



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

Prevention and rehabilitation within long-term care across Europe

European Overview Paper

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I Introduction

In the light of demographic changes and a globally insecure financial climate, governments and actors in health and social care systems are forced to turn their attention to sustainable strategies for coping with the ensuing challenges. Demographic developments until 2050 include both a relative and absolute increase in old and very old people and therefore an expected increase of people with care needs. Moreover, the environment for long-term care (LTC) is characterised by trends towards the rising expectations of private consumers towards services delivered by professional care providers. At the same time a sharp decline in people of working age who constitute the main supply of care workers is also expected. Migrant care workers already play an important role in compensating for financial or human resource problems in national care systems (Di Santo/Ceruzzi, 2010). This is expected to go together with a further blurring of boundaries between formal and informal care and even more pressure on informal carers (Triantafyllou et al, 2010).

As there exists a growing awareness of the increasing pressures on public finances embedded in a climate of uncertainty about economic developments expected for the EU, one important thread in public and political debates focuses on the potential of prevention and rehabilitation (P&R) for older people. While in the past many health and social care systems have focused on meeting the needs of those older people in crisis and immediate need of care, there is now a growing recognition of the need to intervene 'upstream' in order to keep older people healthier and living more independently for longer. This debate is simultaneously, but differently nurtured by, on the one hand, the focus on autonomy and quality of life of older people (humanitarian rationale) and on the other by the potential of the containment of public expenditure – linked to an onus on older people to keep themselves healthy – (economic rationale). However, whether and to what extent increased prevention efforts lead to reductions in costs remains contested as results are to be expected at long range and thus difficult to assess based on evidence.

So apart from conceptualising prevention for the healthier and younger older people, increasingly the debate extends to the P&R potential for older people already in LTC processes. The target group in this report is older people (65+), who regularly and for an extended period of time depend on different kinds of LTC services based on formal (professional) and informal (private) arrangements in order to cope with physical, mental and social restrictions and to manage activities of daily living (ADL) and instrumental activities of daily living (IADLs).

The topic of P&R within LTC is one of the main questions developed by the INTERLINKS consortium, together with issues of quality management and the integration of informal care.

Among the 14 countries of the consortium, seven are participating in the work package (WP3) on P&R within LTC, encompassing Scandinavian, Western, Southern and Central EU countries: Austria, Denmark, Germany, Greece, Slovenia, The Netherlands, and the UK. They represent different types of welfare states and different cultures of care as well as diverse patterns regarding the distribution of responsibility between individual/ family and the state, and the relationship between professional and informal care.

The WP3 group has decided to work with a basic, but wide-spread understanding about P&R: 'Preventing the person from becoming ill or frail in the first place' – primary prevention; 'Helping someone manage a condition as well as possible' – secondary prevention; 'Preventing a deterioration in an existing condition(s)' – tertiary prevention; and 'Providing active support to help someone regain as much autonomy and independence as possible' – and in the group's understanding rehabilitation is seen as the process of restoration of skills by a person who has had an illness or injury so as to regain maximum self-sufficiency and function in a normal or as near normal manner as possible.

With these definitions in mind, complementary perspectives on P&R within LTC can be identified (cf. 7.1: the two layers of P&R in LTC): First, explicit preventive/rehabilitative interventions (e.g. falls prevention, activating care) can be identified. Secondly, high professional quality of care or well-integrated and coordinated provision of services are also considered to have preventive and rehabilitative effects – since poor quality as well as gaps and overlaps in care pathways render poor health and quality of life outcomes.

Taking this perspective, it becomes clear that organisations and (inter-) organisational processes are of great importance in underpinning the content and quality of interventions. Within a comprehensive concept of 'LTC care pathways' we thus need to think also about elements in the general societal environment, such as social support or disability-friendly space of which the presence or absence either promotes or impedes preventive or rehabilitative processes. This second perspective will also be a guiding factor within all this report.

This report elaborates on the findings of the partners during phase I of the INTERLINKS project. In this phase, after building up a quick overview on WHO, OECD and EU level scientific papers and documents as a baseline, each national partner of WP3 delivered a national report on P&R within LTC, using literature and document analysis and an expert panel approach (cf. next paragraph). The national reports described the current practice – the actual state of the art – as well as reflecting national debates on how P&R within LTC ideally should be implemented. The current integrative report was compiled. It took a comparative as well as a synthesising approach in dealing with the national reports, and, in accordance with the INTERLINKS research design, was discussed with and commented on by a 'Sounding Board' at EU level, and further developed thereafter. As it is based on secondary data, the report reflects the state of knowledge available with respect to this defined topic – which is shown to be a topic in a rather initial state of development. It will therefore show a field with limited evidence in policy and practice; however, we chose to consider a broader range of sources than used in narrow definitions, such as those from clinical research. This report will keep this focus rather than repeat the bulk of findings regarding prevention issues for older people in general.

The report structure is based on these previous notions starts in Section 2 describing the methods used to develop the national reports, while section 3 summarises the literature and document scan.

The subsequent sections deal with a series of issues which emerged from the national reports as relevant for our topic. Illustrative (good) practice examples that are linked to each section are added in the Annex. Section 4 starts by highlighting several cultural and structural issues of importance to all the LTC systems and impact on how P&R measures are considered. Section 5 also deals with some major LTC system's determinants: it examines the range of governance mechanisms between state responsibility and hierarchical steering at one end of the spectrum and market mechanisms (choice, competition) at the other, and their impact on the integration of P&R within LTC systems.

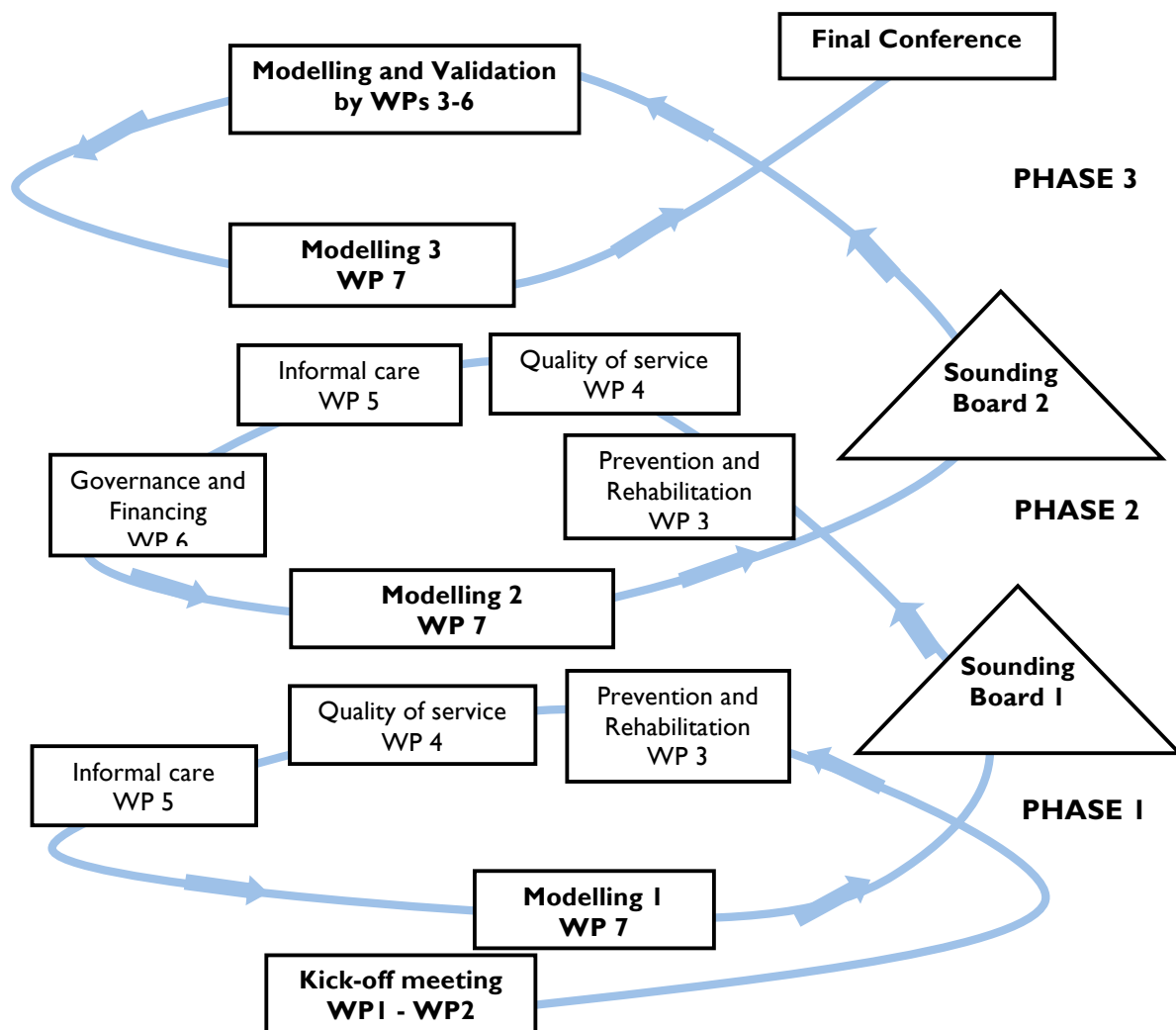
After that, ideas of ‘rebalancing’ LTC systems towards P&R – and the approaches for implementing this idea – are studied. The following Section 7 deals then with patients’ pathways and the questions of multidisciplinary and inter-organisational working, linked to preventive and rehabilitative orientations within LTC. This is followed by Section 8 dealing with the question of self-determination of service users. It raises issues around individual and family responsibility and self-care, at the level of culture and norms as well as political instruments, e.g. personal budgets and self management programmes as well as concerns about ‘blaming the individual’ with care needs. Section 9 addresses the topic of P&R for the special topic of dementia. Conclusive remarks deal with good practice recommendations at practice and governance level, but also with existing gaps in policy, practice and research.

