this model, staff that deliver services are not required to transfer from one employer to another or change their employment terms and conditions.

Under the lead agency model, the NHS board or local authority takes the lead in planning and delivering integrated service provision in their area. Information on which body will be the lead agency is set out in the integration scheme. The Chief Executive of the lead agency has responsibility for developing the strategic plan for the integrated services and a strategic planning group. The lead agency model requires staff to transfer to either the council or the national health board.

The Scottish Government estimated that the initial cost of integrating adult services would be GBP 34.2 million over the five years up to 2016/17 and GBP 6.3 million after this, whilst they would be able to deliver budget efficiencies of between GBP 138 and 157 million (Scottish Parliament Centre, 2016). To ensure that performance is open and accountable, the 2014 Act obliges Partnerships to publish an annual performance report setting out an assessment of performance in planning and carrying out the integration functions for which they are responsible.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=2579

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Peter Macleod
Renfrewshire Council

"The integration of health and social care represents an opportunity to provide the highest quality services to those in need of care and support against a backdrop of raising demand. Having citizens voice driving positive changes in these services is seen as being central to their future success".

3.2. Meso-level cooperation

Meso-level cooperation and integration measures take place at the organisational and/or community level. For instance, Denmark is in the process of abolishing nursing homes and replacing them with multidisciplinary community care services (Kümpers et al., 2010). Often, the motivation for better cooperation or even integration comes from within organisations or partner organisations in the community who see that users could be better supported if the services they use were more closely connected.

Sometimes, national or regional policy-decisions can also drive meso-level integration by promoting inter-professional teamwork, effective leadership information management arrangements.

A key aspect of meso-level care coordination/integration is inter-professional teamwork at both managerial and practitioner levels (Lara Montero et al., 2016). Establishing this kind of teamwork can be complex and often requires addressing differences in the work culture, professionals' views of the user, what 'good care' looks like, as well as different expectations of each other's roles and skills.

Research from England (Rowan et al., 2016) shows that professionals working in multi-agency teams tend to report greater control over key decisions affecting their work but also poorer supervisory support from managers than those working in single-agency teams. Rowan et al.'s research showed that if professionals in a multidisciplinary team are supported by managers from a different discipline, this can often lead professionals to feel inadequately supported. On the other hand, if members of a multidisciplinary team have different supervisors according to their discipline, this can contribute to conflicts and confusion in the team. Solutions to this tension have to be discussed and adapted to the context in which the team works.

Figure 7: Forms of inter-sectoral collaboration, adapted from Integrated social services in Europe (Lara Montero et al., 2016)
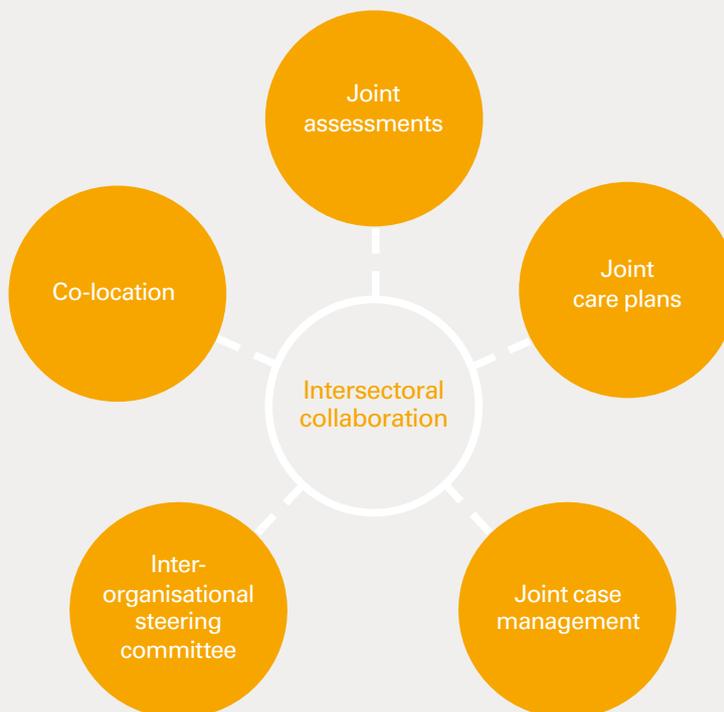
Effective leadership is essential to making inter-professional or cross-sectoral teams work effectively. In particular, leaders play an important role in managing coordination between the different professionals as well as users and carers. Shared leadership and decision-making can be challenging, especially in contexts with established hierarchies. However, with a clear direction and vision, the ability to listen to team members and the skills to support and supervise the team, leaders can be true enablers of integrated care (Nancarrow et al., 2013).

Information management is a key aspect of coordinating or integrating care between different organisations, yet it is also one of the most difficult aspects to change. An international comparison of integrated care models conducted by the King's Fund (Goodwin et al., 2014) found that none of the programmes they looked at had developed fully shared electronic patient records that all health and social care professionals involved in a person's care could access. In fact, many countries have only recently begun to digitalise care records generally, which can be an enormous bureaucratic endeavour.

Examples of meso-level integration initiatives provided by members of ESN's working group on ageing and care often had a shared leadership approach with two or more organisations, often coming from both health and social care organisations. The initiatives focused on distinct points in the care pathway or a specific population group. Key aspects of the integration process in these cases concerned establishing leadership and management structures, data sharing as well as clarity on (new) roles and responsibilities.

Table 10: Opportunities and challenges for health and social care integration at the meso-level

Opportunities	Challenges
Collective goals and values are clearly formulated early on in the integration planning process. This helps to ensure that the whole team is working towards the same vision.	Poor communication between health and care professionals can be a major obstacle to successful integration and requires joint effort to change.
Joint training for health and social care can support new working methods.	Practitioners need to have the right skills to work in multidisciplinary teams with people outside of their own professional discipline.
Organisational leaders who foster a culture where innovation and cooperation is encouraged at every level, including new roles that facilitate a change in structure as well as culture of the organisation(s), can influence positive change.	New integrated practices often require high investment of staff working time, and given the common lack of resources to pay for additional staff, this often has to be organised within the organisation's existing human and time resources.
Strong leadership, commitment and change management within organisations involved in integration are crucial to navigating difficult stages and to guarantee the active involvement of all relevant stakeholders.	Integrating services can be disruptive and create confusion about roles and responsibilities. Therefore, clear leadership and management, are essential to successful integration.
Service users can benefit from having a care coordinator and/or case manager with whom they have personal contact regularly and who oversees coordination and continuity of care.	Supervising interdisciplinary care by bringing together the different specialists whose help the person may need, the coordinator's role is key in monitoring and evaluating the care delivered.
Integrating care at the meso-level takes time but the most robust programmes can evolve and improve though learning from what works and what does not.	Evaluation of meso-level cooperation/ integration projects is often weak due to a lack of data, lack of resources for evaluation, or professional resistance to 'hard' performance measures.
	The absence of systematic evaluation of impact and outcomes can reduce opportunities for learning and improving integrated care.

