



# Policy

# brief

## Towards community long-term care

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**Commitment 7 of the United Nations Economic Commission for Europe (UNECE) Regional Implementation Strategy for the Madrid International Plan of Action on Ageing (RIS/MIPAA): To strive to ensure quality of life at all ages and maintain independent living including health and well-being.**

**Commitment 9 of the UNECE RIS/MIPAA: To support families that provide care for older persons and promote intergenerational and intra-generational solidarity among their members.**

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### Challenging context

The population of countries in the UNECE region is ageing, which is leading to the increase in the number of the oldest old — a group with a higher probability of becoming in need of long-term care. At the same time, the number of those making up the working age population, who will be able to provide care, will decrease. UNECE member States have committed themselves to coping with this growing demand in care services while securing quality and choice for patients and their families. Financial sustainability of long-term care systems and a qualified work force are key elements in securing a high quality of long-term care and protecting human dignity in an ageing society.

### Suggested strategies

Living in a regular home with personal belongings, close to relatives and friends, being able to follow an individual routine and enjoying privacy are the prerequisites for a life in dignity and the social inclusion of people with care needs. Also, this model entails less cost for communities and States than residential care arrangements do. For these reasons, a change in paradigm, away from a prevalence of residential care to more integrative community settings, is envisaged. In community settings, care needs may be met by informal caregivers or with the support of formal care providers. In cases where long-term care within the community is not possible or not desired by the users, residential care shall be tailored to individual needs and its high quality should be ensured..

### Expected results

With an improvement of community care settings and the promotion of informal care, more people can remain in their regular home, which contributes to their social inclusion and personal well-being. At the same time, costs are reduced for individuals, community and national budgets.

### Key concepts of ageing in place<sup>1</sup>:

- **Long-term care:** In this context long-term care services include a wide array of services to people whose limited ability to live independently carries on for an extended period of time<sup>2</sup>.
- **Community care:** Integrative approach of care for older persons, which takes place in their familiar environment with the help of formal and informal care giving.
- **Residential care:** Care that takes place in a residential care home.
- **Formal care:** Care provided by care professionals.
- **Informal care:** Care provided by non-professional care givers. This may include home care. Home care refers to long-term care services provided to care recipients who live in their homes<sup>3</sup>.

### Long-term care needs

The changing demographic context will significantly impact the capacity to meet long-term care needs in the future. As was noted in the 2007 World Economic and Social Survey, “The rate of increase in the number of persons needing help in daily living and the rate of change of the institutional and informal capacity shape the framework of a nation’s system of long-term care as a whole.”<sup>4</sup>

In more and more countries people who have reached 65 years of age can expect to live another 20 years or longer. The rate of increase in the number of persons needing help is significantly impacted by population ageing, in particular by the rapid increase in the group of those aged 80 years and above. This is the result of the incremental deterioration of health at the later stages of life that increases a need of long-term care after the age of 80 years. Since the last decade of the twentieth century, most countries have witnessed an increase in the number and the proportion of people aged 80 years and above. People in that age group represent the fastest growing segment in the population and a critical target for the future long-term care policies. The medium variant of the United Nations population projections<sup>5</sup> forecasts that, in 2050, 40 out of 100 persons belonging to the age group 65 years and above in the EU-15<sup>6</sup> will be aged 80 years and more. The highest proportion in the UNECE region is expected in Germany and Switzerland — 43 per cent. In contrast, this ratio for countries of Central Asia is projected at 21 per cent in the same period.

<sup>1</sup>The components of the continuum vary from country to country not only in terms of terminology, but also in terms of legislation and practice. Nevertheless, the title « Towards community long-term care » was chosen for this brief to emphasize the non-residential aspect of such care.

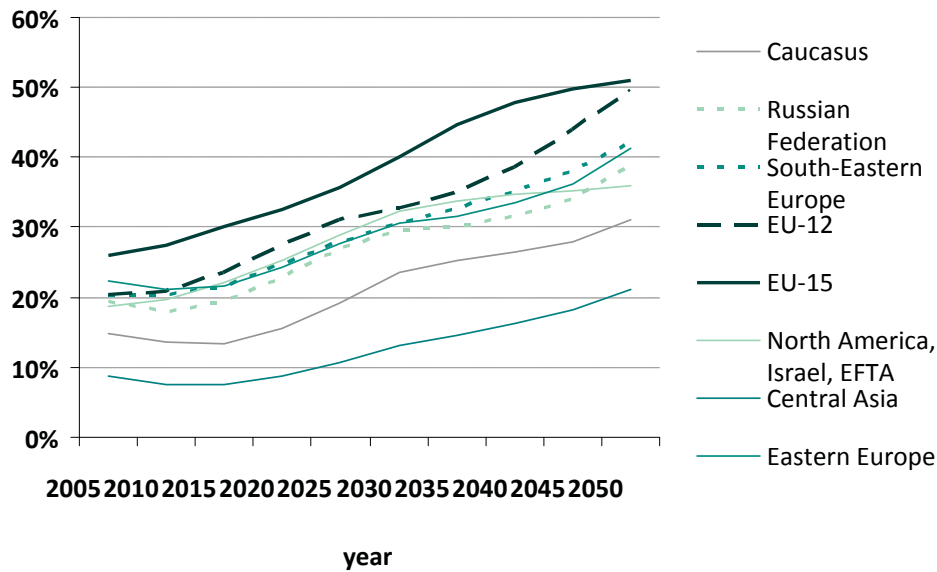
<sup>2</sup>Huber, M.; Rodrigues, R.; Hoffmann, F.; et al. (2009). Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research, p. 20.

