



European
Commission



Peer Review
in Social Protection
and Social Inclusion

Dignity first – priorities in reform of **care services**

SYNTHESIS REPORT

Sweden, 25-27 September 2013

This publication is supported by the European Community Programme for Employment and Social Solidarity (2007–2013).

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Dignity first – priorities in reform of care services

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SYNTHESIS REPORT

European Commission

Directorate-General for Employment, Social Affairs and Inclusion
Manuscript completed in December 2013

This publication has been prepared for the European Commission by



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Luxembourg: Publications Office of the European Union, 2014

ISBN 978-92-79-35330-7

ISSN 1977-7973

doi: 10.2767/58124

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Table of contents

Executive Summary	5
A. Policy context at the European level	7
B. Host country good practice under review	9
C. Policies and experiences in peer countries and stakeholder contributions	11
D. Main issues discussed during the meeting	22
E. Conclusions and lessons learned	26
F. Contribution of the Peer Review to Europe 2020	28
References	30





Executive Summary

The Peer Review covered the Swedish approach to reforming care services for the elderly population putting dignity and person-centeredness first while simultaneously taking efficiency into account. Preceding the Peer Review, site visits covered both robotics and the design of “inclusive housing”, both of which should enable people to stay in their own homes for longer. Held in Stockholm on 26–27 September 2013, the Peer Review was hosted by the Swedish Ministry of Health and Social Affairs. In addition to participation from host country government departments, institutes and organisations, ten peer countries were represented: Belgium, Bulgaria, Croatia, Cyprus, the Czech Republic, Germany, Lithuania, the Netherlands, Romania and Slovenia. They were joined by stakeholder representatives from AGE Platform Europe and the European Social Network (ESN), and by the Thematic Expert, Monika Riedel from the Institute for Advanced Studies, Vienna. Taking part for the European Commission were representatives from DG Employment, Social Affairs and Inclusion. Thematically, this Peer Review was closely linked to a previous one held in Stockholm in 2011 which looked at closing the gap in care for the elderly population.¹

The Swedish policy under review combines diverse elements. The political priorities behind this approach can be summarised under the following headline areas:

- Empowerment and person-centred approach
- Integrated care
- Public reporting
- System performance assessment.

The person-centred approach is supported by more choice among public and private providers of care, and by increased home-based care, made possible partly by exploiting assistive technology. Establishing databases in order to improve care and make its provision more efficient and transparent is another important component. Quality and coordination of care receive high attention, as do prevention and rehabilitation.

The different papers prepared for this Peer Review as well as the presentations given led to wide-ranging discussions.

There was a consensus that increased focus should be put on **prevention** of rising care needs. This, however, needs contributions from the whole society and cannot be provided by the health and care sector alone. Replacing a philosophy of care with a philosophy of prevention, activation and rehabilitation will require additional training and education. Several countries found the experience of shifting tasks and responsibilities across the “boundary” between the health and the social care sector very tough, partly due to different philosophies and cultures in these sectors, but often also due to separate regulations and financing.

¹ “Closing the gap – in search for ways to deal with expanding care needs and limited resources” held in Stockholm (Sweden) on 20–21 October, 2011. <http://ec.europa.eu/social/main.jsp?catId=1024&langId=en&newsId=1423&furtherNews=yes>



Moving care back into private homes will need support from the families and social networks of persons in need of care. Support mechanisms for **informal carers** therefore need to be improved. Policy-makers should devote attention to how the elderly population can play the role of potential carers, and not only as persons in need of care.

Several discussants raised the issue of **data protection**. Building a strong base of patient-centred information, especially when linking diverse data sources and storing data over long periods of time, is likely to raise concern and stimulate public debate. According to the Swedish experience with quality registries, participation and acceptance are highest if registries provide visible benefits for health staff as well as patients, alongside benefits for governance. Sweden has often put the goal of improving quality before the goal of containing costs.

Much of the discussion on assistive **technology** was based on the view that many necessary inventions have already been made, often for purposes other than long-term care (LTC). But the technologies useful in the LTC context still need to be identified, adjusted for this purpose, and made simpler and cheaper. In order to identify and adapt useful technologies, it is essential to involve those persons that are supposed to use them (patients, families, formal carers, but also patient organisations) and to facilitate cooperation among these stakeholders and service developers (in housing, ICT, etc.).



A. Policy context at the European level

Europe 2020, the EU's growth strategy for this decade, aims at making the EU a **smart, sustainable and inclusive economy**. This Peer Review links with the Europe 2020 Strategy with the specific aim to increase person-centeredness of health and LTC services for ageing populations and support social innovation in this section as well as social inclusion for older people. Measures aimed towards this objective will support cost-efficient health and LTC systems, thus containing public spending on health and LTC.

As part of the Europe 2020 Strategy country-specific recommendations (CSR) can be issued by the European Commission to Member States. Only recently such CSR on LTC have been issued to a small number of Member States concerning financial sustainability. Recommendations are based on findings and projections from the **Ageing Report**², a joint document produced regularly by the Directorate-General for Economic and Financial Affairs (DG ECFIN) and the Ageing Working Group of the Economic Policy Committee (European Commission, 2012a).

The **Social Protection Committee (SPC)** has established an ad-hoc group working on ageing issues (SPC-WG-AGE). The working group has spent the last few years focusing on the LTC dimension (from access and quality to affordability), in other words ensuring high quality and affordable LTC within financially sustainable systems. As a first step, an internal European Commission staff working document on LTC was completed to make a clear baseline assessment of existing research and knowledge (European Commission, 2013b). Based on the findings of this document, a new report will be presented to the SPC in early 2014, which is also designed in line with the Social Investment Package, published in 2013.

The Directorate-General for Health and Consumers (DG SANCO) is also working on issues related to the health sector workforce, supporting two aims simultaneously: contributing to achieving the employment goal by raising the number of workers in this growing sector, and securing the necessary human capital to provide high quality services in changing demographic conditions (European Commission, 2012b). It is likely that the **long-term care workforce** will soon become a focus area.

In February 2013, the Commission adopted a **Social Investment Package (SIP)**, composed of one Communication and a number of working papers including one on LTC (European Commission, 2013a, 2013b). The paper on LTC takes stock of the challenges and the differences between LTC systems in Member States, and gives an overview of EU policies in this field. While acknowledging that more resources are needed to cope with rising demand, the paper also emphasises the importance of rehabilitation, prevention, ensuring better conditions for independent living and improving the efficiency of care delivery.