Implementation in practice
Integrated care plan in Catalonia (Spain)

The Integrated Care Plan leads the transformation of health and social services to improve quality of care

In 2014, the Government of Catalonia issued the Integrated Health and Social Care Plan (PIAISS) to promote, lead and participate in the transformation of the social and health care model to achieve person-centred fully integrated care and to deliver holistic care to adults with complex health needs. Integrated health and social care should also help to lower costs, enhance quality of care, and improve outcomes.

Although the PIAISS is responsible for defining general frameworks and guidance for integrated home care, residential care, integrated care and mental health or technology enabling integrated care at the Catalonia's level, the most relevant attribute of the implementation strategy has been the collaboration with a wide range of local stakeholders to establish local partnerships for integrated care at the meso-level.

To implement the initiative, the Local Partnership for Integrated Care in Barcelona was established in 2015. The Local Board for Integrated Care in which all the governance stakeholders are involved (Barcelona City Council, representatives from the regional Health and Social Services Ministries, and service commissioners) has the mission of defining the health and social care priorities and aligning all the initiatives being developed in the city to make sure they comply with the framework provided by the PIAISS.

Some of these initiatives to promote integration are:
- A new model for health and social home care for people with complex care needs being piloted in 2 districts of the city.
- Integrated electronic records: The Catalan Electronic Health Record and the IT system of the local social services (SIAS) are now connected using interoperability standards and support for professionals to use it differently according to their needs.
- A post-referral protocol for activating social home care at the hospital bed, to ensure continuity for cerebral stroke patients.
- Vincles Project: a community project that provides care for older people who feel alone through a social support network they can access using a touch screen tablet.

In order to successfully implement the reforms, three elements have been key. First, even though national leadership is key to creating a common vision to guide the implementation of reforms, these should be made respecting the subsidiarity principle and promoting microsystems partnerships to make things really happen. Second, having a functional approach that caters for looking at care pathways, processes or protocols, collaborative practice between teams and professionals, rather than starting with structural aspects of the strategy, is key. Finally, the transformation is not possible without identifying and promoting professional leadership as the main agent of change for integrated care.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=2578

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Ester Sarquella Casellas
Regional Government of Catalonia (until September 2017)

"The demographic, social and economic challenges we are all facing in our communities demands of us a transformation of our health and social services system to improve quality of care according to citizens' needs. In Catalonia, the Integrated Care Plan leads this transformation but requires departmental and national action as well as a clear consideration of the local dimension through community-based partnerships".

3.3. Micro-level cooperation and integration

Providing more person-centred services is one of the most important aims of the coordination of various strands of care, ensuring that service users are involved in service planning and implementation. This is most relevant at the micro-level where health and social care professionals are closest to service users and informal carers and therefore effective cooperation is crucial to provide tailored support based on the service user's needs and preferences.

Involving service users in integration processes at the micro level is essential, but different forms of involvement should be employed for different people. Not all service users are able to or want to be involved in co-producing services, therefore a variety of methods and tools should be used. An overview of them is given in figure 8.

Figure 8: Degrees of service user involvement, adapted from 'Service user involvement' (NHS England 2015)

Information
– Users are informed about the service but have no influence
– Methods: posters, leaflets, newsletters, exhibitions

Consultation
– Users are asked about their views but have limited influence
– Methods: questionnaires, interviews, focus groups

Participation
– Users can make suggestions and influence outcomes
– Methods: service user/carer reference groups, workshops

Partnership/co-production
– Users share decisions and responsibility, can influence and determine outcomes
– Methods: involvement in governance of schemes, membership of recruitment panels

Control
– Users control decision-making at the highest level and/or monitor outcomes
– Methods: user-led peer support schemes, user-led monitoring

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Whilst most macro and many meso-level integration initiatives only involve service users through information, consultation or participation, partly due to the complexity and scale of the practices, micro-level initiatives can often make use of intimate local knowledge, personal relationships and other assets in the community to involve service users and carers in joint decision-making and giving them more control over the process.

Examples of micro-level integration that were provided by members of ESN's working group on ageing and care focused on staff working together in interdisciplinary teams in an integrated way, often in local community centres or supporting older people in their own homes. There was a clear focus on specific prevention measures, such as integrating podiatry services in residential care in Latvia to prevent foot infections and diseases, or medication coordination between hospitals and residential care services in Belgium.

Table 11: Opportunities and challenges for health and social care integration at the micro-level

Opportunities	Challenges
Involving users and informal carers in the design, planning and delivery of care ensures that service integration evolves around the service user.	If feedback from service users and carers is not considered visibly, it can be a frustrating experience and make them feel that they are only involved in a tokenistic way rather than actually listened to.
Integrated services can be more accessible when they offer one point of contact for all aspects of the service.	Given the small number of people involved, micro-level initiatives can stand and fall with individuals who are willing to invest time and effort into changing the way that care is delivered.
Integrated ways of working can improve the understanding between health and social care professionals and lead them to take co-responsibility for users' wellbeing.	Micro-level cooperation/integration efforts often have to overcome organisational boundaries.
Working in an interdisciplinary team can be an opportunity for health and social care professionals to enhance their own skills and knowledge by learning from their (new) colleagues.	Availability of staff and skills can vary in local areas, particularly in those that have recruitment and retention difficulties.
Integrated teams in the community can implement targeted prevention measures for users at risk of developing specific conditions.	Multi-disciplinary teams that do not include a mental health professional cannot address comprehensively older people's wellbeing.
Given that older people tend to be less likely to seek help for mental health problems than younger people, local multidisciplinary teams can benefit from having a mental health professional who can address this aspect of an older person's wellbeing.	Telecare or telehealth solutions should supplement rather than replace face-to-face care.
Micro-level integration can be supported by telecare or telehealth solutions to support older people in their own home.	

Implementation in practice
Integrated health and social care community centres, Czech Republic

Integrated care pathways for frail older people are provided in new community centres

The Social Services Centre run by the City of Prague provides a variety of services combining the registration for social services (home, daily, short-term in-patient and residential care) and for health care services provided in people's own homes. The centre is able to cover the needs of older people, from rare and irregular home assistance and services to daily and short-term care or residential care. With this system, the service user does not have to change the provider when their conditions and needs change.

This concept is rare in the Czech Republic, where long-term care services are usually provided by the regions, NGOs and church organisations. Cities usually provide only social care, so service users have to deal with two or three organisations in a system that is often opaque and lacks transparency.

With this integrated centre, the experience of care is enhanced thanks to better access to services for users with complex needs. It is also expected that with these centres, resources can be used more efficiently and costs reduced as service users are expected to use the centre's services for longer.

The centre is providing a more integrated care pathway for frail older people and those with complex needs and offers care in a holistic way that recognises the complexity of users' needs. The centre has been running for a few years and other cities in the Czech Republic are now transferring the model and establishing similar centres.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=1782

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Jiri Horecky
Association of Social Care Providers

"Even though health and social care still have their own financing and regulations and are provided by different public authorities, integrated care is becoming more accessible for service users with complex needs in Czech Republic".