2 Methods of research

The following mixed methods were used in WP3, phase I (see Figure I) to create an overview of P&R within LTC for older people: descriptive vignettes; an EU quick-scan literature review; focus group discussions with the National Expert Panels (NEPs) and descriptive, national state of the art reports. The first draft was commented by the INTERLINKS Sounding Board, an expert panel at European level. These sources together provided the information that is now combined and compared in this interim report.

Figure I illustrates the process in which the action research model of the overall project develops cyclically over the full project period in close cooperation with many parties, such as: country partners, health professionals, politicians, economists, users and other experts on LTC, including those at EU level. This interim report describes the first cyclical phase, which takes us up until after the first Sounding Board conference and concerns itself with WP3 – P&R.

Figure I Research model INTERLINKS, project description 2007



2.1 Descriptive Vignettes

Each country partner prepared a poster with brief details for one of two LTC cases concerning the pathways of the client through their country's system(s), from the perspective of the roles of informal care, quality assurance/assessment, P&R, regulation/costs AND focusing on links/interfaces between services/organisations involved, and problems and difficulties perceived (missing links).

2.2 EU literature quick-scan

A more detailed description of the methodology and results from the quick-scan is given in section 3. A rapid search of literature since 2004 was performed on P&R for older people with care and support needs. The inclusion criteria were: older people (65+); published since 2004; and published in English. We included as a first step explicit EU or comparative overviews, esp. systematic reviews of international literature.

Because the data collected was scarce, in the second step we broadened our search criteria and added some non-systematic reviews, national papers that seemed to address topics also of interest from an EU perspective and papers with helpful conceptual/descriptive material. The additional criteria meant that a broader spectrum of topics could be reported. This served to highlight the key issues already addressed in P&R research literature and any gaps or deficiencies in the areas covered. A total of 36 publications were included in the EU quick-scan search for evidence-based knowledge and programmes within WHO literature, EU projects, and OECD documents and these were added to the INTERLINKS online bibliographic tool, BibSonomy.

2.3 Focus group discussions with NEPs

In order to address the lack of evidence and gaps encountered within the quick-scans, particular importance was placed on collecting and sharing practice-based evidence at a national level within this research.

Each participating country invited 8-12 experts to form a NEP. NEPs included representatives of various government and non-government organisations as well as health and research professionals. The WP3 NEPs were to: 1) discuss the current national status of preventive and rehabilitative services within LTC of older people and 2) participate in describing elements of good practice and gaps in P&R in relation to LTC, finally leading to state of the art national reports. By 'state of the art' we mean the current state of play, rather than best practice.

The engagement of NEPs brought to light more current and specific knowledge of national good practice. NEPs were also found to be useful in terms of identifying key national literature, reports and projects to expand upon the somewhat fragmentary findings of the initial EU quick-scan.

2.4 National Reports

The national reports from all the participating countries were brought to a joint WP3 meeting for discussion using different levels of evidence and by discussing the delegates' knowledge and experiences about best practice models in the health care system related to LTC Pathways. Finally the reports evolved a framework of four settings of care: *Community care*: home-care, preventive visits, home nursing, informal home-care, family as care-givers, friends, social network and activities, day-centres, etc. *Intermediate care*: assisted community living arrangements, day-care, respite care, short-term care, nursing. *Acute care*: hospital and emergency care. *Residential care*: nursing homes, old age homes with care units, hospices, for people in need of palliative care.

2.5 Aggregated European report

An interim report consisting of evidence based knowledge from the National Reports on P&R was then produced. A long and intensive process was conducted to combine the most relevant and qualified information. This process took place at a joint meeting in Athens and later continued over the INTERLINKS NING intranet (a communication system made available for this project by the steering committee). The interim report was thereafter presented at the first INTERLINKS Sounding Board conference.

2.6 Validation at EU level: Sounding Board Conference

To ensure the relevance, quality and readability of the report to the EU Commission, a Sounding Board consisting of representatives of agencies¹ expected to have a broad knowledge and experience of prevention and rehabilitation in relation to LTC for older people was invited to the first of two planned Sounding Board conferences (Figure 1). The WP3 report was distributed in advance of and presented at the Sounding Board meeting (18-19 February 2010, Brussels). Two delegates were appointed in advance to comment on the report. The reports by WP4 and WP5 (Figure 1) were commented on by other delegates. Thereafter intensive discussions took place. Comments were again discussed and worked into this final report to the EU Commission.

¹ The INTERLINKS Sounding Board gathers representatives of European stakeholder organisations such as Eurocarers, the Social Platform, the European Social Network, Alzheimer Europe, the European Association of Service Providers for Persons with Disabilities, the European Older People's Platform (AGE), Health Forum Gastein, International Association of Gerontology and Geriatrics, the European Associations for Directors of Residential Care Homes for the Elderly (EDE) and of Homes and Services for the Ageing (EAHSA), international agencies such as the WHO and OECD, and the European Commission, Directorates General for Employment and Consumer Protection, for Public Health, and for Research.

3 EU Literature Quick-Scan

An EU literature quick-scan on P&R within the context of LTC was conducted in order to identify the key findings and gaps at EU level. The overall purpose of the exercise was to map key themes and gaps within the EU literature in order to guide national data collection and reporting. The quick-scan was divided into three literature types:

- *EU scientific literature*: texts and publications drawn from eight key medical, health and social care databases: Health Management Information Consortium (HMIC), Medline, Excerpta Medica database (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Care Online (SCIE), Applied Social Sciences Index and Abstracts (ASSIA), Proquest and Enhanced Business Source Complete (EBSCOHost).
- *EU databases*: Literature from the Cochrane library, The World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD). The online library databases of each organisation were used as the sources for this search.
- *EU projects*: Literature from EU research and development and public health projects. This scan utilised the CORDIS database and the website of EC/DG Health and Consumers/Public Health for identification of relevant projects and related documentation.

The key findings from all quick-scan searches were coded via the INTERLINKS online bibliographic tool, Bibsonomy. The findings were coded in terms of their relation to prevention, rehabilitation, good practice, social inequalities, involvement of target group users and links to other INTERLINKS WPs. Where relevant the findings were also cross-coded into categories related to health and social care settings: community care, intermediate care, acute care, residential care and unspecified settings.

The EU quick-scan for scientific literature on P&R in LTC for older people found that literature concentrated on behavioural interventions/programmes within preventative approaches, assessment tools, and professional models for the delivery of rehabilitative services, i.e. integration of care. More information was identified around mainstream practices and good practice recommendation than about equity issues and service user participation. Our understanding of these areas is expected to grow through the national level data collection.

The key messages from the literature relate to physical exercise, falls prevention, assessment tools and inter-professional co-operation. Physical exercise has benefits for the rehabilitation of people with dementia, particularly psychological benefits. It is also beneficial for both prevention and rehabilitation of falls and related injuries in older people in general, including those with stable chronic conditions. A broader literature on falls prevention programmes highlights additional measures, other than physical exercise e.g. vitamin and mineral supplementation, withdrawal from psychotropic medication, cataract surgery, environment/hazard assessments and hip protectors. Measuring the success of such programmes is seen as problematic due to poor reporting, although individual interventions, e.g. hip protectors, have been found to be highly effective for older individuals and cost-effective at a system level. The European network PROFANE has recommended a core set of outcome measures for falls prevention trials.

Several assessment tools have been recommended in relation to P&R of older people in LTC. Firstly, an ICF core set of assessment criteria has been produced for early post-acute rehabilitation facilities. A

general motor functioning (GMF) assessment scale is recommended for physiotherapists in home care settings. The review also identified the importance of measuring quality of life when evaluating all P&R interventions in older cohorts. Various commentators have outlined the usefulness of nurse-led integrated, multidisciplinary care teams within LTC for older people.

Results of this ‘quick-scan’ of scientific literature at EU level (i.e. cross-country results, reviews, etc rather than merely national findings) show a rather fragmentary landscape of evidence regarding the questions guiding this search:

- The setting-based differentiation did not reflect in the literature results – most of the studies did not link the examined approaches to specific care settings.
- The range of approaches hardly covered the mentioned dimensions: social and environmental aspects were almost entirely unrepresented, while behavioural and health-care related approaches formed the bulk of studied interventions.
- The scientific discussion of what is seen as good practice reflects, not surprisingly, the fragmentary evidence.
- Issues of diversity and equal access seem to remain largely unaddressed so far in scientific research (except one conceptual paper and one on gender differences in geriatric rehabilitation).
- The question of involvement and participation of older people themselves in shaping the services is not addressed regarding our focus; neither is the integration of carer perspectives.
- Steering questions such as quality assurance and governance and financing topics seem to be discussed and studied separately from P&R.

The specific focus of the quick-scan on P&R – *within LTC* – proved to be problematic for all three literature types, each of which identified specific gaps and biases. Within the scientific literature, quick-scan evidence tended to be highly medicalised; social and environmental aspects were seldom mentioned, whereas behavioural and health-care related approaches formed the mainstay of studied interventions. In this way the literature did not reflect the broad understanding of P&R in LTC (cf. Introduction) as used in INTERLINKS. In particular, evidence of the subtleties of primary prevention: ‘preventing the person from becoming ill or frail in the first place’ and the ‘autonomy and independence’ objectives of rehabilitation, may be lost in this health-care focused literature.