<sup>3</sup>Ibid., p. 21.

<sup>4</sup>United Nations Department of Economic and Social Affairs: World Economic and Social Survey 2007, Development in an Ageing World (E/2007/50/Rev.1 ST/ESA/314).

<sup>5</sup>United Nations Department of Economic and Social Affairs, Population Division (2009). World Population Prospects: The 2008 Revision. CD-ROM Edition.

<sup>6</sup>The 15 member countries in the European Union prior to the accession of 10 candidate countries on 1 May 2004. The EU-15 comprises: Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden and the United Kingdom of Great Britain and Northern Ireland.



Source: Calculations based on United Nations World Population Prospects, 2008. Medium variant of the projection.

Although the effect of prolonged lives on health conditions and prevalence of disability is not clear, and the impact of advances in medical science and practice on the quality of older persons' lives is difficult to assess, gains in life expectancy will result in higher numbers of older persons, both in absolute and in relative terms, and potentially also in a higher number of individuals who will need long-term care services. Sustainability of existing residential care schemes is becoming a serious concern, which increases the importance of informal care as a backbone of support for non-autonomous older people. Greater geographical distances between families of different generations, increases in the number of people living alone, a rise in childlessness, smaller numbers of children in families and increases in female employment rates all constitute a challenge for future sustainability of formal care schemes. The future importance of informal care will to a great extent depend on sustainability and reforms of formal long-term care systems.

### *Preference for care provided by professionals and non-professionals*

Care models vary considerably across UNECE member States. The Nordic countries provide support to the highest proportion of frail older persons based on a model of decentralized publicly provided home care services. The proportion of people older than 65 years receiving residential care in the European Union (EU) is on average 3.3 per cent. The highest proportion of persons receiving long-term residential care is observed in Iceland, where 9.3 per cent of persons aged 65 and over years benefit from it.<sup>7</sup> Norway, Finland, Sweden and Switzerland report proportions of residential care receivers between 5 to 7 per cent.<sup>8</sup> In contrast, in the Russian Federation and Lithuania, the share of persons aged 65 and over receiving residential care does not reach 1 per cent. In all UNECE countries for which data are available, the share of beneficiaries of residential long-term care is much lower than that of home care.

<sup>7</sup> See: Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care, p. 90.

<sup>8</sup> Ibid.

<sup>9</sup> United Nations Economic Commission for Europe (UNECE) (2004/5): Generations and Gender Surveys. Available from: <http://www.ggp-i.org/>.

Data available from the UNECE Generations and Gender Surveys<sup>9</sup> show that most people in need of personal care receive only non-professional help. Professional support greatly varies among the countries, and in most cases professional support comes in conjunction with informal support.

### *Possibility to choose*

The acquisition of knowledge about different types of long-term care constitutes the precondition for being able to choose one of those options. As noted in the Madrid International Plan of Action on Ageing (MIPAA), the participation of older persons in assessing their own needs and monitoring service delivery is crucial to the choice of the most effective option (MIPAA, in A/CONF.197/9, para. 104). The care needs of older people are heterogeneous. Therefore, well-grounded, independent information about their care options should be made accessible to them and to the general public. In some countries, information centres provide the visitor with the background knowledge as well as the advantages and disadvantages of each type of long-term care. Another possibility for disseminating information is the Internet.

### **United States of America: National Clearinghouse for Long-Term Care Information**

The National Clearinghouse for Long-Term Care Information is primarily intended as an information and planning resource for individuals who may soon require long-term care, but it includes information on services and financing options that can be helpful to all individuals. The website developed by the United States Department of Health and Human Services outlines the questions one has to take into consideration in planning one's future long-term care needs. Composed of the three main elements of understanding, planning for and paying for long-term care, the aim of the homepage is to provide knowledge about long-term care.

Source: U.S. Department of Health and Human Services (2008). National Clearinghouse for Long-Term Care Information. United States. Accessible at: [http://www.longtermcare.gov/LTC/Main\\_Site/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/index.aspx) (accessed 13 October 2009).

### **Community care**

In order to fully ensure the dignity of older persons, adequate social and health facilities need to be provided. Community-based care arrangements, whether provided through formal or informal care giving, are preferable to residential care arrangements. Community care prevents beneficiaries from being isolated from their familiar social environment and should provide them with greater control over their own lives. In addition, community-based care reduces the cost of professional care involved. Research on the better integration of social and health care for older persons into community care settings in an European comparison was extensively undertaken in the research projects PROCARE<sup>10</sup> and INTERLINKS,<sup>11</sup> which both confirmed that a new model of community health and social care is needed to enhance the care for older persons, particularly in an ageing society.

<sup>10</sup> For further reference, please consult: European Centre for Social Welfare Policy and Research et al.: PROCARE — Providing Integrated Health and Social Care for Older Persons: Issues, Problems and Solutions 04/2002–01/2005, publications available at: <http://www.euro.centre.org/procare/>.

<sup>11</sup> For further reference, please consult: European Centre for Social Welfare Policy and Research et al.: INTERLINKS: Health systems and long-term care for older people in Europe — Modelling the INTERfaces and LINKS between prevention, rehabilitation, quality of services and informal care, available at: [http://www.euro.centre.org/data/1240561652\\_6454.pdf](http://www.euro.centre.org/data/1240561652_6454.pdf).