Chapter 4:
Caring for older people with complex needs

Preventing isolation

Community-based services

Background

Older people with multiple and complex conditions such as dementia or disabilities tend to require health and social care services on a larger scale. Therefore, it is crucial to understand how best to provide support services for them. The challenges and opportunities that the members of the working group shared with us in the context of supporting older people with complex needs is the basis of this chapter.

This chapter will firstly explore how people with multiple conditions can be most effectively supported in a person-centred way. Secondly, the chapter will provide an overview of how health and social care services are supporting people with dementia and Alzheimer's disease and their families. Finally, the chapter will address challenges and types of support for people with learning disabilities growing older to reduce preventable ill health and premature deaths.

4.1. Legal and policy framework

The United Nations Convention on the Rights of People with Disabilities (UNCRPD) is an important human rights convention in Europe, of which Article 19 has been a key focus. The European Disability Strategy 2010-2020 committed the EU to promoting the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services. However, success in achieving this objective has been mixed and there is a risk that the efforts being made to support persons with disabilities in the transition to community-based care may not be seen as relevant for the lives of older persons with a disability (European Network of National Human Rights Institutions, 2016).

> ### The UNCRPD (Article 1) definition of persons with disabilities
> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The definition of persons with disabilities given by the UNCRPD includes many older people with long-term conditions so the UNCRPD as a whole applies in this context. The following articles of the Convention are of particular relevance to health and social care for older people:

Article 19 (a): Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

Article 19 (b): Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Article 19 (c): Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 25 (b): Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons.

Article 25 (d): Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

Article 26: States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

The European Charter of the rights and responsibilities of older people in need of long-term care and assistance sets out rights specifically for older people in Europe, although these are not legally binding.

Figure 9: European Charter of the rights and responsibilities of older people in need of long-term care (AGE Platform Europe, 2010)

Article 1

Right to dignity, physical and mental well-being, freedom and security
– Includes protection from physical, psychological, financial, pharmaceutical or sexual abuse or mistreatment and neglect.

Article 2

Right to self-determination
– Includes the right to expect one's opinions, wishes and choices to be respected even when one is not able to communicate them eloquently, and the right to be consulted and participate in any decision-making processes that affect one.

Article 3

Right to privacy
– Includes the right to personal space and etablished the goal for all involved in one's support and care to avoid any restrictions on one's privacy and intimate relations.

Article 4

Right to high quality and tailored care
– Includes the right to be cared for by people who have the skills required and adequate technicla, strucutral and financial support to respond to one's needs adequately.
– Includes the right to expects that all individuals, institutions and professional bodies involved in on'es care should communicate and cooperate with one anothr and closely align the services they provide to ensure that they are in the user's best interest.

Article 5

Right to personalised information, advice and informed consent
– Includes the right to be informed about one's health and available treatment and care options, the right to access one's personal health records, and the requirement for one's informed consent or that of an appropriate third person on decisions about one's care or treatment.

Article 6

Right to continued communication, participation in society and cultural activites
Includes the right to be given opportunities to participate in social life in accordance with one's interests and abilities.

Article 7

Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion
– Includes the right to obtain spiritual or religious care and the right to reject this.

Article 8

Right to palliative care and support, and respect and dignity in dying and in death
– Includes the compassionate care at palliative care at the end of life and that those treating and accompanying one respect one's wishes and uphoald them wherever possible.
– Includes the right to expect that support from medical and care professionals be offered to those close to the person who is dying.

Article 9

Right to redress
– Includes the expectation that care professionals be traied to recognise signal of abuse and mistreatment and act appropriately to safeguard users from further mistreatment.
– Includes the right to be informed about how to report abuse without fear of negative repercussions, and to expect authorities to responds andintvestigates appropriately.

Article 10

Your responsibilities
– Includes respecting the rights and needs of people living and working with the person and for staff to be able to work in an environment free from harassment and abuse.

The implementation of these and other rights varies considerably between European countries, as national legislation often does not award older people the same rights as younger people with disabilities. A positive example is the Spanish Personal Autonomy and Dependent Care Law introduced in 2006, which gives people with care needs the same right to public support regardless of their age. The law strengthened the rights of people with care needs in Spain significantly, although its implementation and enforcement has fallen short of expectations, mainly due to a lack of financial resources, inadequate governance systems and coordination between health and social care. Insufficient participation of citizens in decision-making has also been an obstacle (Peña-Longobardo et al., 2016).

The Spanish example highlights that whilst it is key to establis rights of people with care needs that encompass all of the lives' facets affected, the crux of the matter lies in the implementation and enforcement of these rights.

4.2. People with multiple conditions

It is estimated that about two thirds of people enter retirement with at least two chronic health conditions (Nolte and McKee, 2008). These complex health problems often affect many aspects of a person's wellbeing and autonomy, and they also pose a great challenge to European health systems in terms of resources, coordination and evidence-based practice.

Mental and physical health issues do not just coincide frequently, they may also cause or reinforce each other. Yet, older people's mental health issues are less likely to be identified and treated adequately, not least because older people are less likely to seek help for mental health issues than younger people. Apart from dementia, depression is one of the most common mental health conditions that older people experience, affecting between 10 and 20 per cent of older people and up to 40 per cent of care home residents in England (Social Care Institute for Excellence, 2006). Depression in older age can be triggered by loss of independence and social contacts, bereavement or loneliness. Depression is also associated with increased perception of poor health, use and cost of care services (WHO, 2016).

The promotion of active ageing (see chapter I), enabling older people to live as autonomously as possible, and the provision of holistic support and care services (see chapter III), can reduce the risk of depression (Social Care Institute for Excellence, 2006). Crucially, the health and social care professionals working with older people need to understand the connection between physical, emotional and mental wellbeing, and be equipped with the skills to care for older people with these complex needs.

Responding to these different challenges associated with supporting people with multiple conditions requires well-coordinated or even integrated services as described in chapter III, including support from multidisciplinary teams. The key to adequate care for people with multiple conditions are individualised care plans that take into account the user's preferences, and their physical, mental and social wellbeing.