There was little data comparing different health settings or that approached P&R at an organisational or systems level. Issues of diversity and equal access appeared also very infrequently within the quick-scan. EU projects on P&R for older people with LTC needs were found to be strongly focused on the creation of information and communication technology (ICT) tools and health promotion activities. LTC services and systems tended not to be explicitly mentioned in EU projects; this proved to be an obstacle in identifying relevant projects in the quick-scan of EU projects.

The following list highlights some general findings that emerged from the quick-scan. The generalised nature of the findings results from the methodological issues discussed above. Indeed, one poignant reflection from the quick-scan exercise is its usefulness in revealing how little can be found when the search is specific to LTC.

- There is a strong research focus and much evidence of good practice in ‘falls prevention’ measures and programmes, and in a range of physical training interventions.
- Specific geriatric assessment tools have been developed and tested.
- Preventive home visits are seen as good practice, yet research tends to focus on the healthier, younger age cohorts of older people.

- Multidisciplinary, nurse-led teams are seen as good practice across settings, particularly for those older people with complex needs and dementia.
- There is scope for improvement in the effectiveness of working across the hospital-community/health-social care divide, i.e. working towards integrated care (cf. 5.3).
- There have been strong 'e-health' and 'health promotion' themes for EU project funding in the field of P&R for older people.

The quick-scan exercise revealed many gaps in the evidence available around P&R for older people in LTC. There are multiple reasons for the P&R field to be characterised by a lack of evidence. P&R are long-term processes which are difficult to conceptualise, measure and prove as specific outcomes. There is a tension between these characteristics and the short-term nature of political timescales, which has often resulted in P&R being under-explored within policy approaches. Further to this, there is a historical tendency to view P&R primarily in medical terms (and therefore to adopt medical forms of evaluation). In practice, these concepts may also have social, behavioural and environmental aspects, and understanding these may require other forms of evidence.

On a practical level rehabilitative and preventive initiatives within EU countries and EU funded initiatives are often short-term pilot projects. Such short-term interventions mean that evidence and good practice learning is fragmented and can easily be lost. Another practical issue is that interventions in one part of the system may produce benefits elsewhere, thus needing a whole system understanding of the issue to be researched. Typically, both policy and research have been too short-term and single-organisation in their approach to enable a full picture of the effectiveness of preventive and rehabilitative measures to be developed. Within the EU governance structure each member state takes responsibility for the development and implementation of their unique health and social care system and outcomes, rather than working to an EU standard. As such, it is at a national level that rich and varied data around LTC policy, strategy and services can be most easily identified. The general cultural attitude adds to the lack of evidence around older people in LTC and P&R. In all countries P&R are seldom associated with older people, especially those in LTC.

From our research perspective, we have learnt lessons from the process of undertaking the EU quick-scan, which informed our future data gathering. Specifically, the search term 'LTC' and to some extent also 'prevention' and 'rehabilitation' did not yield results that gave a comprehensive and balanced picture of developments in this field at EU level. Each of the literature sources searched tended to use more specific classificatory terms, reflecting the undeveloped system level approach within the field as a whole. The value of the quick-scan within the context of the overall INTERLINKS research, was its capacity to confirm the lack of research into P&R within LTC at EU level. It also highlighted how the short-term nature of initiatives and how P&R as concepts lend themselves to fragmentary or lost evidence, where outcomes are difficult to disaggregate and analyse.

4 Cultural and political topics within LTC discourses in Europe

This section seeks to briefly highlight some of those themes that are common among the seven WP3 countries – denoted here using their international country abbreviations – from the perspective of their cultural, political contexts of provision of P&R within LTC for older people.

“Religion, geographical location, the economic situation, the socio-political history or the development of a strong social welfare state are some of many factors which tailor and contribute to what one might call a national culture. Specificities of this national culture are also reflected and inherent in the organisation of social, health and care services ... as well as in attitudes and expectations of people towards these services and towards old age and chronic illness.” (Ruppe, 2009)

Cultural trends and attitudes shift over time – for example in more recent decades we have seen a general engagement with active, healthy ageing, health promotion and prevention. The demographic make-up of cultures is also in constant flux. In particular, urbanisation contributes to changes in how older people are cared for, and in some countries this places new demands on health and social services.

With representation from both the Southern, corporatist-conservative and the Northern social-democratic welfare regimes, from a newer EU member state and from the liberal welfare regime (Esping-Andersen, 1990), the spread might indicate a lack of common ground. As extensively discussed in welfare state debates these regimes are linked to different models regarding the distribution of responsibilities between the individual/family, the state and the market with respect to social security and different perspectives on societal inequalities and redistribution. Therefore they shape different contexts for LTC. We will, however, show that while there is disparity in regulatory and cultural attitudes, similar topics emerge that shape the approaches to P&R within LTC.

4.1 P&R: A narrow conceptualisation and an impeded implementation

There is tension between the labour-intensive, bureaucratic and economically heavy nature of LTC provision and the recognition of the need to respond to the demands of an ageing population by embedding P&R in mainstream services. First in their national reports, several countries describe how the medical bias of their healthcare services works against the development of adequate, patient-centred, P&R needs-led LTC services. The common understanding of P&R, remains often rather limited to the conventional scope of medically founded and linear interventions, rather than to multilayered, systemic or process-oriented approaches. The traditional disease-oriented attitude leads to crisis-focused, acute interventions which relegate P&R measures to a low priority on the political agenda. Coupled with negative stereotyping of chronically ill older people, and the perception of LTC as a ‘dead-end’, this dichotomy between economically-driven services and recognition of growing demand leads all seven countries to report both an increasing lip-service to the necessity to invest long-term in P&R for chronically ill older people and, simultaneously, a distinct lack of evidence of sustained, evaluated interventions, as political rewards are not to be expected at short range.

4.2 Family and gender roles

A further pattern of tension is evident in the relation between consequences of demographic changes and developing family and gender roles. Changing roles, both for women generally and for men in rural settings, increased urbanisation and the dispersal of traditional, multi-generational family units is leading to increased demand for professional LTC services that are flexible enough to meet individual needs and take account of both growing diversity and the socially disadvantaged. This can lead to harmful situations, especially in Mediterranean countries due to their familial nature (Esping-Andersen, 1999). We can see this exemplified in the Greek case:

In the Greek society, amongst others, strong family bonds and the traditional home-based role of women are reasons for generally high levels of informal care in the country. Traditionally, male children used to live near or with their parents, as they took over the farm duties. Informal care of older people was inherent in daily life, with no public care except for a GP or a hospital. Choice and flexibility were not issues that needed to be addressed, as the care was more organic and embedded in the traditional rhythm of life, with women as the quasi-natural carers in a paternalistic society. The sudden increase of the population, which led to a high rate of urbanisation, combined with not yet developed formal structures of LTC in the new-built cities, have led to a gap in care in the modern healthcare system. Although Greece still has a low participation rate for women in the labour market, many modern women refuse, or are unable, to undertake the traditional role of family carer.

4.3 Diversity

In most of the WP3 countries there is a growing number of older people from ethnic minorities. Their specific needs are often neglected by mainstream services. Also, gender specificities, or specific needs of socially disadvantaged populations are seldom taken into account when conceptualising health and social care services. However, there is a growing awareness of the diversity in older people, and some service provision relating to P&R and dealing with specific groups is reported. The UK national report refers to political attention to discrimination due to both age and ethnic minority background; from the Netherlands an emphasis on integration of older immigrants in voluntary work as a measure of social inclusion and health promotion is reported; Denmark funded a series of pilot projects about older migrants and health (prevention, participation in service development, dementia care); and from Germany a number of individual projects for older migrants are reported. However, in none of the countries are these questions studied or tackled extensively and/or globally.

4.4 Access

Equity in access to services for the vulnerable and heterogeneous group of older people is a key policy issue throughout Europe. It has been demonstrated (Huber et al, 2008) that difficulties in accessing health and social care services are in most countries the result of various compounding and interacting factors such as poverty issues, organisational and geographical barriers as well as health beliefs or limitations of health literacy. Research findings for this INTERLINKS report additionally confirm that limited access of older dependent people to integrated services directly as well as indirectly results in a loss of P&R opportunities for this target group.

A common theme that emerges from several national reports is, for example, a *regional or local disparity in access* to services. Chronically ill older people in rural, border or inaccessible areas have less access to P&R services. The aforementioned report by the European Commission (Huber et al, 2008) on “Quality in and Equality of Access to Healthcare Services”, which is based on findings from 8 European countries (6 of which are partner countries in INTERLINKS), identifies the lack of mobility, organisational issues and adequate transport as well as limited service infrastructure in rural areas as important reasons for such disparities, which can have significant impact on health outcomes.

Apart from *organisational and geographical issues*, this European report points to some more key barriers to equal access, some of which have already been mentioned above. E.g. Poverty and cost related issues sometimes appear as underestimated barriers, as EU countries generally provide universal public health coverage and other networks of social security. However, as frequent users of social and health care services, older dependent people have high financial burden due to cost-sharing requirements, private out of pocket expenses or insufficient exemption rules. In addition, in many countries informal payments are expected in return for speedier, better or more personal services (Huber et al, 2008).

Low health literacy often combined with reading problems, lack of adequate information (-technology) and sometimes substantially reduced expectations of older people regarding access and quality of services has been identified as another factor and vicious cycle in the report of the European Commission. In Slovenia, the gradual break-up of the larger family unit has not been accompanied by organised access to sufficient information about available alternative support. For example, the health visitor service in Slovenia is not sufficiently exploited. With regular visits to older people at home, and by undertaking preventive measures, such as measuring blood pressure, blood sugar and some other simple tests, important basic services could be provided and those who really need a detailed check-up could be referred to a physician.