*Informal long-term care*

As the majority of care tasks are fulfilled by informal caregivers, it is important to provide them with sufficient support so that they will be able to manage their duties. If informal caregivers, in particular relatives, are overwhelmed with their duties over a long period of time they may be more likely to consider letting residential care institutions perform these tasks. Knowing about the needs of caregivers and providing support to them in fulfilling their commitments may lead to a decrease in the use of residential institutions and thus to a reduction of costs.<sup>12</sup> Furthermore, support to informal caregivers, such as training courses or other means of advice, contributes to a higher quality of care.

### Ukraine: Training for caregivers

In July 2005 the Ministry of Health of Ukraine established a State Educational Geriatric Centre. The Centre was established on the basis of already existing facilities of the Kyiv Institute of Gerontology and the Kyiv Medical Academy of Post-Graduate Training. The overall task of the Centre is to develop a unified, evidence-based programme of training on ageing in the country.

The Centre aims to develop and implement educational programmes for medical and social workers, as well as volunteers, in the field of care for older persons. Professionals and volunteers are being trained concurrently, so that they can share their diverse experiences in the care of older persons. The Centre's programmes also take into consideration the needs of pre-retired professional caregivers and retired professional caregivers who are willing to re-enter the labour market, in order to assist them in adjusting their knowledge and skills.

Beyond training professional and informal caregivers, the Centre is also engaged in designing and implementing pre-retirement training programmes for various enterprises and the general public.

Source: State Educational and Geriatric Centre, Kyiv, Ukraine, <http://kmapo.edu.ua/en/faculties/fack/jhg>.

**Who cares ?**

The most common informal caregivers are children and partners or spouses.<sup>13</sup> In the EU, the share of children who provide personal care to parents is the highest in Portugal, Spain and the Czech Republic, where it accounts for more than 50 per cent of caregivers.<sup>14</sup> There is a significant predominance of women among caregivers. More than 80 per cent of all caregivers are female in Luxembourg, Spain and Denmark. In Slovakia, Portugal, Italy and Finland, between 75–80 per cent of all caregivers are women. In the United Kingdom and the United States, the proportion of female caregivers is between 58 and 61 per cent.<sup>15</sup> Dettinger and Clarkberg<sup>16</sup> pointed out that men and women in late mid-life respond to care responsibilities in different ways: women tend to stay at home to provide care for a relative, while men postpone their retirement in order to earn more money to cover the financial burden related to long-term care.

<sup>12</sup> For further information on services to support family carers, please consult: Eurofamcare: Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage. January 2003–December 2005, at: <http://www.uke.de/extern/eurofamcare/>.

<sup>13</sup> F Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research, p. 56.

<sup>14</sup> See: Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research, p. 57.

<sup>15</sup> For information on „Who cares?, please see: Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research, p. 56/57.

<sup>16</sup> See: Dettinger, E. and Clarkberg, M. (2002). “Informal caregiving and retirement timing among men and women: Gender and caregiving relationships in late midlife”, *Journal of Family Issues*, 23(7), p. 857–879.

## United States: Middle Class Task Force Caregiver Initiative

Under the Older Americans Act, included in the President's financial year 2011 Budget Request to Congress, a \$102.5 million initiative, additional services will be provided to the Administration on Aging (AoA)'s Family Caregiver Support Program (+\$48 million), to Home and Community-based Services (+\$48 million), to related services to Native Americans (+\$4 million), and to Lifespan Respite Care services (+\$2.5 million) for those of all ages. The goal of this caregiver initiative is to focus specifically on the needs of family caregivers by integrating those needs with the provision of other home and community-based services, including State-funded caregiver programmes.

Data from AoA's national surveys of caregivers of elderly clients indicates that the Older Americans Act (OAA) services, including those provided through the National Family Caregiver Support Program, are effective in helping caregivers keep their loved ones at home. Of the caregivers surveyed, 77 per cent reported that services definitely enabled them to provide care for their loved one longer and that the services they received "helped a lot"; 89 per cent of those caregivers also reported that the services they received helped them to be a better caregiver.

The additional services that are anticipated as a result of this initiative are estimated to result in the following impacts:

- an increase from nearly 200,000 to 755,000 caregivers receiving support;
- an increase from 3 million to 12 million hours of respite care, the service rated by caregivers as the most helpful to their efforts;
- an increase from just over 1 million hours to 9 million hours of adult day care;
- an increase from 3 million to 28.5 million rides for critical daily activities such as visiting the doctor, the pharmacy, or grocery stores;
- an increase from 1.3 million hours to 33 million hours of personal care assistance to seniors unable to perform daily activities;
- an increase from about 250,000 rides to 1 million rides for critical daily activities for Native American seniors.

Source: U.S. Department of Health and Human Services, Administration on Aging. More information about the FY 2011 Caregiver Initiative is available from: <http://www.whitehouse.gov/blog/2010/01/28/caring-caregivers>.

### Care needs met by migration

Migrants constitute an important source of both informal and informal care services, which needs to be acknowledged and adequately framed with appropriate policy and legislative documents. The International Organization for Migration (IOM) recommends that member States advance their understanding of migration issues and that their migration policies encourage social and economic development and work towards the effective respect for the dignity and well-being of migrants.<sup>17</sup>

## The "Certified Trainee" project in Sweden

Certified Trainee was a cooperation project between the Swedish elderly care service, the adult education programme and the employment service. The cooperation aimed to provide immigrants and individuals with a foreign background who are interested in and have the qualities to work in elderly care with education and practical training.

