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# Active Ageing and Prevention in the Context of Long-Term Care Rethinking Concepts and Practices

by Georg Ruppe

#### Introduction

In many countries *long-term care* as well as *prevention* are terms still strongly coined with the ideologies of "being taken care of" and "avoidance" and are thus also often related to passivity. However in recent years in these areas a reorientation can be noted internationally, obviously resulting in the remarkable approximation to concepts of "Active Ageing".

Measures of prevention, for instance, which tend to be characterised by a rather prescriptive and top-down nature (using terms such as: vaccination *schedule*, mother-child *passport*, dietary *guidelines*, etc.), are increasingly being complemented by concepts of "health promotion". The latter are intended to enable the affected person a more active role with a more positive and motivating access to his/her own health maintenance (WHO, 1986 and 1997). However, the motivation *to change one's behaviour* – to "become active" – on a personal level generally presupposes a corresponding *change of context and infrastructure* at the societal level with often far-reaching social policy measures.

In a similar way, "long-term care" cannot any longer be reduced to a passive "keeping" of older and care dependent people in care homes – something the concept has been and still is regrettably often associated with in Austria as well.

"Long-term care", understood as a comprehensive and integrative care concept, is at the beginning of a long and heterogeneous development process in Europe. However, it is increasingly being recognised as a central social and health policy field of action (MISSOC, 2006; OECD, 2005; Commission of the European Communities, 2007). In this context it is clear that a successful and sustainable development of such a comprehensive approach not only requires better integration of health and social systems, more coordination between the formal and informal care sector

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Policy Briefs are a publication series providing a synthesis of topics of research and policy advice on which European Centre researchers have been working recently. and the development of harmonised and transparent quality standards, funding flows and management structures (see Figure 1). Indeed preventive and rehabilitative measures, as well as fostering of individual resources – in particular for socially disadvantaged older people – need to be understood as intrinsic parts of long-term care. This is particularly the case if an extensive period of adult life, during which an ever-increasing number of older people need regular care at different levels of intensity, is to be transformed into a more active, autonomous and worthwhile life. As a network of high-quality and well-coordinated support services, longterm care itself obviously has a strong *preventive and activating* potential.

Hence, as active ageing, long-term care, prevention and health promotion are in many ways closely linked to each other, such a tendency is likely to become more critical in the future. The following sections provide an overview of some international as well as specific Austrian trends in this regard.

#### I Overview of national developments in a European context

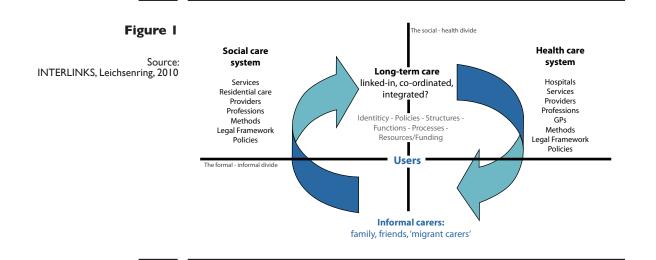
#### **I.I Trends in Europe**

Critical questions about the planning and organisation of health and social care for a growing number of older persons have initiated a great variety of international research approaches and led to an intensive search for policy solutions. In this regard, *long-term care* as a comprehensive approach has attracted growing policy interest (MISSOC, 2006; OECD, 2005). In December 2001, long-term care together with healthcare was added into the *Open method of coordination* developed by the European Council and the EU Member States (COM(2001)723 final). In 2000 the WHO – which had established the concept of "Active Ageing" in the 1990s – defined long-term care in its report "Active Aging. A Policy Framework" as:

"... the system of activities undertaken by informal caregivers (family, friends and/or neighbours) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity." (WHO, 2000; 2000b) O

Ten years on, a systematic development of long-term care is in many, albeit not all European countries still only emerging (Marin et al., 2009). In several Scandinavian and Anglo-Saxon countries (such as Sweden, Denmark or the UK) individual model projects and social policy approaches are already relatively highly developed. However, long-term care as a system is still a relatively unknown concept in most Southern or Eastern European Member Countries (Kümpers et al., 2010). Aside from the heterogeneity of Europe (from a cultural, social and political perspective), the greatest challenges to many countries essentially seem to lie in (1) an often unbridgeable *fragmentation of national health and social systems*, and (2) an *insufficient connection between the professional and private (familial) care sector*.