Figure 10: Elements required to ensure continuity of care for people with multiple conditions, adapted from 'Integrating care for people with co-morbidities' (McShane and Mitchell, 2013)

Management community
Levers and incentives promote and support continuity of care

Relational continuity
People have a trusted adviser they can turn to for help and advice

Informational continuity
A person's records are available across health and social care settings when and where they are needed
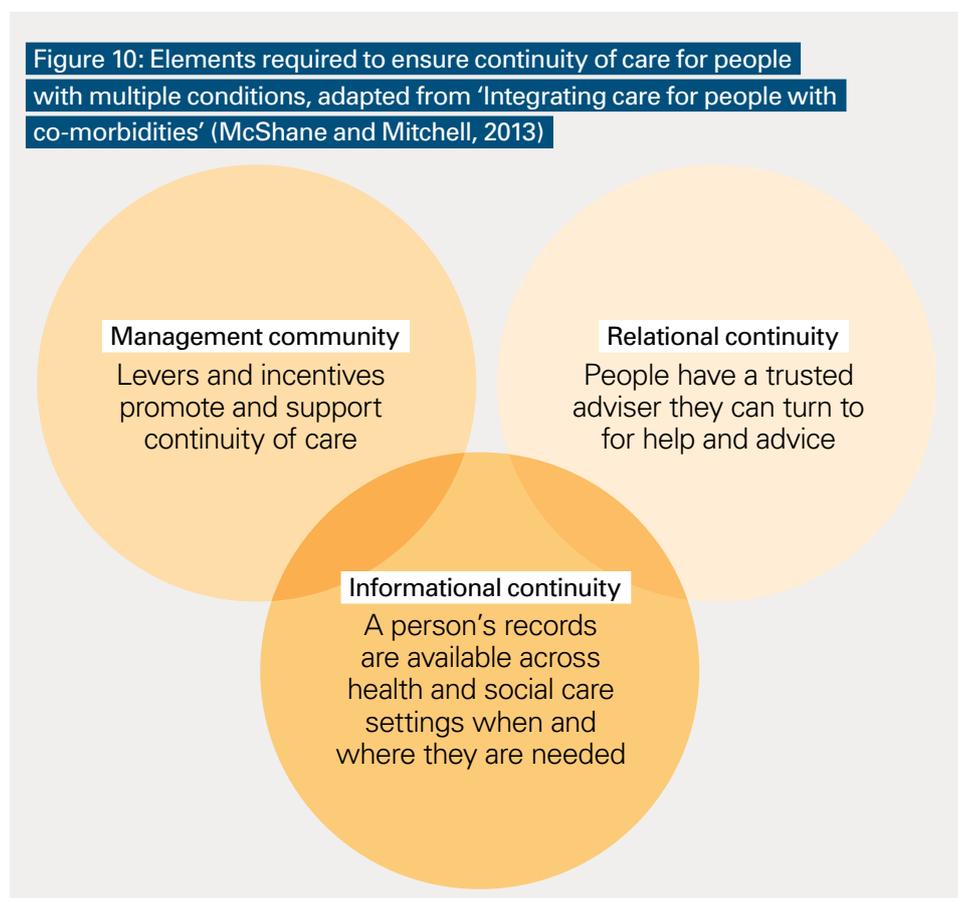
Table 12: Opportunities and challenges for health and social care services supporting people with multiple conditions

Opportunities	Challenges
Digital tools can make it easier to manage repeat prescriptions, monitoring health and consultations remotely at a lower cost and at the convenience of the service user.	The evidence on the effectiveness of digital tools is still emerging, therefore careful monitoring and adequate governance are important.
Integrated community teams can support people holistically and prevent crisis situations that may require admission to hospital.	Given that many social care workers receive little or no training, many are not equipped with the skills and understanding required to care for someone with comorbidities.
Service users and carers often become experts in the conditions they are dealing with, and frequently want to be able to self-manage it as much as possible, which health and social care services should fully support.	Comorbidity can result in contradictory needs and it can be difficult for the service user and the carers to weigh up what to prioritise.
Participatory research on comorbidities is growing and an opportunity to understand them better and to adjust treatment and care options to the evidence.	Supporting people with multiple conditions can be made more difficult because specialist services or advocacy organisations are too focused on their own speciality.
Health and care professionals can help to reduce the stigma associated with mental health conditions that prevent many older people from seeking help by providing information and proactively talking about mental wellbeing.	Mental and physical health services are often not very well coordinated and may have different approaches to care, which can add to the lack of acknowledgement of the interconnectedness of mental and physical health.

Implementation in practice
Person-centred integrated care at home for older people with complex needs in Lidköping, Sweden

Frail older people with complex care needs are cared for by integrated community teams

This initiative is located in the western part of Sweden (Skaraborg county), in six municipalities with around 100,000 inhabitants between them. This example focuses on one of the six municipalities: Lidköping, with around 38,000 inhabitants (almost 22 per cent of them are 65+ and 6 per cent are 80 and older).

The aim of this initiative was to develop person-centred integrated care for very frail older people. This could not be achieved without close collaboration between health care and social services. Two specialised teams were established: the mobile palliative care team and the integrated home care team. These two teams serve patients in all six municipalities and are financed by the county (i.e. the health care authorities).

The palliative team serves primarily younger older people with cancer (and will not be discussed further in this example). The integrated home care team has a responsibility to serve older people with extended needs who are not able to visit the outpatient clinic. The teams serve on average 24 patients at the same time and can be seen as 'a hospital ward at home'. Further, in Lidköping, there is a 'mobile doctor', who primarily visits older people in need in their own homes.

In Lidköping, the home help services and home nursing care are organised in home care teams (home helpers, occupational therapists, physiotherapists and nurses) with the goal of offering older people proactive rehabilitation services at home. Since 2009, home help services work in close cooperation with the integrated home care team and the mobile doctors. The municipal home care nurse is responsible for coordinating the collaboration arrangement and acts as the contact person for the integrated home care team and the mobile doctor.

A 2010 evaluation showed an impressive reduction in the number of visits to the emergency ward (80%), hospital visits (89%) and number of care days at hospital (92%) among the older people supported by the integrated home care team. Municipal costs for home-based care increased, but this was counterbalanced by reduced need for residential care.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=1710

Ingela Hellberg
Lidköping Municipality

"The integrated home care team ensures that fail older people receive appropriate care and support at home. Workers within this team are allocated to specific geographic areas in order to ensure a continuity in the workers visiting older people in their homes, increasing therefore their comfort and safety".

4.3. Supporting people with dementia and Alzheimer's disease and their families

In Western Europe, dementia is the leading cause of years lived with a disability for men over 60 and even more so for women over 60. The percentage of people with dementia rises rapidly with age and given that the highest age groups are also the fast-growing age groups in many European countries, the need to develop effective support services for people with dementia is imperative (Rodrigues et al., 2012). The nature of the condition challenges the way care in the community has been provided traditionally given its unpredictability. This requires a different approach not just at organisational level but by the whole health and social care system.

Therefore, many countries have developed national policies to address care and support for people with dementia and Alzheimer's and for their families, and focus on the need for more evidence on prevention and better understanding of the condition. Figure 11 provides a useful overview of countries that have addressed these important issues in a national strategy.