Finally, the insufficient access to and availability of healthcare and specific P&R measures for dependent older people in institutional care has been recognised in the report of the Commission as well as in most national reports of this project. Especially precarious in this context appears to be the situation of older people suffering from mental disorders, who easily run the risk of stigmatisation, under-treatment of somatic conditions and exclusion from P&R measures (Huber et al, 2008).

Thus, it can be stated that there is a need for further development in research, policy and practice within the area of services for specific – especially socially disadvantaged – target groups.

4.5 Consumer choice and individual responsibility

In some countries freedom of choice is valued as a fundamental right, and this is complemented by the notion of taking individual responsibility for one's own health and the value of self-care. Yet adherence to the concept of free choice can be seen to curtail comprehensive LTC development (DE), where for example provision of medical staff in nursing homes would be considered to supersede the patient's right to choose their own GP. Privately sourced care and treatment is, in general in all countries, a solution which favours the middle class and acts as a disincentive for policy-makers to provide accessible solutions for all citizens, including socially disadvantaged groups. The tension between demand for choice and lack of flexible supply sometimes is compensated by the exploitation of an individual's networks of contacts, which best serve those with higher social status. A further consequence is that the facade of a functioning system is maintained, when in reality there is discrimination and lack of equal

access. Another attempt to counterbalance the scarcity of the formal LTC systems and the limits of informal care is the growing number of largely migrant care workers (e.g. in EL) both largely unskilled or professional. They fill some of the gaps in provision, although quality and competence is largely unregulated. However, especially the latter – with a higher and earlier burden of chronic diseases and functional disabilities – have the greatest needs for integrated preventive and rehabilitative LTC services.

5 Governance: Collaboration versus competition?

This section deals with the tension between cooperation and competition linked to specific modes of governance in the field of LTC, which impact on conditions for integrating P&R into LTC.

New Public Management (NPM) is a term used to describe an influential group of administrative doctrines which have developed over the last thirty years in the reform agenda of several OECD countries, and which are linked to the neoliberal political discourse. Kickert (1997) characterises NPM by eight key features, including: strengthening steering functions at the centre; devolving authority to provide flexibility; and developing competition and choice. A key question that emerged from the national reports is how different countries approach competition and collaboration in their health and social care systems, since a reasonable balance between them seems to be a challenge in all EU countries. Regarding P&R within LTC, this cooperation seems important, since comprehensive care pathways integrating a sound preventive and rehabilitative perspective rely on multidisciplinary and inter-organisational collaboration (cf. also sections 6 and 7). This section represents a first discussion of the following questions (which will be further explored within the work of WP6):

- How are market mechanisms used to improve value for money and quality of LTC services?
- How, by whom and at what level are incentives set for comprehensive and integrated P&R?
- Can competition help to better integrate services and/or enhance quality in yet integrated systems of providers?
- Which models seem to contribute to which outcome?
- Which national approaches can be described as good practice examples?
- At the end of the report four selective country examples are introduced (for full text, see examples I-4, Annex) to illustrate the analytical discussion.

5.1 International policy trends in competition versus collaboration

Besides the well-known challenges of demographic change and a consequent demand on LTC services, all countries in WP3 highlight challenges related to integration of services. For instance, negotiating different legal and financial systems can prove to be a barrier to delivering integrated P&R services in LTC (e.g. UK, DE). The countries display varied approaches to the development of LTC strategies. However, although neoliberal discourses are adopted quite diversely according to the national culture, the influence of deregulation policies and ‘enabling’ governments is a common feature. In general, the competitive market is advertised as a tool for improving quality and efficiency of services, even in cases where clear evidence of this is lacking. For example, in Germany the fact that ambulatory care services primarily act as private enterprises, severely hinders local collaboration. In Denmark, competition between public and private providers – in the context of an, until now, comprehensive public system – is seen as promising to promote the development of innovative care concepts (see Annex, examples I-4 for details).

5.2 Evidence of, and approaches to, competition and collaboration

While the evidence about the impact of steering instruments stemming from new public management concepts, i.e. increasing market regulations on the efficiency of health and social care commission and provision is contested, bringing more competition as an alternative or complementary approach also leads to a series of linked challenges concerning the best way to co-ordinate services and prevent excessive fragmentation.

According to the national reports, effects of competitive and economic measures on care quality are hard to measure. Where incentives induce competition with a specified goal, (e.g. to enhance good local integration), overall care quality might increase. This would be the result of strategic commissioning of services in a way that care providers collaborate and form partnerships (UK, DK, NL), thus increasing potentially the quality and efficiency of the output. However, this requires at least that there is a local guiding and commissioning organisation with enough financial or regulatory power and legitimacy.

If incentives predominantly lead to *competition only on gains and prices*, quality declines are likely to occur (DE). For example, if social care providers compete for the same clients within the same or overlapping catchment areas (see I-Fragmentation of Services in DE in the Annex), this sets up an obvious disincentive to simultaneous collaboration and networking, since their primary objective is their own market share and profit – at the expense of competing services. Therefore, competition within an under-regulated local care environment can seriously impede collaboration, knowledge transfer and joint local responsibility.

In addition, efficiency pressures in marketised ‘care industries’ similarly affect home care and care homes (Oldman/Quilgars 1999). They stress quick performance of care tasks, sometimes characterised as ‘care Taylorism’ (van Houten, 1999), often at the cost of personal and relational qualities of care processes (Malone, 2003). Since the respective systems of care delivery with ‘Taylored’ care tasks are based on a reductionist concept of social care, relational and social aspects of care delivery can be neglected (Pfau-Effinger et al, 2007). This can act as a barrier to the development of more subtle interactive approaches, such as ‘activating care’, and hinder effective implementation and quality of care.

The recent implementation of quality management instruments, such as evaluation procedures and ratings, are seen as a promising approach to regulating competition. These are being implemented and used for LTC improvement in several countries (DE, UK, NL, EL).

The underlying steering mechanism is based on the idea that LTC development and delivery are indicator-driven; if the fulfilment of certain quality indicators is linked to incentives (e.g. more resources), care organisations will follow these indicators/incentives. Depending on how quality indicators are set, they could function as steering instruments for the development of integrated LTC initiatives in P&R. Even if these indicators often do not yet explicitly address collaboration, they might have an indirect impact by improving care quality and pathways and thereby eg. reduce the incidence of avoidable hospital or care home admissions. Thus, however, requires that quality indicators are aligned across service sectors.

5.3 The role of local steering capacities in competition and collaboration

Although balancing competition and collaboration remains a key overarching issue, WP3 countries reported differing experiences. One important differentiator between the countries seems to be the ex-

tent of steering capacities at a local level. Local steering institutions are developed to varying degrees, with integration and coordination of services being strongly dependent on these local institutional structures. The existence or absence of defined and coterminous catchment areas of service providers seems to play an essential role in this. As can be observed in the German case (see Annex, example 1- Fragmentation of Services (DE)), their absence goes together with far-reaching market mechanisms. Service providers acting under strong market pressures, without defined regional responsibilities and mutually agreed territories, are often forced to expand their catchment area to acquire enough clients and are less interested in local collaboration, joint service development and knowledge transfer.

Countries with strong local steering capacities seem to provide a better context for the development of collaborative 'integrated care' approaches to P&R in LTC (e.g. the Danish case, see Annex, example 4). An integrated care approach promotes a comprehensive/holistic view of complete care pathways and general health outcomes and encompasses multidisciplinary perspectives. Preventive and rehabilitative potentials, otherwise hidden by conflicting interests of independent actors, can be discovered and addressed more easily. One element of this might be that professional knowledge is transferred more smoothly if professional actors conceptualise their tasks from a 'whole-systems perspective' on comprehensive care pathways. However, strong local steering and a widely integrated system of LTC development and delivery, promising eventually good quality of care and integrated P&R, implies some restriction of choice compared to a fully developed (and therefore fragmented) market. This tension should be explored further in future research steps.

According to the national reports, it seems as if the countries with the most developed public LTC systems can achieve a better care quality by introducing some competitive incentives (e.g. private providers competing with local authorities' services, (see Annex, example 4 – Implementation of competitive instruments in DK). Such a system could be characterised as markets and networks in the shadow of hierarchy (Scharpf, 1997). Conversely, countries with highly fragmented LTC services (DE, AT), probably even more so if combined with a scarcity of resources, tend to produce poor and underdeveloped services with questionable equity of access (poor development of diversification and knowledge transfer), if market mechanisms are the dominant steering instrument.

In conclusion, the role of a supportive institutional framework for collaboration equipped with some power at a local level (formal or informal), must be emphasised. Innovations such as preventive and rehabilitative approaches in LTC need organisational coherence and coordination rather than fragmentation. This kind of (social) innovation requires new professional goals, routines, values and/or forms of multidisciplinary/inter-organisational cooperation. Therefore a facilitating institutional framework is needed to allow the development, trial and error and practice of new forms of working arrangements by the actors involved. The existence of strong local steering capacities seems to be more important than the question of which actors should be in charge. According to the country examples a variety of steering frames can be functional. They could be either state or other local authorities (UK, DK) or steering capacity implemented in regionalised insurance institutions (see Annex, example 3 – Fragmentation of services with strong local steering capacity in the NL).