The purpose of Certified Trainee was to develop a concept with a transparent procedure in order to make it possible for individuals with a foreign background to enter the Swedish labour market. The project included a specific trainee instruction programme as well as an individual training plan, including language training. The qualification process was based on the training plan, which was complemented by practical guidance through personnel working in elderly care. The ultimate goal was for the trainee to gain the qualification to seek employment in elderly care. The experiences for trainees and instructors who participated in the project were positive. Concrete criteria setting out professional standards made it easier for the trainees to understand fundamental aspects of the profession and also motivated them to learn Swedish. The project was initiated in November 2007 and ended in February 2009. However, the concept that was developed as a result of the project is used today on a daily basis in elderly care in the municipality of Haninge.

For more information about the project, contact Marie Ardman, Haninge municipality, Sweden or check out the website [www.kravmarktyrkesroll.se](http://www.kravmarktyrkesroll.se) (in Swedish).

<sup>17</sup> See: International Organization for Migration (2006). Managing the Migration of Health Care Workers. The Need for Action. August 2006. Geneva: IOM. Available from: [http://publications.iom.int/bookstore/free/HealthCare\\_update\\_EN.pdf](http://publications.iom.int/bookstore/free/HealthCare_update_EN.pdf).

### Employment of informal caregivers

In 2004, on average 40 per cent of informal caregivers in the EU were in paid employment outside of caring duties, while in the Netherlands that figure was even higher than 70 per cent.<sup>18</sup> The reason for that is that remunerated employment alongside caring duties constitutes an important source of income for caregivers. It can also provide a temporary relief from care, which may result in giving caregivers better self-esteem and keeping them from feeling isolated, as they can share their concerns with their colleagues. However, the reconciliation of work and caring tasks also constitutes a challenge which needs the particular attention of policymakers in the area of labour rights.

### Netherlands: Mantelzorg@work

Mantelzorg@work aims at developing instruments for employers to make their business friendlier for employees who are family caregivers. The project was launched in 2005 by Mezzo, the Dutch Association for Caregivers and Voluntary Help and a professional human resources consultancy, Qidos.

In 2005–2007, Mantelzorg@work developed and tested various instruments, in cooperation with four employers, and published the results in a toolkit for employers. The toolkit consists of materials to support awareness-raising campaigns and brochures, as well as material to facilitate workshops for managers and employed caregivers, useful business cases and leaflets for human resources officers. The organizers further distributed over 600 toolkits among employers, national and local policymakers and staff of caregivers' support centres.

Sources: Mantelzorg@work. <http://www.werkenmantelzorg.nl>.

### Different models of financial support for informal care

There are a variety of approaches to financial provision for informal long-term care services, which can be generally divided into two groups: in-kind benefits and cash benefits. Financial support to informal caregivers through in-kind benefits may be granted in the form of providing substitute (respite) care services, trainings or care equipment and facilities. The majority of financial support to informal caregivers, however, comes from cash benefits, either in the form of direct allowances to caregivers or through payments to care receivers. There are various models of financing long-term care in UNECE member States. They may vary between means-tested and non-means-tested allowances, which can be either financed by public resources or through care insurances.

Attendance allowances are usually paid directly to people with care needs. They provide beneficiaries with the financial means to pay informal carers or to finance formal care services. In this case, it is the beneficiary who decides how to use the money granted. These attendance allowances are either tax-funded or financed by care insurances and are often redistributed by beneficiaries in the form of wages to informal caregivers.

<sup>18</sup> See: Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care, p. 68.

## 24-hour care at home in Austria

In Austria, around 80 per cent of all those who require care are looked after by relatives at home. Particularly in cases where around-the-clock care is necessary, it has been common to take advantage of carers who are either self-employed or employed by the family. These carers have often come from neighbouring EU member States.

The Home Care Act of 1 July 2007 and the amendment to the trade regulations of the same date created the basis in employment and trade law for legal 24-hour care in private households for persons who receive long-term care benefit at least from stage 3.<sup>19</sup> This can take the form of an employment relationship with a contract, or with the carer working on a self-employed basis.

At the same time, a financial support scheme for 24-hour care was created – a further important step towards making 24-hour care in private households affordable to the recipients and towards the improvement of the situation of people in need of care and support and their family members. Since 1 November 2008, the financial support may be up to € 1,100 for employed carers and up to € 550 for self-employed carers.

Source: Federal Ministry of Labour, Social Affairs and Consumer Protection, Austria.

### *Formal long-term care*

In cases where caregiving tasks are performed in formal settings, it is necessary to provide affordable and high-quality infrastructure for those institutions. It often already relieves informal caregivers greatly if they can rely on part-time social or health services. Having that relief may help caring relatives to better manage their care duties and ultimately contribute to the decision to keep their dependents in need of care at home instead of institutionalizing them. In cases where long-term care at home is not possible, residential care must be tailored to individual needs according to the degree of inability and must be able to cater for special needs, such as dementia, HIV or palliative care needs.<sup>20</sup>

#### Social support

Social networks and interactions impact the health status and care needs of older persons positively. Also, if older persons have regular social meetings outside their homes this may relieve the informal caregiver of their duties for a time and therefore may contribute to a more positive family atmosphere. To offer support to family caregivers and promote social inclusion of older persons receiving care at home, Governments could encourage municipalities and local non-governmental organizations (NGOs) to facilitate regular social events or clubs for older persons. Furthermore, municipalities may want to consider whether they could offer reduced prices for concerts and other events and how the public transportation system could be better adapted to the needs of older persons, so that they have better access to social networks. In addition to social events outside the house, social support may also be needed in the home of an older person, in particular if the client is otherwise unable to manage to live independently. It is therefore important that each region has sufficient organizations with trained personnel (or volunteers) that are able to offer this kind of support.