Figure 11: The status of national dementia strategies in Europe (Alzheimer Europe 2016)

- Countries with a national dementia strategy in place
- Countries with a neuro-degenerative disease strategy
- Countries with no national dementia strategy
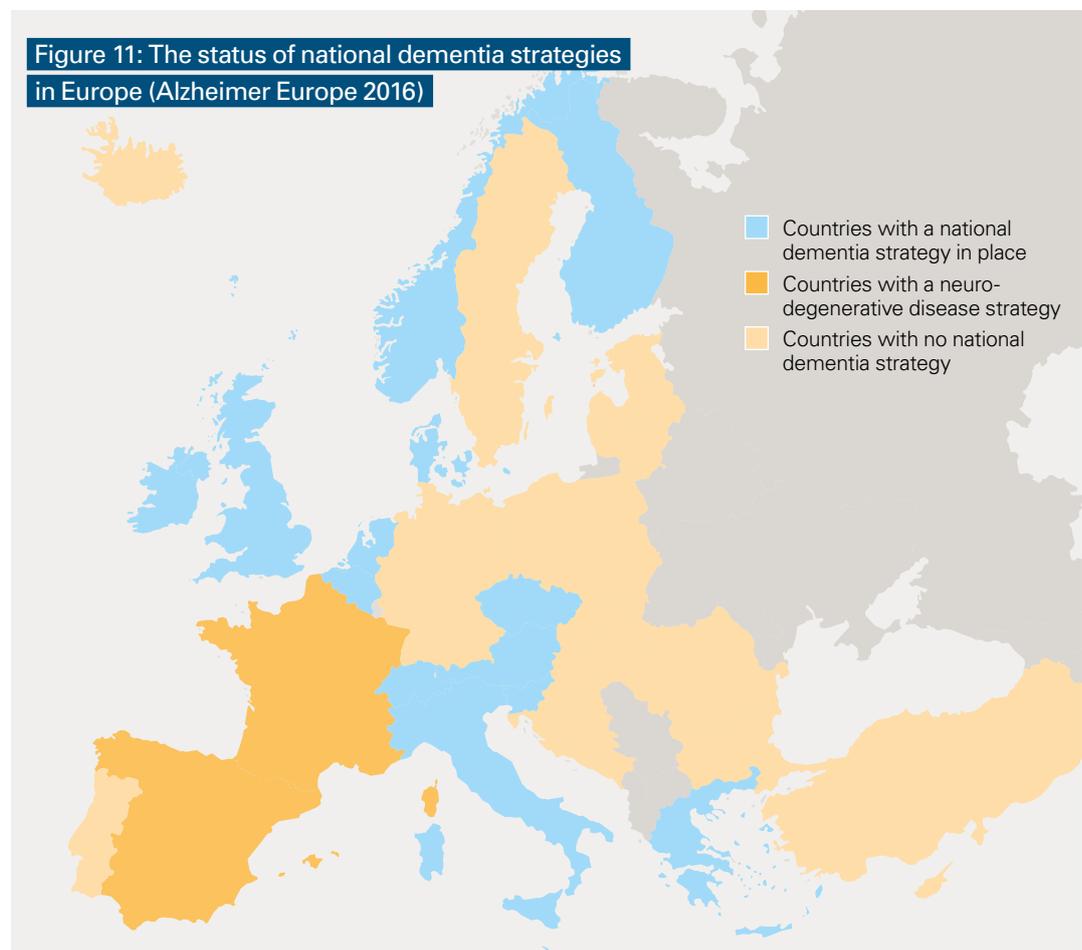
France developed the first national dementia plan in Europe in 2001, which was replaced by subsequent strategies in 2004, 2008 and 2014. The current strategy (Plan Maladies Neuro-Dégénératives 2014–2019) covers not only dementia and Alzheimer's disease but a range of other neurodegenerative conditions. It outlines 94 specific measures to provide adequate diagnosis and care, promote social acceptance and knowledge about neurodegenerative diseases and their social consequences, further develop and coordinate research, and develop democracy and participation in the evaluation and control of health services (Merkle, 2016).

Figure 12: Key aspects of national dementia strategies, adapted from 'National dementia strategies – a comparative approach in Europe' (Merkle, 2016)

Raising awareness of dementia, removing stigma and providing information

Promoting medical and nursing research

Improving diagnosis and integrating early advice

Strengthening the qualifications and skills of professional staff and volunteers

Improving care and support at home
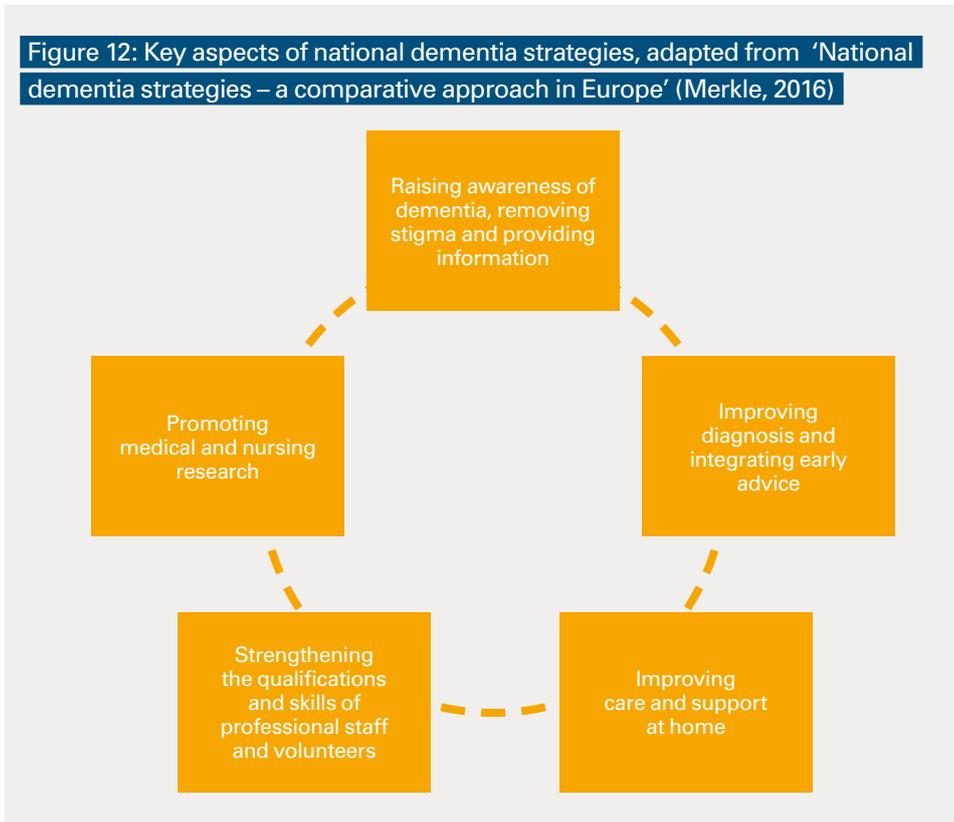
The Swiss national dementia strategy (Nationale Demenzstrategie 2014-2019) outlines national priorities in four action areas (see figure 13), which are implemented jointly by the federal government and the member states of the Swiss Confederation *(Kantone)*. The overarching aim is to support people with dementia and promote their quality of life with consideration for their individual circumstances, including their social environment and other conditions or disabilities.