5.4 Country examples

The country examples in the annex – 1. Fragmentation of services (DE), 2. Overcoming fragmentation of services with strong local steering capacity (NL), 3. World class commissioning (UK) and 4. Implementation of competitive instruments (DK) – constitute complex case studies rather than good practice ex-

amples. They are chosen selectively to illustrate different national experiences with steering approaches to competition and collaboration. We selected Germany to highlight consequences of a fragmented care system with little local co-ordination and strong competitive incentives. The case of the Netherlands shows ways of overcoming fragmentation problems and the English case illustrates local effects of an ambitious 'World Class Commissioning' agenda, where the jury is still out on the issue of effectiveness. The case of Denmark shows how competitive instruments can be successfully implemented to improve the quality of LTC provision, on the basis of a well coordinated and coherent LTC system with strong local steering capacities.

6 Embedding P&R in mainstream services

Preventive and rehabilitative approaches are becoming more attractive as areas for investment as EU countries seek to respond to the challenges of ageing populations, rising public expectations and a difficult financial context.

6.1 Mainstreaming P&R approaches

While many systems have historically focused on meeting the needs of those in crisis, the need to intervene ‘upstream’ in order to keep older people healthier and living more independently for longer is increasingly acknowledged. However, more recently a number of systems seem to have been trying (implicitly or explicitly) to more *fully embed* P&R so that they become a core feature of *mainstream services* and start to *change the emphasis* and focus of the LTC system as a whole:

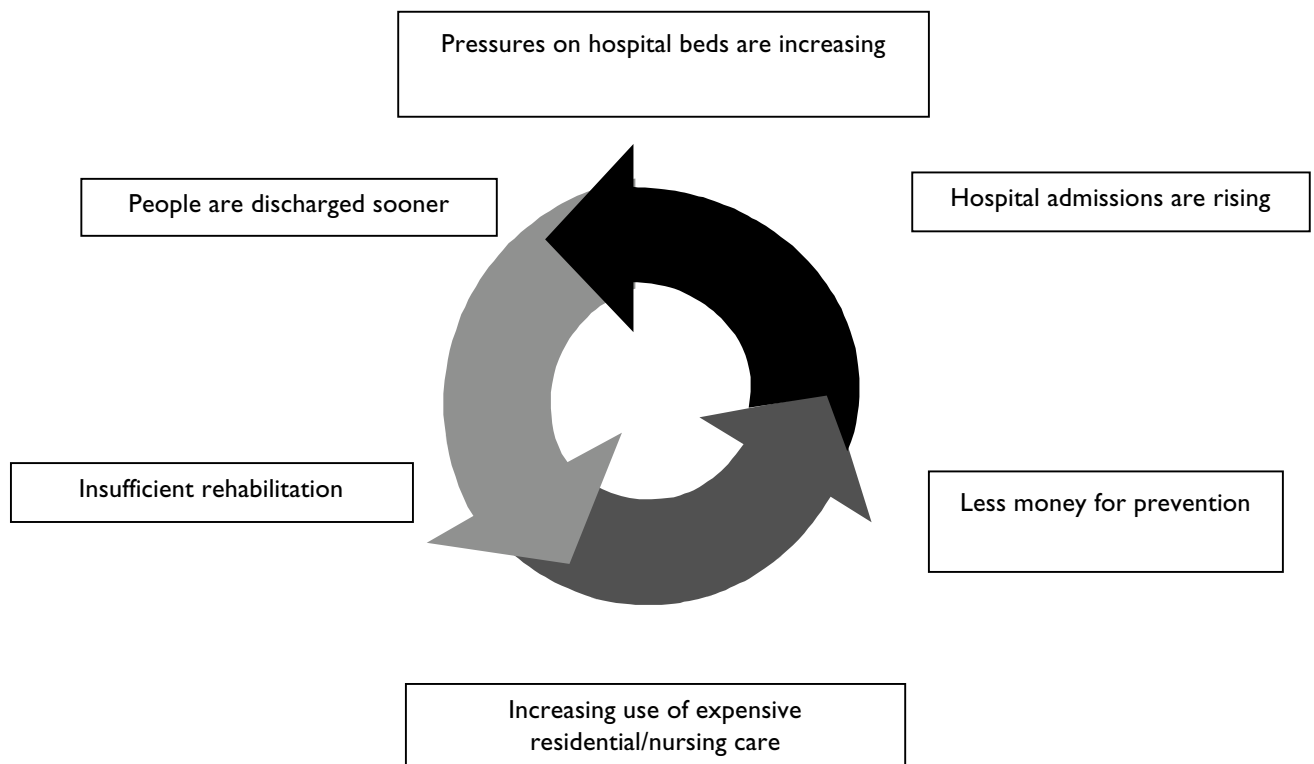
- In Austria, the Federal Ministry of Health identified 2008 as a “year of prevention”, in which special attention as well as additional public funding was dedicated to health promoting initiatives and projects, including those for LTC. In addition, specific health and social care services for older people have seen a range of positive developments in Austria over recent years (including the establishment of multi-disciplinary hospital facilities and assessments for older people suffering from multiple chronic illnesses, mobile palliative care teams, preventive and counselling home visits, etc). However, many attempts to promote greater P&R have come via pilot projects and have not always impacted upon the system as a whole (see below for further discussion).
- In Denmark, a series of ongoing reforms has sought to create a more integrated health and social care system at local level with greater responsibility for promoting P&R, with a national network of multidisciplinary health centres and preventive home visits (see 5 – Preventive home visits in DK, Annex).
- In Greece, the creation of a network of Open Care Centres has sought to provide a network of multi-disciplinary preventive and rehabilitative services in community settings (see 6 – Open care and protection centres for the older people in EL, Annex).
- In the Netherlands, a more preventive and rehabilitative approach has emerged over time with an emphasis about chronic disease management and on the development of more integrated care pathways across service settings.
- In Germany, LTC services emphasise the principle of ‘activating care’, promoting and supporting older service users to draw on their own skills and resources when undertaking daily living activities.

6.2 The English perspective of the ‘Vicious Cycle’

In England, there has been a more explicit recognition of the need to rebalance and refocus the system as a whole. According to the English Audit Commission (1997; 2000), the LTC system is stuck in a ‘vicious cycle’. That means that increasing hospital admissions and the use of expensive institutional forms of care leave less and less money for alternative forms of service provision (thus ensuring even more hospital admissions in future – see Figure 2. To break out of this situation, there is a corresponding need to invest more fully and strategically in both P&R – helping older people to stay healthier, more independent and more socially included for longer and to recover all these capacities as fully as possible

when they do require hospital treatment. Austria, Germany and Greece report a similar acute and crisis-focused approach within their LTC systems. Although it has not yet been formally theorised at a national level in these countries, the countries' reports displayed some national acknowledgement that the focus for investment would need to change in order to embed a more preventive and rehabilitative approach within LTC.

Figure 2 The vicious cycle



Arguably, solutions to the challenges within the vicious cycle remain largely aspirational, with insufficient evidence to back up some of the claims made and with little sign of the long-term political (and financial) support that might be needed to make such changes. Developing a more preventive approach has also been a stated aim of many governments over the years, and it is unclear why we might expect current and future policy to achieve this when previous attempts have arguably had only limited success.

6.3 Barriers to a preventive/rehabilitative re-orientation of LTC

Despite some examples of good practice (see examples 5-7, Annex), the WP3 countries have come up against several barriers to embedding P&R. These seem to be the result of a number of inter-related factors:

- The outcomes of P&R are often very long-term – and political timescales often require much more immediate indications of success.

- Proving you have prevented something is very complex, as impacts and related efficiencies are unclear it can be difficult for policy-makers to buy into large-scale preventive initiatives.
- Investing in P&R arguably requires a degree of double funding (to continue meeting the needs of people in crisis whilst gradually investing in longer-term approaches to reduce future demands).
- P&R are very difficult to conceptualise, and different organisations/professions may be working with different ideas about what these ways of working entail, the desired outcome and the best way forward.
- For many of the WP3 countries the idea of embedding P&R into mainstream services for older people is very much in its infancy. Greater acknowledgement of this priority at a strategic level and a clear vision of the possible activities, services and benefits of the approach are needed to enhance mainstreaming.

The national reports highlighted many further barriers towards embedding P&R in LTC. In Germany, the high level of competition between service providers (specifically including the factor of cost) can, in some cases, be viewed as an obstacle to embedding 'activating care' and its associated preventive and rehabilitative benefits. In practical terms, working conditions, lack of time and low skilled staff hinder the spread of such good practice at a national level. It is thus imperative that regulatory quality assurance measures for home care and wider LTC are sufficiently developed to counteract these negative effects of more market-driven systems. In Austria further barriers are associated with regionally empowered, federal systems. For instance, preventive measures for older people are fragmented and unequally distributed within formal LTC, especially within residential care.

In several countries the organisational and conceptual separation between health and the connected social determinants of health was seen to inhibit the scope for P&R in LTC. The Austrian national report described a national culture which could arguably be over-reliant on biomedical solutions for those with long-term health care needs (cf. Section 4). Rehabilitative and preventive measures are relatively poorly linked to their social and contextual environments and there was a perceived lack of partnerships between different sectors and organisations. A similar trend was apparent in Slovenia, where community-based projects for clients with LTC needs are a recent intervention. Slovenia and Greece also highlighted the need for a much greater policy and legislative focus to form the solid base and shared vision needed as a condition to effectively embed P&R into LTC.

6.4 First steps

For all these reasons, preventive and rehabilitative projects have often been very small, local and time-limited pilots (and therefore unlikely to change the system as a whole). Most notably: the Danish practice example (see Annex, example 5 – Preventive home visits in DK), Austrian projects on counselling, home visits, user and carer information systems and geriatric assessment; a Greek pilot project around modelling safe home environments; a Slovenian pilot of individual social care funding; Greek care centres for older people (see Annex, example 6 – Open care and protection centres for the older people in EL) and pilots on planning and funding rehabilitation services; and a national pilot programme in England encouraging organisational partnerships in preventive and rehabilitative care of older people. With some exceptions, the level of need has been such that pilots act more as a 'sticking plaster' solution or as a 'bolt on' to existing services and can therefore be the first to be hit if budgets are reduced. Against this background, there is a potential role for national governments and for EU funders to develop the evidence base and the case for change by investing in long-term development projects and detailed evaluation.