The SIP focuses on ensuring that **social protection systems respond to people's needs** at critical moments throughout their lives and at developing **simplified and better targeted social policies**. But the SIP also gives guidance to Member States on more efficient and effective social policies in response to the significant challenges they currently face. On the European level, support will be provided with, for example, developing and

² http://ec.europa.eu/economy_finance/publications/european_economy/2012/2012-ageing-report_en.htm



implementing the necessary databases and techniques to identify and develop good practices. In this area, the Commission has been cooperating with other organisations, such as the OECD. A joint project is planned, for instance, to develop a methodology to better map the extent of available and adequate protection against LTC risks in an internationally comparable way. Results, however, are not expected before late 2015.

In the context of the SIP, Member States are urged to **test new approaches**, including information and communication technologies (ICT), to be better prepared for the emerging challenges. Approaches with promising outcomes could then be scaled up. This continues earlier European initiatives aimed at making better use of new technologies for the specific needs of an ageing population. The European Union has developed a series of initiatives, like the European Innovation Partnership Pilot on Active and Healthy Ageing (EIP AHA)³ and the Ambient Assisted Living Joint Programme, which has recently been extended for the period 2014-2020⁴.

Furthermore, the Commission has been providing funding for a number of research projects covering LTC, for instance two large projects ANCIEN⁵ and INTERLINKS⁶, which ended in 2012 and 2011, respectively. They produced comparative material on existing LTC systems in Member States. As stated before, the Commission has also been cooperating with the OECD in order to improve systematic knowledge about LTC (OECD, 2011, 2013).

In the course of the European Year for Active Ageing and Solidarity between Generations (2012), the Social Protection and Employment Committees established “Guiding Principles for Active Ageing and Solidarity between Generations”. These principles highlight the following policies as key routes to independent living in old age: health promotion and disease prevention, adapted housing and services, accessible and affordable transport, age-friendly environments and goods and services, maximising autonomy in LTC (Council of the European Union, 2012).

The policies examined by the peer reviewers in Stockholm were very much in line with these principles as well as with the aims of the Europe 2020 Strategy. Sweden has acted to maintain high-quality care services while supporting the financial sustainability of the system. This has been achieved in part through measures to promote high employment levels in all age groups. At the same time, rehabilitation, assistive technology and user-centred design, and a growing emphasis on home-based care and an age-friendly society are helping to foster self-sufficiency among Sweden’s older inhabitants. This strategy has been supported by a consistent effort to establish databases and infrastructure which are necessary to improve quality of care and develop quality measurement and public reporting. Such a wide-ranging approach can lead to both a more satisfying life for older people themselves and better control of social expenditure.

³ <https://webgate.ec.europa.eu/eipaha/>

⁴ <http://www.aal-europe.eu/>

⁵ <http://www.ancien-longtermcare.eu/> . For an overview, see also Mot, Willemé (2012).

⁶ <http://interlinks.euro.centre.org/>



B. Host country good practice under review

The Swedish policy under review combines a mixture of diverse elements. The political priorities behind this approach can be summarised under the headline areas: empowerment and person-centred approach, integrated care, and public reporting and system performance assessment.

The Act of Free Choice is an important element of patient empowerment and the **person-centred approach**. It aims at adding value by giving the patient the right to choose between provider and treatment alternatives, so that resources are allocated according to the patient's choice. It is up to municipalities if they adopt the free choice system, and 179 of 274 municipalities have already done so. Together with increased choice, private provision of services was encouraged in order to broaden competition and provide a bundle of services with discernible differences between providers. As a result, a significant increase in the number of primary care centres has been observed. As most patients favour care, and if possible cure, at home rather than in hospital, Sweden favours the deinstitutionalisation of care and has the lowest number of hospital beds per inhabitant across the EU. Therefore, municipalities are now obliged to adapt homes where it is necessary, so that high-quality care can be provided at home. Tax reductions for household services aim at reducing the financial barriers to provide support at home. Another element of the person-centred approach is that patients are increasingly involved in research projects in order to develop knowledge of what is really desired by and useful for the target group.

It has been observed that patients in Sweden are less likely than patients in other countries to feel that physicians are well-informed about the patient's medical history. Swedish patients also experience less support in organising their care needs. Therefore new legislation increased shared responsibility for health and social care planning for the individual patient and one physician is appointed to support patients in coordinating their care. New incentive-programmes aiming at promoting **integration of care** and coordinating drug treatments are being rolled out; they apply the principles of money after delivery and rewards for good performance rather than punishment for bad performance.

This Swedish approach is connected with and supported by several initiatives relating to the collection and distribution of information. For instance, national clinical guidelines were developed which integrate health and social care and thus cover the whole care chain. National patient summaries are being introduced in a number of regions, in order to provide a basis of **integrated medical documentation**. An increasing number of quality registers are being implemented and where possible designed in a way that enables authorities, as well as providers of care, to benefit alongside patients who can be provided with better care and cures. An example is the register 'Senior alert' which spans the entire health care process.

The Swedish approach is based on the conviction that **social innovations** alongside technological advancement are necessary to reconcile future care needs with a life of dignity. An important element of these social innovations is seen in a changed philosophy, preferring prevention and rehabilitation over care wherever possible. The Danish model of everyday rehabilitation can serve as a good example in this respect. This change in philosophy is supported by programmes to further increase education and training of staff.



Even though the primary aim of these innovations is to improve the **quality** of care, it is assumed that there will be an additional favourable impact on expenditures. Evaluations to measure this impact, however, are still scarce. Initial results from selected approaches are encouraging.



C. Policies and experiences in peer countries and stakeholder contributions

In this section, policies and experiences gathered by peer countries are described. These are followed by two comments from stakeholder organisations that collected opinions on the topics of this Peer Review from other countries as well⁷.

Belgium

Starting from a comparatively high share of persons being cared for in institutions, Belgium developed a **national strategy** to facilitate a shift towards home care. To develop alternative forms of care/support to home care, a series of projects have been started since 2010 which provide types of service that were not previously financed by the federal system (e.g. case management, occupational therapy, night nursing care, day care). Cost-effectiveness and other aspects of the national strategy are under evaluation.