Currently one of the largest ongoing FP7 research projects on "Health systems and long-term care" with partners from 13 European countries, specifically deals with the integration of these problem areas (see Figure 1).



INTERLINKS<sup>1</sup> uses the following definition of the target group of its research:

"Persons 65+ (old-age) who regularly and for an extended period of time depend on different kinds of long-term care services (medical as well as social), formal (professional) or informal (private) arrangements in order to cope with physical, mental and social restrictions and to manage instrumental activities of daily living (IADLs)."

Visit the INTERLINKS homepage: http://interlinks.euro.centre.org/

I 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" is a 3-year project (2008-2011) with 15 partners coordinated by the European Centre and funded by the European Commission's 7th Research Framework Programme.

As in the previously mentioned WHO definition, the central need for the linking of medical, social, professional and informal services is also clearly expressed in this INTERLINKS target group definition of long-term care.

In both definitions, this linking and integration of services is also described as a prerequisite for quality of life, autonomy, social participation and the managing of activities of daily life (ADLs/IADLs) – i.e. for essential aspects for active ageing. Thus, a comprehensive form of long-term care tuned to individual needs is also the key to health and resources promotion for the large and growing group of older people with various kinds of care needs (Kümpers et al., 2010: 4).

However, the potential of this large target group (both in terms of "active ageing" and the reduction in public expenditure) is internationally often being underestimated and the ideology – not to say, the myth – of "healthy ageing" is instead pursued. Hence, most of the international declarations, research programmes and initiatives for health promotion and prevention are primarily – in terms of prevention of ill health and preservation of working capacity – directed at the still healthy population (Kümpers et al., 2010). A reduction in public health costs and increasing productivity are thereby given top priority. The European Commission in preparation for the European Year of "Active Ageing" in 2012 writes, for instance that:

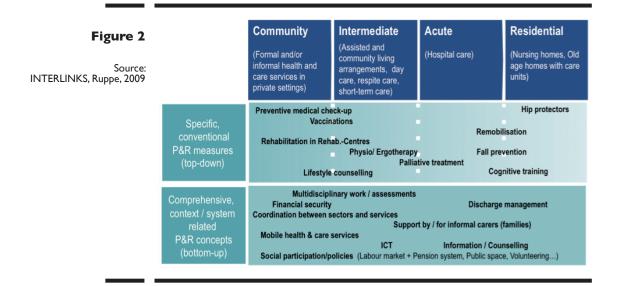
"...a healthy population is critical for economic growth and prosperity in Europe by enabling people to remain active in society for longer as well as by limiting strain on health and social care systems. ...To this end, promoting healthy ageing can help improve labour participation and productivity in older people." (European Commission, 2010: 7f)

From this perspective the concept of "healthy ageing" risks becoming prescriptive as a societal norm, and might even contribute to the discrimination of people who cannot age in a "healthy" or "productive" manner.

The relevance of targeted and evidence-based preventive measures as well as internationally recognised initiatives on health promotion is not in question here. Over the past few years, several large European projects, e.g. "HealthProElderly" or "Healthy Ageing" (see Appendix), have in particular been concerned with highlighting "good practices" and strategies of health promotion for older people. However, it is essential on the one hand not to overlook the growing group of older people with *already existing* support needs as target group for health promotion and rehabilitation. In particular disabled or socially disadvantaged older people are always at risk to be excluded from such measures. On the other hand, one should acknowledge the realistic boundaries of "healthy ageing" and concede the scenario that even people with dependencies or with "lacking productivity" can enjoy ageing in an active way.

In a comprehensive perspective long-term care, which should take place in all areas and "settings" in which people concerned are living, should be defined as a key concept also in the fight against age discrimination.

In the project INTERLINKS, four fundamental care settings (Community Care, Intermediate Care, Acute Care und Residential Care) were distinguished in which preventive or health promotion measures can be implemented (see Figure 2).