6.5 Key points

Key points raised around embedding P&R within LTC at a national, systemic level are:

- The need for investment in P&R is becoming more widely acknowledged amongst EU countries. This can be linked to the challenges of an increasing older population and pressure to run smarter, more efficient systems in a difficult financial climate. Despite this all national reports described that there was some distance to travel in terms of national policy, culture, financial incentives and organisation of services before LTC systems took on a truly preventive and rehabilitative nature.
- Steps towards embedding P&R within LTC can be recognised in all countries in initiatives such as: national awareness raising events, multidisciplinary preventive and rehabilitative services in community settings, e.g. health centres, home visits, emphasis on chronic disease management, case management and activation or re-ablement approaches.
- Initiatives in P&R tend to be small-scale, time-limited pilot projects. This means there is often a lack of the research and evidence of benefits needed to roll out interventions at a national level. In addition the concept of prevention is problematic in terms of being able to prove outcomes and quantify related efficiencies.

Market competition, as well as cultural and historic national approaches, has a cross-cutting relevance in WP3 (cf. sections 4 & 5). They are outlined as conditions which can inhibit the mainstreaming of P&R in LTC systems.

6.6 Country examples

The country examples in the annex – 5. Preventive home visits (DK), 6. Open care and protection centres for the older people (EL) and 7. Intermediate care services (UK) – illustrate national programmes and initiatives which aim to strengthen the countrywide P&R approach for older people with LTC needs. These examples represent cases which go beyond short-term, project-based approaches common to P&R and LTC. Denmark goes as far as placing legal responsibilities on local authorities to provide preventive services. Greek open care centres (KAPI) are becoming increasingly focused on preventive issues, particularly through the activities of the help-at-home network. In England, significant investment has been placed on developing ‘intermediate care’, with rehabilitative services such as ‘reablement’ being rolled out nationally. Similarly to the English intermediate care example, there is a growing emphasis on developing non-acute care services in Slovenia.

7 P&R across LTC pathways

This section outlines to what extent meaningful and sustainable P&R needs to be generated and integrated in the wider context and individual pathways of LTC clients and discusses the challenges related to this findings.

7.1 The two layers of P&R in LTC

Reflecting the basic features of the national reports that have been prepared in a first research phase of WP3, P&R within LTC for older people can roughly be depicted in two layers:

- The first layer comprises a range of rather focused and conventional measures of P&R, such as vaccination programmes, preventive medical check-ups, lifestyle recommendations (e.g. anti-smoking campaigns, counselling for healthy nutrition, etc.), medical rehabilitation, physio/ergo-therapy, falls prevention campaigns including the use of hip protectors and other devices. Almost all countries in WP3 can point to several, long-standing and well implemented public health policies in this direction. A common feature of such measures is a quite narrow focus on one specific problem or disease and a usually strong orientation towards biomedical functions and ideologies. However, most of these initiatives are not in particular dedicated to older people *within* LTC. Additionally, the acceptance and consequently the effectiveness of such top-down measures remains quite limited. In Austria, for example, the uptake rate of a free preventive medical check up once a year is around 11-12% among the adult population and only around 10% among those aged 75+ (Hauptverband der Sozialversicherungsträger, 2006).
- The second layer refers to the direct and indirect preventive/rehabilitative potential inherent in organisational elements, such as elements of coordination and organisation, transition processes between services or the quality of services themselves along the individual LTC pathway of a client. On the one hand, well organised discharge management might directly prevent a person from physical deterioration, if follow-up services or rehabilitation can be provided at the right moment and place. Mobile health and social care services might also directly prevent a person from an unnecessary and even harmful hospital admission. On the other hand, positive effects of social policies, such as disability-friendly public spaces, might increase social participation, life quality and satisfaction of older people and in this way indirectly motivate them to take care of their own health and to make use of health-related entitlements, e.g. free preventive medical check-ups. However, we also know from scientific fields such as psychoneuroimmunology, psychosomatic medicine and psychology on the one side and social psychology and sociology on the other (cf. studies about social capital and health (Kroll/Lampert, 2007), that an increase in life quality as well as feelings of satisfaction or the presence of social networks can additionally have a direct and positive impact on physical health status. Thus, we are dealing with measures that have not been established for preventive or rehabilitative reasons but which act directly or/and indirectly as such.

This section focuses on the second layer, where P&R is mostly generated at the edges and interfaces of specific services. Due to multidisciplinary work and comprehensive approaches, interventions in this layer can take into account different aspects of a service user's life and pathway as well as a bio-psycho-social model of ill health. However, this strength in the form of a comprehensive, complex and overarching approach turns into a challenge when it comes to evaluation, questions of evidence and imple-

mentation of such measures. To attribute a long-term preventive or rehabilitative effect in this second layer to one specific measure is more difficult compared to the rather short-term effect oriented interventions as described in the first layer. Consequently, many long-term and pathway oriented interventions are currently only in the status of (pilot) projects and fail to achieve full health policy recognition and implementation (see Table I).

Table I Specific vs. pathway-related prevention and rehabilitation measures

<i>Specific P&R measures</i>	<i>v.s.</i>	<i>Pathway-related P&R</i>
Independent elements	<>	Context / process / user-related
Predominant professional (medical) paradigms	<>	Multi-dimensional / IMultidisciplinary
Short-term effect oriented	<>	Long-term effect oriented
Evaluation possible / evidence-based	<>	Evaluation / evidence-base difficult
Long-standing and widely accepted measures	<>	(Pilot) projects

7.2 Towards ‘preventive and rehabilitative LTC pathways’ in Europe

Patient pathways have become popular tools for planning, standardising and analysing transition processes across health and social care services. In this project LTC pathway examples from all partner countries have been used and analysed to achieve a better understanding of current LTC provision across Europe as well as of inherent gaps, links and regulations. This aims to make visible the differences in EU developments and endeavours towards seamless, integrated and consequently *preventive* and *rehabilitative* LTC provision.

Some partners in this project, such as Slovenia and Slovakia, had initial difficulties tracing LTC as an existing and consistent concept of service provision in their countries at all. Against this background P&R within LTC was an even less tangible topic. Other countries, such as Austria, Germany and Greece are currently at a stage of development where there are stated intentions to overcome gaps between the social and the health sector and between different organisational structures by mainly upgrading or implementing intermediate structures, such as day-care centres, short-term care or specialised acute care facilities (see below, par. 7.4). Countries such as Denmark, the Netherlands and the UK, while sometimes focused on organisational, top-down and vertical perspectives, are also oriented towards a needs-based, person-centred, horizontal provision of continuous services. In the Netherlands, for instance, patient pathways have turned into work standards in the provision of everyday health and care practice at all different levels. In the UK ‘intermediate care’ does not refer to specific organisational structures but rather to a developing concept amongst professionals and policy-makers, covering a network of P&R services. In Denmark beyond realising the plan to abolish conventional nursing homes, they have substituted them with multidisciplinary coordination and community care services oriented to the individual

needs of clients. Although such trans-EU varieties exist due to different cultural, political or social pre-conditions of countries, there is a common EU endeavour, albeit from a more organisational or a more pathway/user related perspective, to bridge gaps and to improve coordination between services in order to increase efficiency as well as to *prevent* people from unpromising and sometimes deteriorating LTC processes.

7.3 Multidisciplinary work as an imperative

The recognition that consistent and well coordinated care pathways are more economically efficient and have significant P&R potential for users has fostered network approaches and multidisciplinary work at academic as well as at the practical level. Work in multidisciplinary teams around assessments as well as outreach and mobile services which act between settings (e.g. hospital/private) and sectors (e.g. health/care) are some examples of approaches across Europe (see 7.5).

Physio- and occupational therapists, partly also speech therapists (especially after stroke) play an important role in P&R for older people. In some countries, e.g. UK and Denmark, they work in integrated primary health care teams or in mental health care teams for older people. In other countries, such as Germany and Austria, they work mainly in separate practices and have to be involved in individual care pathways.

7.4 Recurring difficulties in establishing P&R pathways

Despite a series of innovative projects and existing good practice examples across Europe (see below, 7.5), the sustainable implementation of preventive and rehabilitative LTC pathways is confronted with recurring difficulties in most countries. For example:

- Establishing P&R interventions that take all or at least most settings into account;
- Providing sufficient evidence and recognition at policy level for the preventive/rehabilitative potential of whole systems approaches and long-term effect-oriented measures;
- Overcoming outdated models of paternalistic and disempowering social care;
- Getting rid of fragmented financial flows and adverse economic/legislative (dis-)incentives which act disruptive for a seamless and 'preventive' way of service provision.

7.5 EU examples of multidisciplinary 'good practice' across patient pathways

This section points to some EU examples of multidisciplinary or inter-organisational ways of working, which contribute to the P&R potential of LTC provision. The sequence of the following good practice models in different countries reflects the above (cf. 7.2) variety of trans-EU approaches and moves accordingly from examples with a more organisational (vertical) approach towards more horizontal and pathway-oriented interventions.