A recently agreed **reform** will transfer some health related responsibilities from federal to lower level authorities. In the new system, only financing of health care will remain a federal responsibility (via health insurance), while lower level authorities will be responsible for nursing homes, social care at home and care coordination.

Due to **shortages in some professions**, Belgium expects – and partly already experiences – a progressive transfer of tasks from GPs to nurses and from nurses to nurse aids.

In Belgium, reforms are subject to extensive negotiation processes, and the care system is segregated along geographical and professional lines. To overcome resulting problems, Belgium aims at simplifying and standardising negotiation structures, at better implementing and clarifying the role of care managers, and at creating synergies between nursing and social care.

There is no national policy for most applications of **technology** in LTC since it is a regional responsibility. There are, however, regional pilot projects with public funding. Notable exceptions are an action plan for a common comprehensive geriatric Resident Assessment Instrument (BelRAI) for the period 2013-2018 and the development of e-health as a means to circulate information between all care-related stakeholders.

Responsibility for **quality** management in LTC is shared between both federal and federated authorities. The current health system performance evaluation aims at measuring performance of the entire health system, including some LTC related indicators. The BelRAI project can likely be used for further development in this area. Along with BelRAI data, the main databases available are the IMA-database (consumption of health care of services reimbursed by NIHDI, the National Institute for Health and Disability Insurance) and the national health survey.

⁷ The country and stakeholder sections rely exclusively on information provided in the country comments papers provided for the Peer Review.

Bulgaria

Responsibility for social services in Bulgaria lies with municipalities. Recent reforms aimed at deinstitutionalisation and at providing more community and home-based services, which resulted in an increase of community-based services of 90% over the period 2008-2012.

Bulgaria adopted a “National Strategy for Reducing Poverty and Promoting Social Inclusion 2020” in 2013. The Strategy includes the specific sub-target to reduce the number of people aged 65 and more living in poverty by 52,000, by the year 2020. In 2012, Bulgaria began to develop a **National Strategy for Long-Term Care** which is expected to be adopted by the Council of Ministries by the end of 2013. The draft Strategy includes measures aimed at deinstitutionalisation and expanding access to services for elderly people and people with disabilities by: creating an adequate network of community-based and home services in order to meet individual and specific target group needs; improving the quality of LTC services; development of special measures for the caregivers to dependent family members; establishing a working mechanism for financing LTC and sustainable increases in the financial resources for community-based and home services; improvement of the mechanism for coordination between the systems for social and health care.

The non-institutional home care services, such as personal assistants, social assistants, and home helpers, have proven particularly effective and popular. Often a family member is employed who otherwise would not be able to work because of full-time care responsibilities. The National Programme “Assistants for People with Disabilities” started in 2003. It succeeded in employing 4,325 unemployed persons as personal assistants, mostly for elderly people, in 2012. To further strengthen **familial care**, a “personal budget for personal assistance” will be implemented nationwide.

Needs-based **planning** of social services was introduced at the regional and municipal level in 2010, resulting in 28 regional and 264 municipal strategies.

To foster quality in social services, the state (via the Agency for Social Assistance) provides methodological support (methodological guidance, trainings and supervisions, stimulation of the professional development in social services) to municipalities and service providers. Control and monitoring are performed by an inspectorate of the Agency for Social Assistance. The Agency for Social Assistance also maintains a **register** of social service providers, while the Agency for Disabled People (ADP) keeps a register of the legal entities in their area.

The mechanisms for **financing** social services and LTC have undergone many changes. In the context of financial decentralisation of social services, an important change was the introduction of unified standards for maintenance expenditure for a client. Its aim is to encourage municipalities to negotiate the provision of social services with external providers. The National Strategy for Long-Term Care addresses long-run financial sustainability, for example by encouraging municipalities and private providers to create services with their own funds and through the application of the “money follows the person” principle.



Croatia

LTC in Croatia was traditionally based on residential care in public institutions. But over the last years, diverse “alternative” forms of care provided predominantly by private for-profit or not-for-profit institutions have gained importance. In 2011, 40% of the total capacities were in residential care, and 60% in alternative care forms like adult foster care or family-type homes, home-care services etc. There are two large additional contracted home-care programmes for the elderly population, primarily targeted at underdeveloped areas. Also in Croatia, primary responsibility for provision of LTC is traditionally taken by the family. Principles of means-testing and user co-payments have been established.

Even though contracted home-care programmes target the poorer population with severe care needs but without family support, no eligibility criteria have been defined and this has contributed to inequities in care received. According to the Social Welfare Act, service provision should respect **free choice** and users should be actively involved in needs assessment and decisions on service provision. However, lack of information and capacity as well as regional imbalances often pose obstacles for the realisation of these principles. Also people preferring home care sometimes apply for residential care due to lack of home care services. In spite of recent approaches in this direction, further improvements in the individualisation of services and a **person-centred** approach are needed.

There is only limited use of **technology** in home help. Three residential homes and one civil society organisation provide a social alarm service.

Up to now, only the traditional approach of **quality** monitoring has been implemented, i.e. certain minimum standards of inputs are required in order to achieve a licence. A recent project in cooperation with the World Bank developed “quality standards of social services in the social welfare system” which cover a broader scope, but have not yet been implemented in eldercare. Before implementation, modifications will have to be developed to better adjust to: special needs in LTC for the elderly (e.g. due to dementia); output measurement, and specific requirements of home care as opposed to residential care.

Available evaluations show that establishing a home care sector has been exerting a favourable **impact on several groups**: It contributes to quality of life of persons in need of care and reduces their risk of social exclusion; it offers job opportunities, particularly for persons with otherwise low employability (young people with little work experience, older and long-term unemployed). Even though evaluations find home care to be **cost-effective**, they also hint at a need for better integration of home care services with the health sector.

Cyprus

Under its programme with the Troika (the EU, the IMF and the ECB), the Government of the Republic of Cyprus has committed to contain social expenditures and to decrease them in the near future. Therefore Cyprus needs to revise its social welfare system and at the same time establish a general health scheme. Currently, health and social care are under the authority of two different ministries.