A striking result from research is that services of high-quality as well as efficient coordination and communication in and between the different settings of care are likely to have a significantly higher preventive potential than one-dimensional - mostly medical - preventive measures (e.g. a hip protector), which are usually not very matched with the complexity of individual life circumstances (Kümpers et al., 2010).

#### 1.2 State of research and developments in Austria

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**Development of** The introduction of a non-means-tested long-term care allowance in long-term care in Austria 1993 constitutes a major contribution for the basic development of longterm care in Austria. With this social sector reform, which had been implemented by a federal law and nine corresponding provincial laws as well as a state treaty (*Pflegevorsorge-Vereinbarung*) between the federal state and the provinces, long-term care needs were for the first time officially acknowledged as a social risk and have become publicly visible in Austria (Leichsenring, K., Ruppe, G. et al., 2009). Some important goals pursued with the introduction of a long-term care allowance were:

- To foster an autonomous lifestyle of people with regular care needs,
- To offer choice in the type of care,
- To support family carers,
- To create new jobs and types of services,
- To offer more incentives for care at home rather than institutional care.

For many of these objectives, in particular the increase in autonomy or the creation of jobs and care services, significant improvements have been achieved since 1993 (Badelt et al., 1997, Leichsenring, K., Ruppe, G. et al., 2009).

In general, the development of long-term care for older people in Austria widely mirrors the previously described European trends and developments. In Austria, as in many other European countries, a strong fragmentation can be observed between the health and social system with regard to management, financing, training or quality standards as well as for the appropriate federal and provincial responsibilities. In particular, a coordinated cooperation between the social and acute medical care sector remains a problem area which has still not been resolved with the latest Austrian health care reform in 2005 (see Appendix) or the working group on "Redesigning Care Provision" (BMSK, 2009).

Assistance to the informal/family care sector through adequate and appropriate formal/professional care services remains unsatisfactory in many areas despite improved support for family caregivers (see page 8) and amendments in respective legal frameworks. It appears that the mere availability and affordability of services is more decisive for the use or non-use of services than, for instance, a professional needs assessment. For many beneficiaries of the long-term care allowance an average maximum of two available hours of professional care is a huge shortcoming to the actual support needed (Leichsenring, K., Ruppe, G. et al., 2009). Because of this situation, the need for support by migrant carers and the pressure on mainly female family carers are rising (see also Triantafillou et al., 2010). Relatively recent research results on the situation of family carers in Austria can be found, for instance, in the large-scale "Vienna Informal Care Study (VIC 2008)" (see Appendix).

Missing or uncoordinated care processes, inadequate quality and costs of services as well as too much or too little medical or care support (keyword "over-medicalised vs. under-supplied nursing homes") not only hold health risks for carers and care recipients but also reduces the preventive potential of comprehensive long-term care.

Prevention and health In contrast to long-term care, in the area of prevention and health propromotion in Austria motion in Austria there exists a clearly stronger legal<sup>2</sup> as well as structural<sup>3</sup> basis, which is certainly also internationally regarded as exemplary.

> The Austrian Law on Health Promotion is based on the Ottawa Charter and currently allocates a budget of 7.25 million Euro annually for health promotion measures across Austria (BMG, 2010). The Fonds Gesundes Österreich ("Foundation Healthy Austria") represents since 2006 an official activity area of the Gesundheit Österreich GmbH ("Health Austria Ltd.") and constitutes the national competence and funding centre for practical projects, activities and campaigns in the area of health promotion. This has led to the initiation of a variety of prevention and health promotion projects in recent years. Austria also participated as a partner in the two above-mentioned large EU research projects, i.e. "HealthPro Elderly" and "Healthy Ageing" among many others.

> However, in the area of primary prevention, despite all valuable initiatives (e.g.: Vorsorge Neul"Prevention new"), the accessibility of target groups and, hence, the efficiency of many relevant measures have their limitations. For example, the free health screening for all Austrians from the age of 18 (see Appendix) is used by approximately 11.3% of men and 15.5% of women and within the group of 75 plus by only 10.5% of males and 9.5% of females – together with a significant West-East difference in Austria (Hauptverband der Sozialversicherungsträger, 2006). Reflecting wider European trends and research (Kümpers et al., 2010), in Austria health promotion initiatives are predominantly directed to the younger and generally healthier "older people". At the same time most of these initiatives - despite usually claiming a comprehensive approach - are coined by exclusively medical themes (nutrition, physical exercise, fall prevention, etc.).