The first two examples of P&R good practice – one from Austria and one from Germany – have been selected as their scope of influence is mainly focused on the organisational/institutional level. In both cases existing structures in a defined setting (acute care/residential care) are 'upgraded' by means of

more comprehensive and multidisciplinary services in order to improve the quality of existing services and to bridge gaps to neighbouring settings and structures:

In Austria clinical **Facilities for Geriatric Acute Care and Remobilisation** (see Annex, example 8) have been introduced gradually since the year 1999 when a plan for nationwide implementation and quality standards for such units was drawn up. These facilities are specifically directed towards older people suffering from multiple chronic illnesses. Based on a multidisciplinary assessment a comprehensive treatment regime and an individual plan for remobilisation and reintegration are offered to the patient.

In Germany a **Rehabilitative short-term care unit** (see Annex, example 9) located in a care home is currently being pilot tested in a project by Caritas Bremen. As a result of the last health care reform in Germany this project intends to provide an integrated care concept based on contracts with two health insurance funds. A key feature of the project is intensive rehabilitative care provision combined with the organisational support of a bridging person and the aim to enable people to live at home again.

Despite a more comprehensive approach, both of the mentioned examples of good practice are still closely allied with one specific setting/organisation. To implement and provide evidence for measures which improve coordination and transition processes across the *whole* system and thereby allow for more preventive/rehabilitative patient pathways appears to be the most challenging task. The German national report highlights this difficulty:

“The most complex good practice level regards interventions that are targeted to link several or all (...) settings and thereby create new care networks in the interest of better pathways for patients through the ‘whole system’. Ideally these initiatives are oriented locally and act as community-based projects involving already existing care organisations and persons.” (Dieterich/Kümpers, 2009)

An example of such a tangible ‘local initiative’ in Germany, namely **Support centres for older people and family carers in Berlin-Tempelhof** (see Annex, example 10) aims to achieve a more inclusive preventive/rehabilitative approach.

In consideration of a good practice example from Denmark we find that in this country strong emphasis is already given to the nationwide construction of *preventive and rehabilitative networks*, which over-arch different settings and sectors and put a focus on the continuity of service delivery at the clients’ level. The short description of P&R services at new **Health Centres in Denmark** in the Danish national report provides a lively example of this development (see Annex, example 11).

In addition, in the UK, **preventive and rehabilitative ‘intermediate care services’** are health policy concepts and practical services which act along clients’ pathways (horizontal) rather than at a single institutional (vertical) level (see Annex, example 7).

8 Promoting self-determination and self-care in Europe

In this section, the principles and promotion of self-determination and self-care will be examined in the context of P&R within LTC and from the empirical basis of the seven countries participating in WP3.

Without doubt, the principles of self-determination belong to the central ethical framings of international policies for health and social care. The WHO already claims in the Alma-Ata declaration of 1978 that health care should be organised “at every stage (...) in the spirit of self-reliance and self-determination”. Self-Care is defined by WHO (1983) as:

“... activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals”.

Regarding LTC, the CARMEN EU Project (Care and Management of Services for Older People in Europe Network), supported by the European Commission from 2001 to 2004 and managed by the European Health Management Association (EHMA) has put the issue centrally on their research agenda:

“Future research ... should contribute to the following objectives: to optimise opportunities for the self-determination, integration and participation of older people in society, by maintaining independent living in a secure environment and by exerting significant choice over their own lives (including decisions on care delivery).” (Nies, 2004: 7)

The concepts of self-determination and self-care represent values that recently seem to have gained importance in regulating social welfare and social policies within EU countries. This is visible in principles and policies of ‘enabling’ governments. Tendencies towards greater individualisation and self-determination have also become more pronounced regarding health and social care. Such claims are found at policy level as well as at the consumers’ level, e.g. brought forward by self-help groups.

In the field of LTC current tendencies to stimulate self-determination can be observed in practice-oriented concepts such as ‘activating care’ or decision making at the end of life (advance directives/living wills), but also in terms of regulation/steering policies as new management strategies which increasingly focus upon individual responsibility.

The ideal of self-determination can be analysed in the context of LTC as an ambivalent goal:

On the one hand it allows care policies which focus on the resources and abilities of older people with care needs and stimulates professionals’ support for their clients’ functioning in daily life. Their freedom to live autonomously may be limited in practice by restrictions in available options, primarily due to physical and mental health problems, financial constraints, environmental barriers, limited support services and/or a skill deficit of professionals in their ability to empower patients, and the necessity of adapting their lives to fit in with other family members. Nevertheless, the ability to compromise and prioritise regarding the importance of different elements to an individual’s well-being and quality of life, has

been identified as a major factor contributing to ‘successful ageing’ (Kelley-Gillespie, 2009). Both informal and formal caregivers can help to maintain independence in older people by supporting them in making often difficult decisions about their own care. In this sense, the concept of self-determination goes along with enhancing the control of older people about their lives. Supported self-determination thus can have an activating and therefore preventive impact; moreover, the concept comes as an anti-thesis to traditional paternalism which is still wide-spread in services for older people.

On the other hand, the current ideal of the self-determined, responsible and autonomous older person who freely chooses his/her allies (family, friends, paid professionals) to help him develop a person-centred plan of services and support, also carries with it some problems. It can be criticised for a potential ‘middle-class bias’, as arguably it is better educated, higher income, higher status subgroups, who are also predominantly those in better health, who will be those better equipped to conform to the ideal and plan their services appropriately. It also may lead to a “shaming attitude” regarding patient’s responsibilities when they do not succeed in this regard. This indicates that such inequalities must be considered carefully when developing policies around self-determination.

As Europe is a mosaic of different countries, economies, cultures and people, the ideal of self-determination and self-care regarding P&R within LTC is handled and approached differently, depending on each country’s culture, health system and kinds of services available, which in turn depend on the governance and financing systems of each country and vice versa.

The following paragraphs highlight some central dimensions of LTC organisation which influence the attitudes towards and promotion of self-determination in the countries.

8.1 Individual case-management as support for self-determination

In some European countries (UK, NL, DK) a personalised, tailor-made approach, through independent needs assessments and preventive visits by multidisciplinary assessment teams or nurses, aims to provide the older person the freedom to develop a person-centred plan of services. Allies, such as family members, friends, or professionals, and training opportunities (Expert patient programme, UK) may help older people in decision-making, ensuring that their autonomy and dignity are respected as far as possible.

In other countries (AT, DE, EL, SI) more controlled, rigid programmes of care are provided as a nurse or a medical board or a GP decides if and which co-financed or free in-kind services will be provided. In these countries case management is less often provided and there are more problems relating to fragmented care, competitive services, unclear patient pathways, or gaps in care. The individual responsibility for one’s own health, induced by fragmented service provision and co-payments for care services, means that service users in these countries already act as ‘consumers’ of care services, rather than as passive recipients of formal services. Neoliberal ideas assume that a direct financial and practical impact of bad health on individual and family circumstances leads to increased preventive and rehabilitative efforts by older people and their families. However, evidence for that hypothesis is limited to very specific situations. In general, health behaviour is dependent on socio-economic status, especially education. So overall, the need for individual self-care functions as a compensation modus within care systems with coordination deficits – as far as users are capable of filling coordination gaps. But the call for the self-regulating individual can also be understood as a shift of responsibility from the state or society, or from

professional care to the individual clients and service users – therefore it can be viewed as an ingredient of a neoliberal deregulation of social welfare.

8.2 Personal budget control

The discussion of self-determination engages with current innovative financing models in LTC. The question of which authority should control the individually granted funds for purchasing care and support is answered differently among the countries. The way in which the delivery of services is planned shapes the degree of freedom and autonomy for the consumer to have control over the budgeted funds. However, policy and culture play also a crucial role here.

In the UK and the Netherlands, the control of a personal budget is allocated to the older person in the form of direct payments, or as cash payments instead of care provision. However, in Denmark, in a more state-protective policy, the consumer is generally not involved on a daily basis with economic aspects of care provision, as citizens pay for these services by way of high taxes. In other countries (AT, EL, DE) care provision is defined by levels of assessed needs and levels of (co-financed) support. The term ‘personal budget’ is understood as the degree of care and/or the level of social protection to which the older person is entitled. In Slovenia, public coverage and personal budgeted funds have relevance only in cases where older people or their families fail to cover the expenses themselves. This illustrates that organisational mechanisms within the health system do in fact structure (regulate) the amount, purpose and direction of the expense (i.e., where the money will be spent).

The responsibility and accountability of living with one’s own choices may be seen from different angles, depending on the opportunities and choices one may have in planning, coordinating, and receiving P&R services within LTC. Some countries (NL, UK) strive for a demand driven instead of a supply driven system of services, and offer opportunities for direct payments or cash payments, personal planning or even a contract of service between the consumer and the different services. The responsibility and accountability may not be the same as in countries (AT, EL, SI) where the take-up of services depends on local availability, personal information, costs for out-of-pocket contributions and lack of financial means to co-pay these services. It should be highlighted that in these countries exhaustive co-payments may lead to the irreversible pathway of residential care, as personal funds and convertible property may be used for paying public or private services. This makes a return to non-residential living arrangements impossible. Conversely, in Denmark older people are fully dependent on the assessment by a local authority case manager in collaboration with therapists and home nurses.