<sup>19</sup> Stage 3 means that the patient has a need for care for at least 120 hours per month.

<sup>20</sup> See also RIS/MIPAA Commitment 7.



### Slovakia: Training courses in social care provided by Samaritan

Samaritan is a small non-profit organization co-financed by the Slovak State, the European Social Fund and by payments from clients and other sources. It cooperates closely with the Slovakian municipality of Martin and provides mainly home care for older persons with severe disabilities, including social and transportation services.

In addition, Samaritan organizes training and retraining courses in social care for jobseekers. For example, in the project “Step by step towards a new system of social service provision” in the region of Turca, Samaritan trained 140 unemployed people from the region, of whom more than 85 per cent found a new job in the sector. In January 2007, the Ministry of Labour of the Slovak Republic supported Samaritan’s activities by acknowledging it as a “Best Practice in Social Services”.

Source: Samaritan website: <http://www.samaritan.sk/> (accessed 23 October 2009).

### Warm Homes in Israel

JDC-ESHEL is a non-profit organization founded and supported by the Israeli Government and the American Jewish Joint Distribution Committee. It has established specific programmes to foster social interaction among the elderly, which have benefitted 3,500 participants so far.

One programme of JDC-ESHEL called “Warm Homes” is designed to bring together older people who are living in rather isolated conditions. Two times a week a group with up to 15 older persons meets at a host family’s place. The host family would have received beforehand particular training on how to deal with that situation and is also supported financially to cover the costs for food and drinks for the gathering. Group members are linked together according to similar family backgrounds, common interests and hobbies. The format of the meetings is defined by the group itself. It can include preparing a meal together, playing chess or discussing fields of interest.

Source: JDC-ESHEL. Warm Homes, [http://en.eshelnet.org.il/category/Warm\\_Homes](http://en.eshelnet.org.il/category/Warm_Homes) (accessed on 20 July 2010).

#### Health services for outpatients

Many people with long-term care needs may choose to live in their own home. In cases where daily care needs can be covered by informal carers, or where patients are independent enough to manage daily life on their own, trained care personal and general practitioners can step in on a regular basis to provide the required medical care. The intensity of this care can be easily adapted to the individual care needs of the person concerned and to the availability of informal care by relatives. To further ensure well-being and to provide emergency aid if necessary, the older person can wear a safety alarm dispatcher. The user must press a button on the alarm dispatcher every 24 hours to signal their well-being. If not, a carer will receive notification. Additionally, in case of an emergency, the person could press another button on their dispatcher to receive help. Further assistance might consist in the creation of hotlines, which older people can call at any time to get support.

## Czech Republic: Distress Care Areion

Areion is a distance social service provided by the Czech NGO Life 90 (Život 90). It helps approximately 1,300 frail older persons and persons with disabilities to cope with a sudden emergency situation caused by injury, deterioration in their health condition, endangerment by another person or by social exclusion. Thanks to Areion, clients can reach the maximum degree of self-sufficiency which enables them to go on living in their homes.

The household of a client is equipped with a special station device customized according to the client's needs, plus a mobile distress button. In an emergency situation, the client activates the mobile button, which sends a signal to the household station. The station directs an emergency call to the operator who communicates with the client via telephone.

In addition, the operator can consult a database containing all the relevant data about the client. Having assessed the situation, the operator instructs a rescue service, police or providers of social and legal services. The household station device further monitors movement of the client. If it does not record any movement during a pre-set period, it automatically calls the operator.

In 2005, the project won the Markopoulos Prize of the Ministry of Health of the Czech Republic for extraordinary well-functioning projects addressing the needs of seniors and people with disabilities.

Source: Život 90. Tísňová péče Areion. <http://www.zivot90.cz/4-socialni-sluzby/10-tisnova-pece-areion> (accessed 23 October 2009).

### Part-time care centre

If informal caregivers are engaged in gainful employment and dependent relatives need constant attention, day or night care centres may offer the adequate support to reconcile caring and work duties. Also, if persons have care needs, yet can manage to live on their own for a great part of the day, part-time care centres constitute a good alternative to residential institutions. Even if the family simply needs some respite from their caring duties, day-care units can play an important role in providing relief.

In a typical day-care centre the day starts with the collection of the older persons from their home by special transportation. After breakfast at the centre, activities are offered which aim to meet the individuals' abilities and interests. These include social and cultural programmes, occupational therapy and various physical activities. In addition, personal services such as bathing, grooming, foot-care, physiotherapy, special counselling and laundry services are an integral part of many centres, too. At noon, a hot meal is served, and in the late afternoon people are brought back to their homes. Night care centres offer support and supervision for persons with severe care needs during the night.

### Integrative residential care

Living accommodations as well as 24-hour care is provided by nursing homes for older persons who choose not to live in their own homes any more. These long-term care facilities offer comprehensive care, including professional health services, personal care and services such as meals, laundry and housekeeping. In many UNECE countries nursing homes have specialized units, such as those for physically frail persons, persons with mental disabilities or those with 24-hour care needs. Other residential homes have organized caring for persons with special needs within the same unit, so that patients do not have to move if they become less independent, which contributes positively to their ability to orientate themselves. In general terms, depersonalization (removal of personal possessions), rigidity of routine (e.g., fixed times for waking and eating), block treatment (processing people as groups without individuality) and social distance (symbolizing difference between staff and residents) should be actively avoided in residential settings to guarantee the well-being of the person in need.<sup>21</sup>

<sup>21</sup> See: European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities (2008). Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. Brussels: European Communities.