Figure 13: Action areas and goals of the Swiss National Dementia Strategy 2014-2019, adapted from 'Nationale Demenzstrategie 2014-2019' (Bundesamt für Gesundheit BAG, 2017)

Action area 1: Health competence, information and participation	Action area 2: Needs-based support services	Action area 3: Quality and professional competence	Action area 4: Data and knowledge transfer
Goal 1 Raise awareness and reduce prejudices	**Goal 3** Availability of flexible, high-quality, needs-based support services	**Goal 5** Consideration of ethical guidelines	**Goal 8** Provide information on available dementia care
Goal 2 Strengthen participation and provide comprehensive information for users and carers	**Goal 4** Guarantee funding for needs-based support services	**Goal 6** Quality assurance for the entire course of the disease **Goal 7** Promote and strengthen professional competence	**Goal 9** Promote exchange between research and practice

Most people with dementia continue to live in their own home and their communities, therefore many countries in Europe have recognised the need for communities to become more 'dementia-friendly'. Dementia-friendly communities in Belgium or the UK, for instance, try to raise awareness of dementia, tackle stigma attached to the condition, and encourage learning about it. They seek to empower people with dementia and enable them to actively participate in and contribute to their community. This requires appropriate care and support for the person with dementia as well as their families and carers. The ultimate goal is to enable people with dementia to live the best possible life for as long as possible (Alzheimer Europe, 2015a).

One of the best-known examples of dementia-friendly communities is found in the Belgian city of Bruges, which participated in ESN's seminar on the social services workforce in Bratislava in November 2016. Local NGOs, social and health services, the local government and local businesses have been working together since 2010 to be more respectful towards people with dementia and interact with them on an equal basis. Key elements of Bruges' efforts are:

- Improving knowledge about dementia amongst the general population as well as among health and social care workers.
- Creating a more positive attitude towards people with dementia.
- A dementia information centre.
- Integrated care support at home.
- Dementia counsellors.
- Specialised dementia care experts, nurses and occupational therapists working with the person in their own home;
- Peer support groups for people with dementia.
- Volunteers who are trained in supporting and caring for people with dementia.
- Dementia-specific training for families.
- Social activities such as music afternoons, literary evenings, seasonal celebrations.

In later stages of the condition, care needs are not only increasing, it can also be more difficult to respond to them adequately due to the fact that people with dementia can experience great distress and anger, which they may express in aggressive and challenging behaviour. Alzheimer Europe (2015b) provides a practical guide for health and care professionals to deal with ethically challenging situations in hospital and residential care.

They emphasise that there is no one solution to these situations, but that it is important to reflect on them in the team, and establish ethical guidelines to steer professionals making situational decisions that require weighing up risks and safety concerns against personal autonomy and rights. Ethical questions can also arise in end-of-life care for people with dementia or Alzheimer's disease, where the preference, wishes and beliefs of the person should be respected as much as possible (Alzheimer Europe, 2008).

Table 13: Opportunities and challenges for health and social care services supporting people with dementia or Alzheimer's disease

Opportunities	Challenges
A wealth of guides and examples on how to become 'dementia-friendly' is available.	Establishing a 'dementia-friendly' community requires commitment from individuals and organisations.
Providing adequate information about the conditions as well as support and care opportunities can reduce the stigma and anxiety that people with the diagnosis and their families might have about the condition.	Evidence on how dementia and Alzheimer's disease can be prevented, delayed, slowed down and dealt with, is still emerging and often focuses on medical aspects, therefore holistic research involving people with the condition is still in demand to improve care and support.
Dementia-specific training for health and social care professionals is becoming increasingly important to ensure adequate care, not only in specialist but also generalist services.	In later stages of the condition, people with dementia can become increasingly aggressive, frustrated and upset, which can lead to very challenging situations for the care staff and family members. Training them in how to handle these situations is therefore very important.
Involving people with dementia in professional training can help to reduce prejudices and reservations. It can also help professionals to understand the complex way in which dementia can affect a person's life.	Care workers who care for people with dementia in a care home or their own home with no formal training can be ill-prepared to support people with complex needs and challenging behaviour appropriately.
Taking time to understand what the person is communicating verbally or non-verbally – if possible also with the help of their families – is important to understand their wishes and to provide person-centred care.	Dementia can make it difficult to understand what is important to the person and how they experience certain aspects of their condition. High turnover in the care team supporting the person can make it even harder to provide person-centred care.
Telecare solutions like sensors that detect movement, gas or moisture can contribute to keeping people with dementia safe in their own home, especially during the night.	There may be different expectations from carers and people with dementia themselves. Carers and family members can be more concerned about safety and reducing risks while the person with dementia may think it is more important to be independent and may find it difficult to be 'monitored' in their own home.
Questions about end-of-life care choices should be discussed sensitively with the person with dementia and their family members early on to ensure they have time to discuss and make these decisions before it can become difficult for the person to articulate their preferences.	Availability of and access to palliative care and end-of-life support varies in Europe and therefore tends to be underused, which can lead to people dying in hospital even though they expressed a preference for dying at home or in a hospice.
Community-based palliative care teams as well as residential care services can support people with dementia and their families at the end of their lives if they are well trained in dealing with dementia.	

Implementation in practice
Integrated support and care services for people with Alzheimer's disease (MAIA), France

Integrated health and social care services support people with Alzheimer's disease to live self-determined lives

The MAIA (Maisons pour l'autonomie et l'intégration des malades Alzheimer) model set up governing bodies and common tools to bring together services in geographical areas and to develop joint responsibility for individual needs of health care and social care. The goal is to bring together the right stakeholders to assess care needs, facilitate the correct care and to appoint case managers to bring together services for people with Alzheimer's disease in France.

At the first stage of the project, 17 pilot projects were carried out in different municipalities under the supervision of the National Solidarity Fund for Independence (CNSA). At the second stage, the pilot was rolled out to several areas in France and managed by the regional health agencies. There were 252 MAIA programmes deployed in France at local or county level in 2014, promoted by different bodies (local authorities, health networks or hospitals). Due to its success, the programme has opened up its support to people with long-term conditions other than Alzheimer's disease or dementia, even though that remains the focus.

A coordinator is responsible for the pilot in a defined area, where case managers work with service users and different services (40 cases followed by the equivalent of a full-time coordinator). The practice developed a record-sharing procedure. Protocols between health and social care services have been established to share and evaluate information between professionals. Tools have been merged in order to make information sharing easier (tools for needs assessments, referrals to other services, and promotion of service awareness).

Information sharing with service users has led to an easier access and understanding of existing services in the area and the way they complement each other. The programme has provided health and social care professionals with tools for sharing information and managing complex cases jointly. It has also improved professionals' understanding of other roles in the health and social care system, and influenced organisations to communicate more with stakeholders.