Only persons entitled to public assistance can get free LTC services. Other persons are expected to cover the cost of their care and they have the freedom to choose which service they receive. Beneficiaries may receive cash benefits that include the monthly fees paid for residential/day care, a home carer's salary (up to EUR 393.58 for full-time care) and social insurance contribution, as well as pocket money for persons who live in public residential homes and community homes. Cash allowances vary depending on the needs and the type of care required (maximum EUR 240).

The state may (co-)finance a private home carer, for example a family member or an NGO worker. **Care-giving family members** are required to stop working for that purpose, or to have a low socio-economic status in order to receive funding. Home care is also provided by state home carers. 24hrs care provided by live-in and typically migrant care workers in the private household constitutes an important type of care. A new project called "Subsidisation of social care services within the framework of family and employment reconciliation", co-financed by the European Social Fund, aims at supporting unemployed women who provide care for family members.

The Cypriot approach is **patient-centred** in so far as the frequency of home care, or day care or the need for residential care, is based upon individual needs, defined jointly by the claimant and a social services officer. Persons in need of care have the possibility to choose the type and provider of care.

The use of **technology** in home care is still in its infancy in Cyprus.

14

Following the current reform of the social welfare system, long-term social care is expected to take a different form and be disconnected from public assistance. Current plans for the future provision of residential care propose, inter alia, to establish a **quality monitoring mechanism**. There is no legislation yet regulating the provision of home care, but a law for this regulation is under preparation which will also set up minimum quality standards and specify requirements regarding the qualifications of carers. Currently, quality monitoring in residential care and day care centres uses legally defined minimum standards as well as regular inspection of the centres. In the field of home care, monitoring relies on regular visits by social service officers and close cooperation with NGOs and local authorities providing home care programmes.

Czech Republic

In the Czech Republic, a joint legal act defining LTC across the health and social care sectors is still under preparation. Therefore, currently different regulations apply with regard to financing, accessibility and quality measurements.

The social home care providers are financed through two main resources: users' payments and state subsidies, and to a smaller degree from contributions of the founder, gifts, business activities, etc. There is no general binding framework applicable to state subsidies. The users pay social home care either from their income (mainly retirement pensions) or from their care allowance, which can be granted in four levels ranging from CZK 800 (ca. EUR 31) to CZK 12,000 (ca. EUR 460) per month for adult recipients.



According to the Social Services Act, persons are offered free social counselling and freely **choose** between a range of diverse social services. The Act also gives people room to participate in the decision-making processes pertaining to the scope, types and accessibility of social services in their municipality or region.

Medical home care is fully covered by the health insurance system for enrolled persons, if it has been prescribed by the family doctor or GP. Along with nursing care, services also encompass rehabilitation (physiotherapist or ergotherapist) and relevant specialist services.

Few **technological** applications to home care are widely used in the Czech Republic. Of some importance are systems for emergency care, with the AREION system being the largest. AREION offers provision of or mediation to achieve emergency care in different medical and social constellations. Recently, a new alliance (Open Alliance of Assistive Technologies - OAAT) was formed between companies and organisations working on assistive technologies and universities like the Czech Technical University. OAAT aims at developing clear and coherent strategies to solve the needs of chronically ill and disabled citizens, in order to allow them to stay in their original environment as long as possible.

In social home care, quality is ensured by **quality standards** of social services that are defined and inspected by the state. Providers need to be licensed by the regional authority to provide certain types of services. There are quality standards referring to procedures, staff and technical matters. Quality standards are perceived to have improved patient-centeredness of home care.

The most important **problem** seems to be the lack of an integrated national strategy regarding LTC and of a common definition of LTC. The structure of the institutional arrangement is not transparent, with some of the LTC institutions located in the health care system and some in social services.

The current economic crisis and the resulting cuts in public budgets have put LTC provision under pressure. Even though the total amount of state subsidies has been decreasing between 2009 and 2012, state subsidies for social home care have been rising slightly. Nursing home care is fully covered by the health insurance system. Due to deficits of the biggest state health insurance company, no new capacities have been subcontracted since 2010. Thus, the capacity of nursing home care remains stable in spite of slightly increasing numbers of people in need. Note, though, that nowhere close to all residents in nursing homes would be defined as persons in need of LTC.

Germany

The reform taking effect in January 2013 aimed at improving care choices and individualised care and at broadening entitlements for persons with reduced capacities to lead an independent life (mainly dementia patients). Improved care choices relate to the inclusion of a new type of non-medical home care service as benefits in kind, and time allotments for family carers in addition to the former activity-based service complexes. Furthermore, LTC insurance has begun to support new group homes (special apartments) for the elderly. By December 2015, 3,000 group homes will be set up and supported with max. EUR 2,500 per person, up to a budget limit of 30 million euros.



To support the use of **technology** in home care, LTC insurance funds can grant subsidies for home adaptation for up to EUR 2,557 per measure. Development and use of specific ICT or Ambient Assistive Living systems have not been a priority in German LTC policy so far, but are attracting increasing attention which has resulted in an array of diverse pilot projects. The Federal Government funds research which specifically targets the retention of mobility and participation in social life, starting with the documentation of preferences and mobility patterns of elderly persons. Furthermore, there are a number of pilots for online counselling, internet platforms and e-learning possibilities.

Approved providers of LTC are required to operate a **quality assurance and quality management system** and to apply expert standards. Medical review boards of statutory and private health insurance audit home care services. There are standard inspections at least once per year which cover outcome quality, but sometimes complaint-driven and repeat inspections are possible in addition. Since 2008, inspection results must be published, leading to intensive debate about transparency criteria. Indicator-based measurement of outcome quality is under preparation at the federal level, but initially will cover LTC facilities only. Procedures for the more complex task of home care are to be developed later on.

Family caregivers can receive several means of assistance, including pension credits and payment of pension contributions, if certain criteria are fulfilled. Since 2012, counselling must be provided within two weeks of application, and insured persons receive a rehabilitation recommendation along with an assessment of their care needs. Rehabilitation for family caregivers has become easier to secure.

A federal pact on **geriatric training** was signed in late 2012, and aimed at raising the number of trainees in elderly care by 10% annually and at encouraging re-training for geriatric nurses.

To insure long-term financial **sustainability**, contribution rates to LTC insurance were raised with effect from January 2013 (1.95-2.05% or for persons without children, 2.2-2.3%). To promote supplementary private insurance for LTC, a programme to subsidise premiums by EUR 5/month was introduced in 2013 and applies under certain conditions.