## Germany: Housing and Care Contract Law (former Homes Act)

The Housing and Care Contract Law strengthens the rights of older, frail and disabled persons, when they sign a contract for accommodation with care or support services. The Law is designed as a modern consumer protection law, implementing article 1 of the German Charter of Rights for People in Need of Long-Term Care Assistance, as described as a right to self-determination and empowerment.

The Law entered into force on 1 October 2009. The most important provisions of the Law are:

- Consumers have the right to pre-contractual information in easily understandable language on services, fees and results of quality inspections.
- Written contracts are generally concluded for an indefinite period of time. A time limit is only permitted if it does not contradict the interests of the consumer.
- The agreed fee must be reasonable. A pay increase is possible only under certain conditions and requires explanation.
- Changing the care and assistance needs, the entrepreneur must offer an adjustment of the contract. Exceptions require a separate agreement.
- A termination of the contract by the entrepreneur is possible only due to an important cause. There are, however, special termination options for consumers.

Source: Federal Ministry for Family Affairs, Senior Citizens, Women and Youth: <http://www.bmfsfj.de/BMFSFJ/aeltere-menschen,did=129296.html>

Charta der Rechte hilfe- und pflegebedürftiger Menschen: <http://www.pflege-charta.de/>

### *For frail people*

As long-term care requirements can vary among older persons, frail people might only need limited assistance and can otherwise enjoy an independent life. The required services may entail help with everyday tasks, such as bathing, dressing or using the bathroom. For these groups of nursing home inhabitants, fall prevention and mobility play important roles. Therefore, when constructing nursing homes, the need to offer the opportunity for societal inclusion through social interaction and participation should be taken into account.

## Slovakia: Developing communication with municipality and family via Internet

The care facility Kaštiel in the municipality of Stupava initiated a project called “MosTsoM” (I am a Bridge). The aim of that project, which was implemented from July 2009 to November 2009, was to introduce personal computers (PCs) and Internet connections into that care institution, in order to promote older persons’ integration into the community.

The newly introduced infrastructure offer increased opportunities for older persons to get involved in the facility’s self-government and its administrative matters, as they have greater access to information. A further positive output of the project is that older persons living in Kaštiel have acquired new social contacts with the inhabitants of the town Stupava and can now communicate more easily with relatives and friends via Internet. Even virtual participation in family celebrations is possible. The introduction of PCs and free access to Internet in the facility, as well as in the park, not only reduces isolation, but also gives the clients the possibility of decreasing stereotypes associated with seniors and people with mental disabilities.

Source: <http://ddstupava.eu.sk/> (accessed 12 May 2010).

*For mentally frail people*

Dementia is a very common condition in old age; its prevalence ranges from 1.6 per cent in the age group 65–69, to over 15.7 per cent in the age group 80–84, to 46.3 per cent in the age group 90 and above.<sup>22</sup> Significant gender differences were detected, since women tend to have a higher prevalence rate, according to Alzheimer’s Europe. Patients with this disease require particular care, since dementia changes a patient’s perception of the environment and ability to understand abstract thoughts, as well as slowing down activities of the daily routine. Staff needs to be particularly trained to meet the caring needs of these patients, as well as to be aware that often particular patience is necessary.

**Flagship Project Dementia — Germany**

In residential care, a special focus was set on long-term care of dementia patients by the German Federal Ministry of Health. In order to further improve the quality of life of people with dementia, a State-funded programme was initiated with the aim of identifying already existing structures and possibilities for care; overcoming deficits concerning the implementation of medical and health care of dementia patients; and achieving a specific qualification for people involved with the care of dementia patients. For that reason, a survey, an expert meeting and a session with concerned institutions, lobby groups, NGOs and federal and State ministries were organized. Particular attention was given to the promotion of 29 projects, for which financial support was suggested and which are related to one of the following topics:

- Topic 1: Effectiveness of therapy and care
- Knowledge gaps in the use of non-pharmacological therapy and in consultation and care measures for dementia patients shall be filled.
- Topic 2: Evaluation of care structures
- Knowledge shall be increased on how cooperative, interlinked structures of care for dementia patients can be created. By involving different professions and institutions, the goal of an efficient and need-oriented care for dementia patients can be achieved.
- Topic 3: Securing evidence-based provision of care
- Elimination of deficiencies in implementation of guidelines and recommendations in the health care of dementia patients shall be achieved.
- Topic 4: Evaluation and development of skills by a specific target group of caregivers
- This includes the improvement of specific skills of a target group of caregivers in care, assistance and consultation of dementia patients, and the dissemination of successful measures into practice. The point is to examine the existing skills of caregivers and to analyse scientifically the impact of measures aimed at improving those skills on the patient’s status.

● Source: Federal Ministry of Health, Germany. Leuchtturmprojekt Demenz. [http://www.bmg.bund.de/cln\\_091/nn\\_1168762/SharedDocs/Standardartikel/DE/AZ/L/Glossarbereich-Leuchtturmprojekt-Demenz.html](http://www.bmg.bund.de/cln_091/nn_1168762/SharedDocs/Standardartikel/DE/AZ/L/Glossarbereich-Leuchtturmprojekt-Demenz.html) (accessed 21 October 2009)/

● Federal Ministry of Health, Germany. Themenfeld 3, Sicherung einer evidenzbasierten Versorgung, InDemA. <http://www.bmg.bund.de/SharedDocs/Downloads/DE/Standardartikel/L/Glossar-Leuchtturmprojekt-Demenz/InDemA,templateId=raw,property=publicationFile.pdf/InDemA.pdf> (accessed 21 October 2009).