The encouragement of personal and social resources and thus of health and activity in old age has to take place in the various social policy areas such as education, pension and labour market policies, housing, volun-

Gesundheitsqualitätsgesetz ["Law on Health Quality"] BGBI. I Nr. 179/2004; 2 Gesundheitsförderungsgesetz ["Law on Health Promotion"] BGBI. Nr. 51/1998).

e.g. Fonds Gesundes Österreich (FGÖ) ["Foundation Healthy Austria"]. 3

teering and not least in the social and health care sector. However, the existing potential for a "healthier", more autonomous and even active aging under incipient or existing long-term care needs is generally underestimated and needs to be strongly encouraged. The next section will present some selected measures and initiatives in Austria which address or foster this potential.

#### 2 Success and problem areas of longterm care provision in Austria

The following examples are initiatives or approaches concerned with improved care and transition processes *in* or *between* different kinds of LTC-related structures or professions. They constitute essential build-ing blocks for a comprehensive and in this way *preventive* long-term care system in Austria. The initiatives themselves – according to the previously presented classification – are based in various settings of care.

**Community care** In Austria several measures to support informal carers and in particular family members in the private setting (community care) have been implemented which may eventually have preventive effects both for carers and care recipients.

Among such measures are, firstly, direct <u>in-cash services</u> such as, for instance, the already mentioned long-term care allowance or the public coverage of social health and pension insurance contributions or the costs of replacement care in case of temporary illness or unavailability of a caring family member (entitlement restricted to a minimum level of care needs according to the long-term care allowance assessment).

Secondly, there exist <u>advisory measures</u>, such as the Austrian *Pflegetelefon* ("Care Telephone") or the Internet platform <u>http://www.pflegedaheim.at/</u> (information on care at home) run by the Austrian Ministry for Social Affairs, regional service centres and various forms of advisory or preventive home visits at the federal or regional level (Österle, 2001; ÖBIG, 2008).

Thirdly, <u>in-kind services</u> such as publicly co-funded home care by various providers should be mentioned as well as different forms of respite or short-term care which have to be co-funded by users (see the "price calculator" example in the Appendix). These latter services have the inconvenience that they are often not taken up by those at highest need due to high costs, traumatising change of environment for the care recipient, lack of available places in the region, lack of flexibility, etc. Additionally, sufficient information about appropriate services and their availability is often lacking (Pochobradsky et al., 2005).

However, traditional family structures and thus the role of relatives in care and support are subject to constant change. Support from informal carers will obviously be indispensable in the future but their availability will most likely be quite limited in the longer term. In Austria at present 80-85% of vulnerable older people are cared for at home by (mostly female) family members (BMSK, 2008). At the same time the Eurobarometer survey from 2007<sup>4</sup> shows that a majority of the surveyed Austrians do not want to live together with older family members in need of care. The same interviewees also reported excessive dependency in old age on family care in combination with insufficiently available professional and community care services. Moreover, it may no longer be a preference of future generations to be cared for by children or grandchildren, particularly regarding physical care (Ruppe, 2006).

A valuable initiative in Austria in this respect has been, for instance, the setting-up of the society Alzheimer Angehörige Austria/AAA ("Alzheimer Relatives Austria" – see Appendix), which offers self-help, information and several social activities (e.g. the "Alzheimer Café") for people suffering from dementia as well as their relatives, neighbours, friends and other informal carers.

Intermediate care In the area of intermediate care - currently an important approach and concept in the health care policy of Great Britain (see Appendix) - there exists much potential for integrated and preventive long-term care, in particular also in the sense of "active ageing". Initiatives creating links between the medical, nursing and private care of clients and thus allowing for an autonomous ageing in the home environment should be mentioned. In Austria for instance, "Mobile Palliative Teams" as part of a national plan for graded hospice and palliative care (OBIG, 2004) represent such an initiative. Composed of multi-professional mobile teams, this kind of service slowly started to gain importance and to act as an essential role model for the care of older persons with multiple morbidities in their own home. Day care centres offering care (incl. meals), social activities and individual therapeutic measures for older people are still under-developed in relation to existing demand in Austria (Pochobradsky et al., 2005). In order to allow for a more flexible and individualised transition from the hospital to the home, institutions such as day clinics<sup>5</sup>

<sup>4</sup> Health and long-term care in the European Union, Dec. 2007, Special Eurobarometer B 283, wave 67.3, fieldwork May-June 2007.