Lithuania

The Lithuanian LTC system is still influenced by the post-WWII period when only public medical and care services were allowed and there was a strong emphasis on services provided in institutions rather than the patient's home. In 1996, development of non-stationary social services began, but did not include medical services. The current law on social services from 2006 stipulates that social services should create conditions for the person to live at home, to manage independently and facilitate co-ordination with employment, personal health care and special assistance measures.

Needs for social services are assessed by municipalities, according to the person's level of physical and social independence. All municipalities provide social services at home, but integrated social and nursing care is underdeveloped, especially with regard to nursing care at home. Nurses from out-patient clinics and polyclinics are supposed to provide nursing



care at home after their work in the clinic, but this system is not very effective and many persons in need go without nursing care at home.

In 2012, the Integrated Help at Home Development Programme was launched, with the aim of ensuring accessibility, facilitating team building of different professionals and creating various services of integrated help at home for different target groups like young or adult disabled persons or family members. In September 2013, a large pilot project was started where mobile teams of specialists provide integrated help.

Persons in need of care have the right to **choose** a provider, and the municipality must arrange to finance the person's selected provider. Instead of receiving services in kind, persons can opt to receive cash and then use this to pay for help.

Recent programmes relate inter alia to the adoption of **technology**, e.g. to improve the communication between provider groups and municipalities. A special internet portal to inform older citizens has been established. Older citizens are encouraged to use public access computers (nine of ten public libraries offer this service for free) and internet for health, employment and e-government issues.

Social care institutions are responsible for the **quality** of services, while the Department of Supervision of Social Services at the Ministry of Social Security and Labour is responsible for assessment, control and supervision. Social care standards are adopted for specific groups of people, but also institutions. Institutions are assessed and inspected at least once every 5 years. The Department collects data of licensed social care institutions and registers it in a database.

Netherlands

The Netherlands is currently preparing for a major **reform** of the LTC system. Currently, most LTC is covered by social insurance. Under the reform, responsibility for most of this care (including home care from 2015 onwards) will be shifted to local authorities. Some tasks including nursing care will be shifted to health insurance, and only care in institutions for elderly and disabled persons will remain under social insurance. Recent reforms introduced financing based on intensity of care; care providers are obliged to use a care plan which acknowledges the client's preferences. As centralised capacity planning for nursing homes was abolished, providers no longer need permissions to increase capacities. Personal budgets as an alternative for services in kind became so popular that costs accelerated and restrictions are now being implemented, e.g. turning the former cash allowance into a drawing right.

Currently, the Netherlands and Sweden spend a larger share of GDP on LTC than most other EU countries. The reform aims (inter alia) at deinstitutionalisation, i.e. municipalities should enable older persons to remain longer in their homes, thus giving informal carers a bigger role, and reducing the role of formal care, especially in forms of residential care.

The Netherlands has had mixed experiences with **adapting technology** at home, with higher propensity to innovate in health care than in LTC, where cultural change seems to play a rather large role.



The programme “visible care” (Zichtbare zorg) stimulated transparency and **quality** assessment. In the care for elderly it started in 2004/5. After years of development, adjustments and evaluations, a much reduced list of indicators was agreed which consists of care related items and client experience on seven topics: physical well-being, domestic and living conditions, participation, mental well-being, sufficient and competent personnel, quality of care organisation, quality of care and safety. Outcome measures of all institutions and other information to support choice for clients are now published annually⁸. The Quality Institute set up beginning 2013, is meant to stimulate and facilitate quality assessment, develop guidelines and professional health standards etc.

Romania

In Romania, it is expected that the demographic shift due to rising life expectancy and low fertility will be compounded by the choice of many in the younger population to emigrate. High relative poverty among the elderly in recent years could be reduced to levels close to those of the average for the general population, but its prevalence among elderly women is likely to remain a challenge. Romania is among the countries with the highest proportion of cohabitation of the elderly with younger generations, thus increasing the probability of intra-household support in case of need of care.

Home-care services are considered to be social services and can be provided in an integrated model together with medical services. Home-care services are organised, developed and administrated and often provided by communities. With 123 out of 167 social service centres, and typically far larger centres, NGOs are even more important providers of home-care than communities, even though not all centres provide home care. Many NGOs operate based on a contract with local authorities. NGOs can receive subsidies from state and local budgets.

Local authorities can employ personal assistants for persons with the highest degree of disability. While home-care can be granted on an unlimited basis, the costs of home medical services provided by NGOs and family doctors are covered by the national Health Insurance Fund for a maximum period of 90 days/year. There are large regional disparities in the availability of home care services, and often care needs are not fully covered. Public and private providers find their demand for care staff outstrips supply, even though employment in care has been growing. Home care attracts an unusually high share of voluntary workers, and roughly 80% of volunteers have graduated from professionalisation courses.

In theory persons with certified care needs can choose a provider, but this is only possible in areas where there is sufficient capacity to allow for **choice**. Financing of services is centred on services themselves, not patients, but at the level of service providers there is **patient-centred care** in so far as there is a dedicated registry of each case.

Medico-**technological** equipment of home care providers is very basic and reportedly needs to be improved.

⁸ See www.kiesbeter.nl.



Providers of home care are required to hold an accreditation for social services and medical services. Standards for accreditation rely mostly on inputs and procedures and accreditations need to be renewed every three years. While these administrative data are used to assess **quality** on a regular basis, there is only scarce evidence of more in-depth analyses using e.g. surveys. In general, beneficiaries of social services express high satisfaction. This, however, may reflect not only actual quality but also a cultural component.

Slovenia

For historical reasons, LTC in Slovenia is dominated by residential care. Home care was introduced only in the late 1980s, and was increasingly developed in the late 1990s. Governance of home care is split between community nursing and home help. Community nursing is governed by the Ministry of Health, entirely financed by health insurance and provided by community nurses. Due to a rising need for curative nursing, community nurses can devote less and less time to preventive tasks, which highlights the need for structural changes. The 211 municipalities are in charge of home help and thus are obliged to organise, provide and finance (at least 50% of the price) of the services. Home help is mostly provided by public agencies. About 1.7% of the population 65+ receive formal home help, which is well below the national goal of 3%, and even further away from the newly decided goal of 3.5% for the period 2013–2020. Prices charged and types of services offered vary across municipalities, and often there is no possibility to choose among providers.