<sup>22</sup> SALzheimer Europe (2009). Prevalence of dementia in Europe. <http://www.alzheimer-europe.org/Our-Research/European-Collaboration-on-Dementia/Prevalence-of-dementia2/Prevalence-of-dementia-in-Europe>.

## Le Plan Alzheimer 2008–2012: France

In order to improve the quality of life for Alzheimer’s disease patients and their carers, the French Ministry of Work, Solidarity and Public Services launched the “Alzheimer’s Plan, 2008–2012”. The plan envisions the creation of centres, Maisons pour l’autonomie et l’intégration des malades Alzheimer, to inform the concerned persons and their relatives about the mental disease and to coordinate the steps to be taken. The plan furthermore outlines the importance of an adequate treatment of the disease, as care should be adjusted to the specific needs. Therefore, two different types of care schemes are offered according to the severity of the disease. Patients with a moderate degree of Alzheimer’s can take part in social and therapeutical activities in a protected environment, but live otherwise in their regular home. For residents with severe behavioural dysfunctions, small units are built providing night and day care, where the patients live and spend their time.

Source: Le Ministère du Travail, de la Solidarité et de la Fonction Publique (2009). Le plan Alzheimer 2008-2012. <http://www.travail-solidarite.gouv.fr/espaces/personnes-agees/grands-dossiers/maladie-alzheimer/nouveau-plan-alzheimer-entre-vigueur-2008-.html> (accessed 13 October 2009)

One important aspect to consider is the number of residents living in one unit or group home. A small group enables the caring staff to become familiar with an individual. This has a twofold effect: first, the dementia patients feel more confident; second, the working atmosphere and conditions improve for the involved staff, as they can cope better with their workload.<sup>23</sup>

### *For people with severe care needs*

People with severe care needs might need intensive and 24-hour care, including medical treatment, washing and feeding, or palliative care. The infrastructure of nursing homes attending to patients with severe care needs should be adjusted to the particular needs of inhabitants, such as measures to adjust the elevators for patients’ use, easily accessible floors and gardens and appropriate sanitary facilities.

## Recommendations: Quality and choice of community long-term care

### *Choice*

#### Availability

In order to guarantee a choice for patients and families it is important that different options of care are available. In the context of informal care this means that options for reconciling care duties and working life are enshrined in national labour laws. In cases where the duties of caring for a dependent relative are so heavy that it is not feasible to reconcile care and work, financial support to caregivers may be provided. In the context of formal care, availability means that a selection of different types of care exists in cities as well as in rural areas, so that patients are able to choose the care that is tailored to their needs, be it complementary formal care, informal care or residential care.

<sup>23</sup> Ministry of Social Affairs and Health, Association of Finnish Local and Regional Authorities (2008). National Framework for High-Quality Services for Older People. Available at: [http://www.stm.fi/c/document\\_library/get\\_file?folderId=39503&name=DLFE-6710.pdf](http://www.stm.fi/c/document_library/get_file?folderId=39503&name=DLFE-6710.pdf).

Access and affordability      Access in this context may refer in particular to access to information about different options for care. National health ministries should consider the best way to disseminate such information. The Internet offers many possibilities for spreading information. A further option would be to have counsellors who are specialized in informing individuals, families or groups about options for and financing of long-term care. In addition, physical access to care services and facilities should be ensured, particularly in rural and remote areas. Patients and their families should be able to afford the type of care which best suits their needs and which, at the same time, has an adequate standard of quality.

### *Quality*

Security      Long-term care needs to meet certain standards of quality in order to be safe and to let older people live a life in dignity. Safety of the environment and skilled caregivers are the key elements for high quality care. In addition, residential care services need to meet certain requirements in terms of particular care needs of patients with dementia, HIV/AIDS or patients in palliative care.

Training and ratio of care personnel to patients      The quality of long-term care is closely related to the qualifications of staff delivering the services. Lack of adequately trained staff may negatively impact the health and well-being of patients, whereas more time spent with the patient, better knowledge about his/her needs, and the provision of care according to those needs may have a positive impact. According to an Organization for Economic Cooperation and Development (OECD) survey of 19 member countries, staff shortages and staff qualifications are the most important concerns of Governments.<sup>24</sup>

A sufficient ratio of health care staff to patients needs to be established in both urban and rural areas, since an adequate distribution of professionals between better-served and least-equipped regions is needed. It may be therefore desirable to implement a broader approach which encompasses not only staff increase but also additional resources for improving the working environment and working conditions.

<sup>24</sup> Organization for Economic Cooperation and Development (2005). Policy Brief: Ensuring quality long-term care for older people. Paris: OECD. Available from: <http://www.oecd.org/dataoecd/53/4/34585571.pdf>.