The full practice example is available here:
http://www.esn-eu.org/raw.php?page=files&id=1781

4.4. People with learning disabilities growing older

Fortunately, the life expectancy of people with learning disabilities has increased in recent decades, but it is still significantly lower than that of the population average. Older people with learning disabilities have often experienced inadequate or no support, exclusion and discrimination during their lifetime, especially considering that the public's attitude towards disabilities has only recently changed towards inclusion, promoting independency and autonomy, and anti-discrimination.

Older people with learning disabilities are at higher risk of a poorer quality of life than other older people as well as younger people with an intellectual disability. According to Christine Bigby from the Living with a Disability Research Centre (2016), this affects:

Physical wellbeing: Higher risk of frailty; undiagnosed and poorly treated health conditions; secondary health problems related to their disability.

Emotional wellbeing: Impacted on negatively by frequent moves and high rates of mental health problems.

Interpersonal relationships: Small networks that tend to shrink further with age; few social connections outside the family and the care system; loss of peers at retirement.

Material wellbeing: Reliance on (small) state pensions with little wealth or private resources.

Personal development: Lack of replacement for work or day programmes; low expectations of participation; lack of informal networks that could enable participation.

Self-determination: Decisions about care, living arrangements and leisure time are often made by others driven by the availability of resources or others' preferences

Social inclusion: High risk of institutionalisation; difficulties related to staying in their family home or supported accommodation as age-related conditions develop; low participation in mainstream volunteering or community organisations.

Rights: Loss of parents or other advocates can impact negatively on rights being respected; few enforceable rights to services.

Data on learning disabilities are rarely collected at national level, therefore we know very little about the proportion in different age groups. Evidence form the UK reveals that in 2012 about 23 per cent of the total population of people with learning disabilities were over the age of 60 (Emerson et al., 2013). In 2012, it was estimated that the life expectancy of men with learning disabilities was 13 years below that of men on average, and that of women with learning disabilities was even 20 years lower than for women on average (Heslop et al., 2012).

An inquiry into the premature, i.e. preventable deaths of people with learning disabilities in the UK (ibid.) concluded that the main factors contributing to these were:
- Difficulty or delay in diagnosis, further investigation or specialist referral.
- Lack of adjustments, for instance to accommodate attendance of clinic appointments.
- Lack of coordination of care between different agencies and with end-of-life care.
- Inadequate documentation and record-keeping.
- Health and social care workers with a lack understanding of assessment of mental capacity.

Research shows that people with disabilities are at higher risk of developing certain age-related conditions. For instance, people with Down Syndrome are more likely to develop dementia than the general population but conventional screening tools are often not sufficient to detect dementia in people with Down Syndrome early, therefore a combination of different tests and assessments is required (O'Caoimh et al., 2013).

People with autism are more likely to develop depression and anxiety in older age, and many of those who are aware of their autism often suffer from the lack of close relationships and feelings of not being understood or taken seriously. In addition, secondary effects of unhealthy lifestyles, medication, institutionalisation and social exclusion contribute significantly to lower life expectancy and poorer health (Autism Europe, 2012).

Table 14: Opportunities and challenges for health and social care services in supporting people with learning disabilities in older age

Opportunities	Challenges
Every older person with a learning disability is different and will have different needs and wishes, which require an individualised approach.	Many health and care services lack the resources to provide proper individualised support to older people who lack the resources to pay themselves for additional services.
Providing information and advice in an accessible language is key to making sure people are adequately informed and understand their condition and care options.	Given that the number of older people with learning disabilities is still small in many countries, there may be little incentive for services to make their information on age-related support and care accessible.
Many conditions and early deaths of older people with learning disabilities are preventable. Therefore, better support throughout their lives could improve healthy life expectancy.	The legacy of inadequate care, discrimination and exclusion that many older people with learning disabilities experienced during their lives can contribute to ill health or unhealthy behaviours.
Research on the age-related issues for people with learning disabilities increasingly involves people with disabilities themselves. If value is attached to their experiences this can provide important evidence.	There is little evidence yet on the interaction of learning disabilities and age-related conditions such as dementia, which results in a lack of evidence-based prevention, early detection and care.
The growing number of people with multiple conditions and complex needs can be expected to force services to individualise care and be more prepared to adjust services to individual circumstances.	Care workers in services for people with intellectual disabilities often lack the knowledge and skills to adapt to age-related needs.
	Hospitals, residential care homes and other services for older people are often poorly equipped for caring appropriately for older people with learning disabilities.
Talking about death and end-of-life support is as important for people with learning disabilities as for other older people, yet it may require more flexibility, time to support decision-making and ensuring that care plans clearly spell out the preferences of the person regarding guidance for their care at the end of life.	Older people with learning disabilities are rarely asked about their choices and preferences for end-of-life care.

Implementation in practice
Jenny's Diary – A resource to support conversations about dementia with people who have a learning disability

Helping people with learning disabilities to understand what dementia is and how to face it

Jenny's Diary is a booklet free to download in English, German, Italian, Mandarin and Norwegian (text only) that explains what dementia is, how it can affect the life of a person with a learning disability and what kind of support is available. It was developed in Scotland but could easily be used in other contexts.

Illustrated by photos of Jenny, a person with a learning disability, from her day-to-day life, the booklet describes in plain language how Jenny experiences her dementia, difficulties she has in coping with it and what support she finds to deal with it.

This is a great example of an accessible information resource for people with learning disabilities that can be used by professionals to start and support a conversation about dementia with them. It may also help reduce the fears a person with dementia may have.

> The full practice example is available here:
> http://www.esn-eu.org/raw.php?page=files&id=2577

❝❝

Karen Watchman
Senior Lecturer in Ageing, Frailty and Dementia University of Stirling, UK

"Jenny's Diary was developed in response to research identifying that the diagnosis of dementia is often not shared with people who have intellectual disabilities. With a focus on maintaining supportive relationships and implementing non-drug interventions, it is a recognised good practice resource across Europe and beyond with multiple translations".

Investing
in later life
Checklist

Integrated person-centred services

Community care

Checklist

This checklist has been designed to provide recommendations for directors and professionals working in social services providing care for older people to assist them in their development and implementation of services.