Persons entitled to institutional care can choose a **home care assistant** instead of moving into institutional care. A home care assistant is typically a family member who lives in the same household, supports their everyday life and is financed by public and private means. This right needs to be seen in the context that in Slovenia, there is a larger share of the population preferring nursing homes over other elderly care options than in any other EU Member State (European Commission, 2007). Also in Slovenia, there is a special **cash benefit** for care. It can be used freely and typically serves to help cover the cost for formal or informal care for an individual.

The most developed type of assistive **technology** in Slovenia are social alarms, which were introduced in the capital, Ljubljana in 1992, but only recently achieved national coverage. The new system of social alarms operates from one central call centre and is far cheaper than using many systems as was the case previously. New legislation is expected to incorporate this sort of service into public social services. In the area of home telehealth services, there are some pilot projects but they have not yet been included into the public home care system. The most developed service seems to be the system of teleconsultations in the blood transfusion service, providing blood transfusion establishments all over the country with immediate access to specialists. There is one “smart home” - IRIS, located at the University Rehabilitation Institute, which serves two functions: besides being a research lab, it allows potential users to try out solutions in practice. Several government papers have proposed goals for further development of the use of technology in LTC in Slovenia, but progress and results are not yet evident.

As in many countries, there is a national strategy for measuring **quality** in health care in Slovenia, but no national strategy for quality management in LTC. The new Resolution on the National Social Assistance Programme 2013–2020, however, requires that all

providers of social services with at least ten employees acquire a certificate from certified quality management systems. Home help providers are controlled professionally and administratively by a special commission/inspection (at least every three years). Furthermore, family members of eligible persons may also ask for a quality evaluation. Family assistants are obliged to report to the social work centres on an annual basis. Centres for social work must also provide information /feedback from persons in need of care annually. Monitoring data on community nursing collected by the National Institute for Public Health is used more for administrative purposes than for quality improvement in primary care. Data are collected via a harmonised data collection sheet from municipalities and are input- rather than outcome-oriented. Measuring client satisfaction is not mandatory; the providers who do include this element are not able to compare their results easily with other providers because this is not a required or standardised element.

There is no systematic approach to quality assurance properly defined by law, but several activities across different fields are being developed and will need to be integrated into a uniform system. There are many private as well as public initiatives to ensure and measure quality in care processes and results.

New legislation is planned which should achieve better integration of services, better accessibility (e.g. introduce LTC coordinators for more patient-centred care), systematic support for non-professional carers, more prevention and more rehabilitation.

AGE Platform Europe

20

According to several of the AGE Platform Europe's members, the current economic crisis has already had an impact on older persons' **access** to care services, elevating barriers and often re-directing an increasing share of care back to families. In case of care needs most older people prefer home care, so some local and regional authorities have developed initiatives to promote age-friendly environments for this form of care. There is, however, still no holistic approach to care services in many EU countries which limits the impact of some targeted and local policies on the overall care system.

Technology and, more specifically, ICT can provide support for people to live more independently. Experience has shown that older persons need to experience technology to see how it can improve their daily life. Affordability is often an obstacle to widespread use of some solutions opened up by technology, as is acceptance by older people and their families. Low acceptance may be related, inter alia, to the current focus of ICT in emergency care, which is invariably associated with negative connotations.

In many countries, there is still a lack of **transparency** and public information on the quality of care, especially related to outcomes. Furthermore, AGE calls for action to combat **elder abuse**.



European Social Network (ESN)

Recognising the complex structure of national care systems, the ESN comment paper draws attention to the public authorities' role as commissioners and planners of social services. For example the Scottish government is preparing legislation that supports joint commissioning between the health and the social sector to improve community planning by introducing integrated budgets.

Integrated case-management can be used to overcome the information barrier about different care options. It is important that case-management is provided by professionals who have the capacity to pull different resources together. ESN stresses the medical as well as the social aspect of prevention; close cooperation between social and health services, housing and civil society organisations may prevent social exclusion and loneliness.

Some ESN members stressed the lack of data and evidence on results from the use of **technology** in home care. There are, however, some promising results of evaluations of telehealth and telecare in England and in Scotland (Scottish Government, 2012). In spite of the potential of technologies, they are not yet widely used in many countries. Several obstacles have been identified, including not enough public (co) funding and the lack of compatibility when different administrative levels (like municipal social services and national health services) cooperate, for example in teleassistance systems.

Information collected within the ESN network confirmed that the more traditional measures to monitor quality are predominantly being used (mostly minimum standards for accreditation of providers, and mandatory occupational qualifications), while registers are seldom available. In the area of home care, often only the organisation providing care is monitored, but not the service itself. In some countries, transparency and user feedback are used as a tool and results of inspections or service user feedback are published. Even though there are not yet many evaluation systems that measure the quality, effectiveness and efficiency of implemented measures, the comment paper by ESN provides a selection of initiatives in several European countries or municipalities that have the potential to balance quality and accessibility of care services and sustainable finances.



D. Main issues discussed during the meeting

Swedish approach in general

Due to its novelty, there is a lot of interest among peer countries regarding **integrated guidelines** covering health as well as LTC services. It was explained that such guidelines were developed for selected conditions only, partly due to lack of evidence-based practice of what to do (and what not to do).

Several countries expressed interest in the Swedish practice of more **flexible boundaries between professions**. Debates and resistance from some professional groups did occur also in Sweden, but could be overcome. For instance, transferring some tasks and competences from medical doctors to trained nurses had to go along with some explanatory efforts. Softening boundaries between professions as well as introducing social innovation need additional education and/or training, at least during initial phases.

Building a strong base of patient-centred information, especially when linking diverse data sources and storing data over long periods of time, is likely to raise concerns regarding **data protection**. The Swedish approach sees the patient, not the state, as owner of the data. Patients are given the opportunity to refuse the inclusion of their data into a registry, for example. According to the Swedish experience, registries are most successful (in terms of participation) if they provide visible benefits for health staff as well as patients, alongside benefits for governance.

22

The discussion supported the Swedish view that there should be an increased focus on **prevention**. It is, however, not always easy to define and measure where prevention ends and acute care begins. Furthermore, prevention is relevant both before the onset of (severe) care needs, but also for persons with already high care needs who can benefit from prevention measures.