## Bibliography

- Alzheimer Europe (2009). Prevalence of dementia in Europe. Available from: <http://www.alzheimer-europe.org/Our-Research/European-Collaboration-on-Dementia/Prevalence-of-dementia2/Prevalence-of-dementia-in-Europe>.
- Dettinger, E. and Clarkberg, M. (2002). "Informal caregiving and retirement timing among men and women: Gender and caregiving relationships in late midlife", *Journal of Family Issues*, 23(7), pp. 857–879.
- Eurofamcare: Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage, and Usage. January 2003–December 2005. Website: <http://www.uke.de/extern/eurofamcare/>.
- European Centre for Social Welfare Policy and Research et al.: PROCARE – Providing Integrated Health and Social Care for Older Persons: Issues, Problems and Solutions 04/2002–01/2005. Website: <http://www.euro.centre.org/procare/>.
- European Centre for Social Welfare Policy and Research et al.: INTERLINKS: Health systems and long-term care for older people in Europe – Modelling the INTERfaces and LINKS between prevention, rehabilitation, quality of services and informal care. Descriptive note available from: [http://www.euro.centre.org/data/1240561652\\_6454.pdf](http://www.euro.centre.org/data/1240561652_6454.pdf).
- European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities (2008). Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. Brussels: European Communities.
- Federal Ministry of Health, Germany. Leuchtturmprojekt Demenz. Webpage: [http://www.bmg.bund.de/cln\\_091/nn\\_1168762/SharedDocs/Standardartikel/DE/AZ/L/Glossarbereich-Leuchtturmprojekt-Demenz.html](http://www.bmg.bund.de/cln_091/nn_1168762/SharedDocs/Standardartikel/DE/AZ/L/Glossarbereich-Leuchtturmprojekt-Demenz.html).
- Federal Ministry of Health, Germany. Themenfeld 3, Sicherung einer evidenzbasierten Versorgung, InDemA. Available from: <http://www.bmg.bund.de/SharedDocs/Downloads/DE/Standardartikel/L/Glossar-Leuchtturmprojekt-Demenz/InDemA,templateId=raw,property=publicationFile.pdf/InDemA.pdf>
- Huber, M.; Rodrigues, R.; Hoffmann, F. et al. (2009). Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research. Available from: [http://www.euro.centre.org/detail.php?xml\\_id=1601](http://www.euro.centre.org/detail.php?xml_id=1601).
- International Organization for Migration (2006). Managing the Migration of Health Care Workers. The Need for Action. August 2006. Geneva: IOM. Available at: [http://publications.iom.int/bookstore/free/HealthCare\\_update\\_EN.pdf](http://publications.iom.int/bookstore/free/HealthCare_update_EN.pdf).
- JDC-ESHEL. Warm Homes. Webpage: [http://en.eshelnet.org.il/category/Warm\\_Homes](http://en.eshelnet.org.il/category/Warm_Homes)
- Le Ministère du-travail, des relations sociales, de la famille, de la solidarité et de la ville (2009). Le plan Alzheimer 2008-2012. Information available from: <http://www.travail-solidarite.gouv.fr/espaces/personnes-agees/grands-dossiers/maladie-alzheimer/nouveau-plan-alzheimer-entre-vigueur-2008-.html>.
- Mantelzorg@work. Website: <http://www.werkenmantelzorg.nl>.
- Ministry of Labour, Health and Social Affairs of Republic of Italy, 2004–2005 Immigration Pilot Project Website: [http://www.lavoro.gov.it/Lavoro/md/AreaSociale/Immigrazione/formazione\\_estero/progetti\\_pilota.htm](http://www.lavoro.gov.it/Lavoro/md/AreaSociale/Immigrazione/formazione_estero/progetti_pilota.htm).
- Ministry of Social Affairs and Health, Association of Finnish Local and Regional Authorities (2008). National Framework for High-Quality Services for Older People. Available from: [http://www.stm.fi/c/document\\_library/get\\_file?folderId=39503&name=DLFE-6710.pdf](http://www.stm.fi/c/document_library/get_file?folderId=39503&name=DLFE-6710.pdf).
- Organization for Economic Cooperation and Development (2005). Policy Brief: Ensuring quality long-term care for older people. Paris: OECD. Available at: <http://www.oecd.org/dataoecd/53/4/34585571.pdf>.
- United Nations Economic Commission for Europe (UNECE) (2004/5). Generations and Gender Surveys. Geneva: UNECE. Available at: <http://www.unece.org/pau/ggp/Welcome.html>.
- United Nations Department of Economic and Social Affairs: World Economic and Social Survey 2007. Development in an Ageing World (E/2007/50/Rev.1 ST/ESA/314).
- United Nations Department of Economic and Social Affairs, Population Division (2009). World Population Prospects: The 2008 Revision. CD-ROM Edition.
- U.S. Department of Health and Human Services (2008). National Clearinghouse for Long-Term Care Information. United States. Website: [http://www.longtermcare.gov/LTC/Main\\_Site/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/index.aspx).
- Samaritan. Website: <http://www.samaritan.sk/>.
- Život 90. Tísňová péče Areion. See webpage: <http://www.zivot90.cz/4-socialni-sluzby/10-tisnova-pece-areion>.

<b>Checklist : Community long-term care</b>		
<b>Main areas</b>	<b>Areas of implementation</b>	<b>Key elements</b>
<b>Community care by informal caregivers</b>	Employment	Labour rights
		Work/care time models
	Financial support	Cash benefits: through taxation or social insurance
		Attendance allowances
	Migration	Labour rights
		Social rights
<b>Community care by professionals</b>	Social support	Social inclusion
		Participation
	Health services	Medical services
		Care services
	Part-time care centre	Day care
		Night care
<b>Residential care homes</b>		Units for frail persons
		Units for mentally frail persons
		Nursing units
<b>Quality and choice</b>	Choice	Access
		Affordability
		Availability
	Quality	Security
		Training of personnel
		Ratio of caregiver to patient