<sup>5</sup> So far in Austria three day-clinics have been established in connection with departments for acute geriatric care and remobilisation.

for geriatric remobilisation and follow-up treatment as well as initiatives for the general implementation of <u>discharge management</u> are of great importance (see "PIK" in the Appendix as well as Grundböck, 2001; Grilz-Wolf et al., 2004).

Acute care In the field of medical acute care for older patients in Austria, the introduction and ongoing expansion of departments for <u>Geriatric Acute Care</u> and <u>Remobilisation</u> (AG/R) in public hospitals should be highlighted. So far approximately 40 units for geriatric acute care and remobilisation (i.e. approx. 1,440 beds) have been established in six out of nine Austrian provinces (GÖGmbH, 2010). The fundamental concept of AG/R Units is to provide a geriatric assessment, multi-professional therapy, remobilisation as well as the social reintegration of patients into their home environment. Providing comprehensive treatment regimes with appropriate professional expertise, organising discharge and follow-up procedures in due time and taking into account the individual social environment of each patient constitutes the preventive effect and the contribution of AG/R Units to "active ageing".

Quality standards and national goals for the systematic expansion of AG/R departments have been laid down in the Österreichische Strukturplan Gesundheit ("Austrian Structure Plan Health") recently revised in the year 2010 (GÖGmbH, 2010).

However, the prevailing lack of specialist training in the area of "geriatrics" in Austria is problematic and obstructive to the coordinated and professional further development in this area of care. Mobile and multiprofessional geriatric teams, which could be based in hospitals respectively in such departments of AG/R, are still an outstanding development. The Clinic for Acute Geriatrics in Zurich or the Chair for Geriatrics with its corresponding clinical departments at the hospital of Nuremberg (see Appendix) could, for example, serve as international role model institutions in this area.

Institutional care In the institutional care sector a general tendency towards small-scale living and caring arrangements can nowadays be noted. Forms of communal and <u>sheltered housing</u> or <u>shared apartments for care recipients</u> that allow for the utmost possible autonomous and active ageing with the appropriate intensity and quality of care are regarded as pioneering initiatives. By contrast, large-scale and impersonal nursing home structures with rigid management and often hospital-like formats are judged to foster a passive rather than an *active* concept of ageing. However, large nursing homes are Ø

still being established in Austria, such as the newly built nursing homes (called *Geriatriezentren*) in three boroughs of Vienna – each with around 300 places and with permanently integrated medical care.

However, the difficult issue of how to supply the best medical and institutional care to older people with advanced dementia or severe multi-morbidity – and often without any social or family support – remains. In this context, issues concerning the development of new structural concepts about a better integration of palliative care and equally delicate ethical questions – such as where, when and how are we allowed to die in our society? – need to be addressed.

The construction of small-scale living arrangements is constrained by the legal framework as well as the formal requirements for the operation of such housing units, which private providers have difficulties to fulfil.

The issue of quality of life in the context of institutional long-term care obviously depends not only on the size of the institution but to a large extent on the applied quality standards within this institution. The safeguarding of dignity, autonomy and independence as well as individual preferences and the possibility of participation and continuation of a social life are decisive factors for the quality of life of residents. The "National Quality Certificate for Nursing Homes in Austria (NQZ)" was introduced a few years ago and focuses on these dimensions.

The NQZ is an Austria-wide uniform external assessment instrument for nursing homes, which – as part of a quality management system – have already implemented a self-assessment (about 30% of the approximately 900 existing nursing homes in Austria). The focus is not on the structural realities but rather on the process and outcome quality. As part of the certification for each home, proposals and recommendations for further improving the quality of life of residents and the quality of work of employees are drawn up. The NQZ is not mandatory but is based on the positive incentive and self-motivation of the nursing homes to actively and systematically deal with quality development.