I: Supporting active ageing

Supporting volunteering

- ✔ Employ professional volunteer coordinators and supervisors and ensure they have the skills to support volunteers and service users adequately
- ✔ Work with local organisations to reach potential volunteers and beneficiaries of voluntary activities
- ✔ Establish quality indicators against which the service is regularly assessed
- ✔ Build relationships with partners in politics, your administration, NGOs and private organisations to ensure sustainable funding for the initiative
- ✔ Provide good information and advice about voluntary activities and services to both potential volunteers and users
- ✔ Involve older people actively in the planning, implementation and evaluation of voluntary activities and put their preferences at the heart of the initiative

Prevention and early intervention

- ✔ Use a holistic approach to prevention that considers health, social and environmental aspects
- ✔ Use e-health solutions to improve people's health literacy and promote control over their health and social conditions
- ✔ Embed prevention and early intervention in your strategy with clear objectives and implementation plans
- ✔ Adjust and tailor prevention and early intervention strategies to people with lower levels of health literacy, people in rural areas, socially disadvantaged groups, migrants, people with disabilities and those with mental health problems
- ✔ Provide rehabilitative physiotherapy and occupational therapy to support recovery after hospital discharge
- ✔ Create age-friendly environments to enable older people to participate in community activities and remain autonomous
- ✔ Implement falls prevention measures, including strength and balance training and combatting fear of falling
- ✔ Promote self-care where appropriate

Rehabilitation

- ✔ Provide multidisciplinary, person-centred rehabilitation services to support older people after a hospital stay
- ✔ Incentivise continuity of care after an older person has left a service to avoid care gaps
- ✔ Make sure service users are visited at home after a hospital stay and make helpful adjustments in the home where possible
- ✔ Involve family members or friends in the rehabilitation process to make sure that the service user is supported
- ✔ Discuss with the service user how they are coping with the condition, any fears and concerns that they may have, as well as obstacles to social participation
- ✔ Consider telecare or telehealth solutions to support the person in their own home

II: Supporting formal and informal carers

Recruitment and retention of social care staff

- ✔ Ensure that training and work placements enable trainees to learn about best practice, strategies to cope with stress, and how to deal with conflicts with service users and the physical burden of care work

- ✔ Involve service users/carers in recruitment processes

- ✔ Create recruitment strategies that try to attract men and unemployed people to your workforce

- ✔ Keep workloads at a sustainable level through robust planning, time-based s taff allocation, stress management and prevention measures

- ✔ Ensure regular performance reviews and discuss potential development opportunities with your staff

- ✔ Ensure policies to prevent unfair treatment and discrimination are in place and enforced throughout the organisation

Supporting care workers who care for people in their own homes

- ✔ Give home care workers access to the same training opportunities as residential and community care workers

- ✔ Support service users with a personal budget in their role as employer with information and advice on how to choose staff, how to manage rotas, and how to manage risk

- ✔ Allocate enough time for home care visits to allow workers to provide high-quality, compassionate care

- ✔ Make use of telecare and telehealth solutions to relieve care workers of some of the unpleasant aspects of bodily care, improve efficiency of documentation, and ensure reliable, seamless care monitoring

- ✔ Provide specific training courses or workshops to help workers adapt to new technologies and feel confident to use them in their daily work

- ✔ Organise regular team meetings for home care staff

- ✔ Put in place robust policies and procedures to deal with verbal or physical abuse against care workers

Supporting informal carers

- ✔ Improve the quality of care that informal carers provide through flexible training related to general care skills (personal hygiene, manual handling, etc.) and specific aspects of medical care (administering medication, home-based dialysis, colostomy bag management, monitoring of blood and insulin levels, etc.)

- ✔ Support informal carers own wellbeing through peer support groups, respite care or counselling

- ✔ Involve informal carers in team meetings

- ✔ Provide clear information and advice about the specific of the individual as well as general health and care issues

- ✔ Include advice on benefits and other financial support in information material targeted at informal carers

- ✔ Consider co-designing support services with informal carers

Macro-level cooperation and integration

- ✔ Design macro-level care integration around primary care that promotes community resources

- ✔ Consider co-location, i.e. putting different services under the same roof, and pooling budgets from different organisations

- ✔ Secure long-term funding beyond project stage early on to ensure the sustainability of the service

- ✔ Involve universities or researchers in the process to provide evaluation and contribute to the evidence-base on service integration

- ✔ Evaluate initiatives as part of a systematic approach and use evaluation outcomes to improve the service further

- ✔ Discuss and solve legal, ethical, public and professional aspects of privacy and data protection to enable the use of digital data sharing solutions

Meso-level cooperation and integration

- ✔ Formulate collective goals and values early on in the integration planning process to ensure that the whole team is working towards the same vision

- ✔ Establish joint training for health and social care professionals

- ✔ Establish a culture where innovation and cooperation is encouraged at every level, including adjustments in the risk management strategy of the organisation

- ✔ Provide strong leadership, commitment and change management

- ✔ Employ a care co-ordinator and/or case manager who oversees coordination and continuity of care

- ✔ Establish robust evaluation procedures and use this for learning and improvement

Micro-level cooperation and integration

- ✔ Involve users and/or their carers in the design of integrated services as well as in the care planning process and delivery

- ✔ Offer one point of contact for all aspects of the services for the service user

- ✔ Establish integrated ways of working, foster understanding between health and social care professionals and encourage them to take co-responsibility for users' wellbeing

- ✔ Support opportunities for those working in an interdisciplinary team to enhance their own skills and knowledge by learning from their (new) colleagues

- ✔ Implement targeted prevention measures for users with risks of developing specific conditions through local integrated teams

- ✔ Include a mental health professional in interdisciplinary teams working with older people

IV: Caring for older people with complex needs

People with multiple conditions

- Use digital tools to manage repeat prescriptions, health monitoring and consultations remotely
- Employ integrated community teams to support people holistically and prevent crisis situations
- Support self-management as much as possible and make use of the expertise that the service user may develop over the course of their illness
- Get involved in or support participatory research in comorbidities to improve care
- Provide information and talk to service users about mental health

Supporting people with dementia and Alzheimer's disease and their families

- Work towards establishing a dementia-friendly community to promote the participation and inclusion of people with dementia
- Provide adequate information about the conditions as well as support and care opportunities to the service user and their family
- Provide dementia-specific training for health and social care professionals
- Involve people with dementia in professional training
- Take time to understand what the person is communicating verbally or non-verbally
- Consider telecare solutions like sensors to help keep people with dementia remain safe in their own home, especially during the night
- Discuss the person's wishes and preferences for end-of-life care and death early on together with their family
- Ensure community palliative care teams are well trained in supporting people with dementia and their families

People with learning disabilities growing older

- Provide information and advice in an accessible language to make sure that people are adequately informed and understand their condition and care options
- Involve older people with learning disabilities in planning and evaluating your services
- Ensure that care workers in services for people with learning disabilities have sufficient knowledge and skills to adapt to age-related needs
- Ask older people with learning disabilities about their choices and preferences for end-of-life care and talk to them about their options

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Glossary of key terms

Ageism
Discrimination or unfair treatment based on a person's age.

Carer
A person who provides paid or unpaid care in a formal or informal capacity.

Co-morbidity
The simultaneous presence of two chronic diseases or conditions in a person.

Informal carer
Non-professionals who have no contract regarding care responsibilities but provide care to family members, close relatives, friends or neighbours.

Personal budget
Amount of money allocated by a local authority to ensure a person's assessed needs are appropriately met.

Re-ablement
Services for people with poor physical or mental health to help them accommodate their illness by learning or re-learning the skills necessary for daily living.

Service user involvement
Process by which people who are using or have used a service become involved in the planning, development and/or delivery of that service.

Social care
Range of services supporting children or adults with daily living and personal care.