Partnership between family and formal care

There was intensive discussion regarding **country-specific preferences** for care settings: for example a high share of intra-family provision of care in countries like Romania is linked to a high degree of cohabitation of the elderly with younger generations, and intra-family support is higher in times of high unemployment due to costs of formal care. What may seem to be a national preference can sometimes be explained as a consequence of a lack of availability or resources. Even in a “rich” country like Germany the ceiling for benefits forces some families to resort to family care. Furthermore, several (especially newer) EU Member States observe a shift in the traditional distribution of responsibilities, for example, in countries like Slovenia and Croatia where the main kind of LTC used to be provided in nursing homes.

Croatia hints at evidence that care for the elderly is a larger obstacle for women’s careers than childcare, thus highlighting the need for special **support for informal carers**. In Scotland, a certain proportion of municipal funds are supposed to go into such support mechanisms, and there is a systematic approach to assessing the support needs for informal carers. Several countries have implemented measures to better reconcile employment



and care, e.g. by more flexible work hours or by introducing monetary benefits aimed at improving possibilities to pay for support. Such policies are supported by Czech evidence which found that leaving the labour market in order to provide informal care is the most expensive form of LTC. On the other hand, there are concerns that cash benefits can lead to financial exploitation of family members, or can become a burden on the public budget if not designed carefully and well executed.

The role of the family in the care process might change if social networks increasingly take on some of the traditional roles of families. As it is only some of the older population which have care needs, many older persons are in a position to act as carers themselves, thus providing a large additional resource. In Scotland, there have been positive experiences with systematic skills assessment as opposed to a needs assessment at the time of entering into retirement.⁹

Social innovation

There was consensus that additional education needs will arise if a philosophy of care is replaced by a philosophy of activation and rehabilitation. Several countries found the shifting of tasks and responsibilities across the **“boundary” between the health and the social care sector** very difficult to achieve. An added dimension is that families need to be involved in rehabilitation. In Romania, where NGOs play a significant role in the provision of care, it is actually the NGOs which tend to be more innovative because public bodies often postpone innovations in order to deal with acute care needs.

Separate financing mechanisms further contribute to making the boundary between health and social care more conspicuous. Databases which are currently operating separately also need to be harmonised, if they are to be used to their full potential. Sweden provides good examples in this regard, in terms of data collection as well as comprehensive guidelines.

The critical role of discharge management was emphasised. Belgium has developed a tool to help assess rehabilitation needs; the system is known as “BelRAI” (Belgium Resident Assessment Instrument). Further examples of good practice in place across Europe can be found via WeDO (Wellbeing and Dignity of Older people), an informal network which aims to promote quality in LTC in Europe¹⁰.

Technology

Much of the discussion emphasised that many useful technologies have already been developed. Since these are often for purposes other than LTC they need to be identified, adjusted for LTC purposes (e.g. technologies may be used in hospitals where training and safety is already in place but this is not the case in private households), and made affordable. Legal issues also need to be fully resolved; for example, who is responsible for the shut-down of telecare in case of a power failure?

⁹ See comment paper by the European Social Network ESN. <http://ec.europa.eu/social/main.jsp?catId=1024&langId=en&newsId=1903&moreDocuments=yes&tableName=news>

¹⁰ See <http://www.wedo-partnership.eu/>



In order to identify useful technologies, it is essential to involve the people they are designed for (patients, families, formal carers, but also patient organisations). It is vital to facilitate cooperation among these stakeholders. In the Netherlands, for instance, there has been a positive experience with staff in home care using tablet PCs according to their own needs. This means nurses themselves decided on how to use these tablets in order to improve quality and/or efficiency of service provision, rather than having external experts design support-tools for them.

Quality assurance and measurement

The presentation of Swedish quality registers, particularly the register on BPSD (Behavioural and Psychological Symptoms in Dementia)¹¹, proved to be of interest to many countries. In the course of the discussion, the Swedish experts clarified a number of issues:

- Involving medical experts for diseases covered is indispensable for the successful development of registers
- Registers are predominantly used on the aggregate level, to acquire quality indicators and compare across institutions or over time. There are comparative reports that are publicly accessible. Registers which can be used by individual care providers or patients are well received.
- The BPSD register uses guidelines; there are efforts to develop clinical pathways but they are not yet included
- Extra staff are required during the implementation phase for the BPSD register but gradually patients' conditions improved so much that staff saw an improvement in their overall workload
- GPs are asked to work with a number of quality registers. Nursing staff work only with the BPSD register; it is seen as a tool to support the professionalisation of their work and to make their efforts and results more visible. As such it is well received by nurses.
- The BPSD register contributes to improved quality of life for patients while reducing medication considerably
- Different registers use different outcome measures, from international questionnaires like EQ-5D or SF-36 to disease-specific outcome measures. Most indicators used in registers are quantitative process indicators.
- Currently, Sweden is very cautious about linking budget allocations or economic incentives with the registers as it might jeopardise their function as tools for quality measurement and improvement. Where elements of pay-for-performance have been introduced, it is at the local level, not the national level, and payments go to municipalities or councils, not to carers or doctors.

With regard to different measurement methods and practices for quality assurance, the OECD, in cooperation with the European Commission, recently produced a comprehensive report (OECD, 2013). In collaboration with the European Commission, the OECD will continue to work on **comparable measurement** of quality in LTC; results of the current project are expected in 2015.

¹¹ See <http://www.bpsd.se/in-english/>



All peer countries reported difficulties in defining and implementing suitable quality assurance instruments and processes. It was therefore suggested that a European **network** of national agencies should be set up to assess the benefits of social or technological innovations in order to facilitate mutual learning and knowledge transfer.



E. Conclusions and lessons learned

Compared to other countries, Sweden is in a relatively comfortable situation with a rich (though sometimes not yet very well coordinated) availability of data. Several reasons for this have been identified:

- Strong legislation regarding data collection
- Much involvement of patients and also other stakeholders and professionals
- Patient rather than state ownership of patient data, so that patients can deny access to data
- The goal of making the data immediately useful and usable for several stakeholders, at times including the patient.

This all-encompassing approach has helped overcome resistance to intensive data collection and storage including increased paperwork for doctors and other staff.

Although there are no evaluations available yet, the **freedom to choose** appears to be popular with patients. However establishing a variety of options can be costly and not all countries are in a position to provide multiple options currently.