What remains problematic and clearly contrary to the concept of "active aging" are frequent decisions for permanent nursing home admission, which are taken without any adequate geriatric assessment – particularly without any performance test – beforehand. In addition to this disruptive experience for the older person, such decisions usually imply important financial obligations, usually causing a de facto "expropriation" of the person's wealth (including personal savings and property). Thus a return

to one's own home becomes highly unrealistic and related efforts for rehabilitation and reintegration within the nursing home will be discouraged or put into question from the beginning.

#### **Policy recommendations**

Prevention and health promotion as well as the curative possibilities of modern medicine certainly contribute in many areas to a healthier and longer life in our times. However, with a steady increase both in life expectancy and chronic diseases in later life, today more older people do not comply with a normative and often idealised image of "healthy ageing". They live and age – often for decades – with health limitations and dependencies in different areas of life. However this growing and often socially disadvantaged and 'hard to reach' population group requires special attention and should be recognised in its potential to pursuing a modern concept of "active ageing". Among others, the following points seem to be necessary or recommended:

- Productivity in the economic and physical health in the medical understanding should not be a prerequisite or priority of "active ageing".
- According to international trends and in terms of "active ageing", a new and comprehensive understanding of *long-term care* should be strongly promoted and necessary structures, forms of cooperation and framework conditions need to be developed in Austria. Indeed long-term care is not synonymous with entering a nursing home or the need for 24-hour care!
- It should be a central aim of long-term care to offer frail older people with long-term support needs a coordinated network of appropriate therapy, care or support at the right time and place in order to best compensate for dependencies and to promote and maintain individual resources for autonomous, dignified and active ageing.
- The integration and coordination of social and medical as well as formal and informal services is an essential prerequisite for the development of a successful system of long-term care.
- Prevention, health promotion and rehabilitation are integral elements of long-term care. Besides short-term and performance-oriented measures, quality standards of services as well as optimised care processes in and *between* separate institutions provide long-term care at the system level with a larger preventive and activating potential.

- Institutions and initiatives that can perceive and support older people in their individual social context and in their often complex dependencies and needs are essential building blocks of good long-term care and "active ageing" likewise.
- Special attention and support has to be given to older people, who act as informal caregivers themselves and, thus, are at high risk to suffer from related physical, psychological and social problems.
- Supportive institutions and initiatives are often characterized by the following attributes:
  - multi-professional and interdisciplinary work
  - mobile and flexible services
  - comprehensive assessments and professional counselling
  - means-tested financial grants
  - comprehensive support and health promotion for informal caregivers
  - thorough communication and coordination
  - provision for rehabilitation and social reintegration
  - discharge and interface management
  - small-scale housing and care units

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## **Appendix**

Alzheimer Relatives Austria (AAA) http://www.alzheimer-selbsthilfe.at/ Chair and Hospital for Geriatrics /Nuremberg http://www.geriatrie-nuernberg.de/index.php?id=11 Clinic for Acute Geriatrics in Zurich http://www.stadt-zuerich.ch/waid/de/index/kliniken/klinik fuer akutgeriatrie.html Discharge Management within the project "PIK" http://www.pik.or.at/index.php **HealthProElderly** http://www.healthproelderly.com/ Health Reform 2005 in Austria http://www.bmsk.gv.at/cms/site/attachments/5/8/1/CH0650/ CMS1272017449498/hausbetreuungsgesetz.pdf Health Screening in Austria http://www.sozialversicherung.at/portal27/portal/esvportal/channel content/cmsWindow?action=2&p menuid=59337&p tabid=3 Healthy Ageing http://www.fhi.se/healthyageing Intermediate Care UK http://www.nhs.uk/Livewell/Staywellover50/Pages/Intermediatecare. aspx

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Price calculater for home help services by Volkshilfe in Lower Austria http://www.preisrechner.at/index.php Vienna Informal Care Study (VIC 2008) http://www.wu.ac.at/altersoekonomie/projekte/vic2008 The European Centre is a UN-affiliated intergovernmental organization concerned with all aspects of social welfare policy and research.

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- An international centre of applied social science and comparative empirical research on social policy and welfare
- An information and knowledge centre providing social sciencesupported social policy intelligence through a think-net
- A platform initiating future-oriented public policy debates on social welfare issues within the UN-European Region

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