In order to better **align informal care and formal care**, the pool from which informal care can be drawn needs to be redefined. Intra-generational support for the elderly has the potential to develop and grow, especially if new social networks can be exploited to this end. Nevertheless, informal care will need increasing support. In this context, evaluations can be used to identify efficient forms of support. As LTC is generally needed and provided by more women than men, attention should be paid to impacts on gender balance/equality.

In order to better exploit the potential of **prevention and rehabilitation**, more evaluations of what works in different circumstances are needed. A number of Member States face some common difficulties: In many Member States, there is still a segregation of responsibilities for financing and provision between health care and social care, but there seem to be different philosophies or cultures in each sector as well. This might become an obstacle if one wants to achieve a transformation from a culture of care to a culture of rehabilitation and empowerment to tackle life more independently, also after the onset of so-called care needs.

Several Swedish experts stressed that a wealth of useful **technology** is already available, but needs to be (1) improved in terms of simplicity, user-friendliness and sometimes safety, (2) made marketable in terms of cheaper production and ultimately, market prices, and (3) sometimes adapted to the specific LTC context. It therefore might be worthwhile putting more emphasis on development, rather than basic research.

With regard to **quality measurement**, systems in most countries still have much room for improvement and typically struggle for similar reasons. Systems of cooperation and mutual learning, within the countries but also on an international basis, are therefore critical.



Some conclusions one can draw from Swedish experience are:

- We need to critically think about “traditional” patterns of care provision and question their relevance and validity for today, e.g. with regard to medications
- High-quality care including person-centeredness are not necessarily more costly than lower quality options
- It is crucial to involve specialists in designing quality measurements for specific diseases, but also to get also other health staff like nurses and their experience on board.



F. Contribution of the Peer Review to Europe 2020

The combined measures outlined by the Swedish host country paper have the potential to contribute to all five headline targets of the Europe 2020 Strategy favourably.

Employment

Measures to facilitate the combination of providing informal care with formal employment have the direct potential to extend total hours worked in several ways, i.e. by removing barriers to take up work or by allowing carers to extend work hours (e.g. from part-time to full-time). Croatian delegates, for instance, reported that currently it is still care for the elderly rather than care for children that can pose serious challenges for female employment.

Some supportive measures may involve job creation, related to all levels of qualification: tax exemptions for domestic help can increase job opportunities for low skilled persons, qualification measures for care staff lead to higher-skilled carers, and require also more teachers in nursing and related areas. The increased application of technologies and development of improved care processes can lead to newly created jobs in fields which are tangential to the core health and care sector (like ICT and social research), thus also increasing job opportunities for persons not prone to care work in their original orientation.

R&D/innovation

Swedish experts underlined that investigations into making existing solutions cheaper, simpler and safer, rather than just putting efforts into developing new solutions are needed. To concentrate research in the development of products which are useful and marketable, to ensure close cooperation between all kinds of stakeholders including users and experts are all necessary components of R&D for the care sector.

Climate change/energy

Even though these issues were hardly discussed at the Peer Review, they may be affected if care regimes will be changed on a large scale. Wherever care provision is being shifted to a different care setting, necessities for transport and travel will change and alter energy consumption. For instance, deinstitutionalisation is likely to increase travel of care staff providing home care. Patients taking over some of their own care tasks, e.g. due to technically improved aids and devices, are likely to reduce travel time and energy. The increased use of electronic equipment (and their production) also consumes energy.

Education

The health and care sector is one of the very few with growth potential. In the Swedish experience, the transition towards a care regime focused on the individual and promoting their independence rather than on organisations providing care, requires well-educated staff. Increased education, like higher proportions of university-trained nurses, therefore contributes to the goal of Europe 2020 as regards education.



Poverty/social exclusion

This Peer Review raises the issue of dignity in care services, and especially in services provided in the home of the person in need of care. This issue is of high importance as many of the older EU Member states are currently striving to replace (costly) residential care with (less costly) home care. Home care, however, is often linked to higher demand for informal care provided by family members, thus potentially increasing current and future poverty risks of (mostly female) providers of informal care. The Czech delegates reported their experience that care regimes which make use of informal carers are most costly when they require that informal carers give up their employment. Therefore, professional staff in home care are called on to support families in their individual situation; this, however, may need additional training to acquire special skills, e.g. to improve multi-professional cooperation and communication.

For historical reasons, however, home care services are not yet very developed in some of the newer EU Member states. It is therefore of high importance especially for these Member States that knowledge and experience with different forms of improving quality and efficiency in home care (without posing obstacles to employment possibilities of the affected families) is shared. Therefore, we need a culture of transparency and mutual learning, which again needs to be based on a qualitatively sound and accessible information base.

There are several more avenues along which dependency of older persons can be avoided or alleviated, for example:

- By promoting all-generation housing, built to facilitate independent use by older and frail persons
- By familiarising persons with ICT to enable them to better keep in touch, thus reducing social exclusion
- By improving their possibilities to exploit existing IT-based support tools
- For some population groups, this may require offering more affordable ICT services.

In general, society needs to become more aware and open-minded with respect to afflictions of old-age and (sometimes easy) ways to cope. Progress in this regard should not be confined to health and social services, but should encompass all society.



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European Commission

Dignity first – priorities in reform of care services

Luxembourg: Publications Office of the European Union
2014 — 30 pp. — 17.6×25 cm

ISBN 978-92-79-35330-7

ISSN 1977-7973

doi: 10.2767/58124

This publication is available in electronic format in English, French, German and Swedish.

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Dignity first – priorities in reform of care services

Host country: **Sweden**

Peer countries: **Belgium - Bulgaria - Croatia - Cyprus - Czech Republic - Germany - Lithuania - Netherlands - Romania - Slovenia**

Stakeholders: **AGE, ESN**

EU countries face a common challenge: maintaining and improving the quality of elderly care while ensuring it is both accessible and financially sustainable. A Peer Review in Stockholm (September 2013) explored the Swedish approach to care reform, and organised a common discussion with peer countries on these topics.

Sweden has managed to maintain a particularly high standard of care. Experts from Sweden and ten other EU countries, as well as representatives from the European Commission and stakeholders, met in Stockholm to explore Sweden's efforts to make care more person-centred without jeopardising long-term financial sustainability.