8.3 Access to services: issues of financing and choice

There is a noticeable range between the seven WP3 countries, in terms of appropriate formal or informal support that will help the older people in LTC to achieve quality of life. There is also variation in the nature of funding of the support, i.e. either by provision in kind or via monetary payments (state benefits or out-of-pocket payments), which the service user has the choice of how and when to use. In Denmark almost all health provision is paid by way of the tax system and covers every need for P&R within LTC, although there is some degree of choice for the consumer between public or private providers; but the state (regions) also ensures the quantity and standards of quality of the provision. In the Netherlands and the UK a mixture of community-based services, such as meals on wheels, assistive technology, personalised physical/leisure activities, in combination with cash care allowances and benefits aim to ensure

maximum support for older people with LTC needs. In other countries, a non-means-tested (AT) or means-tested (DE, EL, SI) allowance is provided after a needs assessment, aiming to enable the individual to purchase flexible professional or informal services at home, which acts as a preventive measure against institutionalisation and dependency. In-kind services that are provided after a needs assessment by a nurse, a GP, or a medical board underlie quite different regulations about co-payment.

The current trend to focus on ideals of self-determination and self-care reflects a change of attitude by policy-makers, professionals and users, emphasising a greater responsibility of the individual and family, and the provision of funds instead of services.

The position of the consumer is thought to be strengthened by free counselling and advocacy, in order to promote informed consumer choice. If this kind of policy is not guided by sustained responsibility and accountability of public services, in the end users are made responsible, e.g. for not adequately processing a budget, when in fact the budget might not be sufficient, or appropriate services are not accessible to them. It may evoke concerns about leaving alone vulnerable groups and 'blaming the individual'. Other constraints such as local (un)availability of appropriate services, lack of personal information and lack of financial means to (co-)pay services, as well as inappropriate support for those with mental health needs, may also act as barriers to a person's free choice. These matters differ, not only between European countries, but also between regions within the countries.

In conclusion, at the policy level a trend towards increasing and supporting self-care and self-determination is noticeable. Cash allowances or in-kind services are provided in different degrees within the EU countries. Debates are ongoing as to whether the transfer of authority from the state to the individual may reflect a political effort to camouflage the tendency of shrinking public responsibility and accountability, leaving the individual to cover his/her own care needs including P&R within LTC, as may be claimed is done in Austria, Greece, Germany and Slovenia.

From the perspective of equal access to care, innovative approaches of empowerment of disadvantaged subgroups and community-based participative projects might offer solutions to enhance the individuals' autonomy and independence but without delegating responsibility for care organisation away from health and social care systems. To illustrate this, three good practice examples will be presented in the Annex: 12-Integrated health care for older people (DK); 13-The national system of personal budgets programme from England (UK); and 14-Homecare re-ablement services which operate within this system (UK).

9 Special topic: Dementia

From a ‘Weberian’ perspective Dementia can be seen as an ‘ideal type’ of P&R implementation in the LTC system as it illustrates and triggers all the issues previously discussed.

Dementia is a major topic in LTC. Firstly, in ageing societies the prevalence of dementia is rising, in both absolute and relative terms. In residential care it will be the main task in the coming decades. Coupled with this, dementia care poses specific challenges for professionals, care workers and informal carers, therefore requiring special efforts regarding qualification, training, knowledge transfer and support structures. In responding to this double challenge, some activities at European level focus on how to prepare health and social care systems. For example, the Alzheimer Europe project “European collaboration on Dementia – EuroCoDe”, financially supported by the European Commission under its programme for community action in the field of public health (2003-2008), compiled knowledge about dementia care among others regarding social support, psychosocial interventions and risk factors and prevention (see especially Alzheimer Europe, 2008). The Council of the European Union decided on ‘Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease’ (2916th Employment, Social Policy, Health and Consumer Affairs Council meeting, Brussels, 16 Dec 2008).

Regarding LTC, the Council Conclusions did not relate explicitly to P&R; however, they made a point about integrating health and social care, and about promoting secure and friendly environments and social inclusion for dementia patients and carers, thereby raising issues which were identified in this report as having preventative and rehabilitative effects. In the ‘Dementia in Europe Yearbook 2008’ by Alzheimer Europe strategies for primary prevention² to delay onset of dementia are particularly featured. These do not relate specifically to P&R within LTC. The recommendations for social support for dementia patients and carers, however, list multiple interventions suitable to promote patients’ and carers’ health and well-being including information, advocacy, psychosocial counselling, flexible respite care, which taken together support patients and carers and their interactions in order to prevent precarious care situations and avoidable deterioration in quality of life.

They are also directed to empowerment and self-determination – as dementia especially endangers these aspects of quality of life. Furthermore, the recommendations underline that in this field services also have to be orientated to cultural and social diversity. Within the “General Framework for Care and Support” (Alzheimer Europe, 2008: 29ff) some topics are highlighted with respect to P&R in LTC for dementia patients and their carers. First, as an element of secondary prevention, the importance of early diagnosis is referred to as opening access to subsequent services and treatment (including medication) to “use all possible means to maintain both the quality of life and functional capacity of people with dementia” (Alzheimer Europe, 2008: 33). Furthermore, a general rehabilitative approach shaping the complete care pathway of people with dementia is postulated, referring to the rationale of the ICF³. As dementia affects all aspects of a person’s capacity, care pathways have to be shaped to use all opportunities to recognise, support and (re)train lost (as far as possible) and remaining skills and functional capacity

² Strategies of primary prevention as described here focus especially on cardiovascular risk factors partly linked to behavioural topics such as exercise, nutrition and smoking; and on psychosocial risk factors such as living alone and without social participation (Alzheimer Europe, 2008: 123 ff).

³ WHO (2001) International Classification of Functioning, Disability and Health (ICF).

(Alzheimer Europe, 2008: 31). So in dementia care, the main elements reappear which have been already identified with respect to general requirements for P&R within LTC.

As Good Practice examples Alzheimer Cafés (The Netherlands) and the Daisy programme of Denmark are presented in the Annex.

10 Summarising conclusions

This report aimed to explore the state of the art and the current development of P&R within LTC. It has been confirmed that this topic is in an initial state of development – at research, policy and practice levels – and much development is required. However, the national reports also showed a great range of diverse health and social care systems embedded in different cultural and political contexts and developments trying to build a wide range of conditions for P&R implementation. A number of topics at policy and practice level emerged as important for most, if not all, of the participating countries as in general, P&R within LTC require complementary perspectives.

Apart from explicit preventive or rehabilitative interventions, topics of professional quality and care integration are seen as having substantial preventive and rehabilitative effects. Conversely, poor quality, gaps and overlaps in care pathways render poor health outcomes. Furthermore, we need to include the general societal environment and its importance for P&R for older people with LTC needs. Elements such as social support or disability-friendly space can act either to promote or impede preventive or rehabilitative processes.

The quick-scan of EU sources confirmed the lack of research into P&R within LTC at EU level. It also highlighted the short-term nature of initiatives and how P&R as concepts lend themselves to fragmentary or missing evidence, where outcomes are difficult to disaggregate and analyse.

Comprehensive P&R within LTC are given inadequate focus in all countries, despite aspirational statements to the contrary in some countries. The provision that can be evidenced is largely medically-centred and fragmentary. Health promotion and prevention are still seen as most usefully targeted at those of working age, while being chronically ill and old is often still given less focus. These reasons contribute in all seven countries to the lack of political commitment to invest the necessary resources in adequate P&R for older people in need of LTC.

Regarding in particular prevention and rehabilitation, LTC developments are linked to societal discourses regarding changing roles in families and societies, with extensive debates about the attribution of responsibilities for care and to other services to the individual on the one side and on the other to society / the state.

One of our main conclusion is that governments' efforts to promote the integration of P&R in LTC need to handle steering instruments carefully. Market instruments can counteract collaborative processes needed to shape comprehensive care pathways. Therefore competitive instruments need to be oriented towards enabling or at least not undermining the cooperation needed for integrated care pathways. The form of local governance also impacts significantly on opportunities for integrated LTC pathways and shapes the opportunity for users to participate in these matters.

Key points raised around embedding P&R within LTC at a national, systemic level are that the need for investment in P&R is becoming more widely acknowledged amongst EU countries and that steps towards embedding P&R within LTC can be recognised in all countries in initiatives such as: national awareness raising events and multidisciplinary preventive and rehabilitative services in community settings. However, initiatives in P&R mostly tend to be small-scale, time-limited pilot projects. All national reports described that there was some “distance to travel” in terms of national policy, culture, financial

incentives and organisation of services before LTC systems would take on a truly preventive and rehabilitative nature. There is also often a lack of research and evidence of benefits needed to roll out interventions on a national level.

As barriers to the sustainable implementation of preventive and rehabilitative LTC pathways, the following recurring difficulties were identified: it is a complex and difficult process to provide sufficient evidence and recognition at policy level for the preventive/rehabilitative potential of whole-systems approaches and long-term effect-oriented measures, to overcome outdated models of paternalistic and disempowering social care, and to eliminate fragmented financial flows and adverse economic/legislative (dis-)incentives which are disruptive to a seamless and 'preventive' way of service provision.

Self-determination, and responsibility and accountability for living with one's own choices may be seen from different angles, depending on the real opportunities and choices one may have in planning, coordinating and receiving preventive and rehabilitative LTC services. At the policy level a trend towards increasing and supporting self-care and self-determination is noticeable. Cash allowances or in-kind services are provided to different degrees across the EU countries. Debates are ongoing as to whether the transfer of authority from the state to the individual may reflect a political effort to camouflage the tendency of shrinking public responsibility and accountability, leaving the individual to cover his own care needs, including P&R within LTC.

Dementia represents a major challenge to P&R within LTC. All kinds of interventions to maintain self care capacities and quality of life have to be further developed. Especially with dementia, traditional ideas have to be challenged to open and adjust P&R services to the needs of patients and carers.

The coming task for WP3 in the second cyclical phase is to identify/propose strategies for overcoming the documented barriers in this report and, moreover, to use former and suggest new successful and active ways to a better P&R care pathway construction for older chronically ill people in need of LTC.

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12 ANNEX – Description of EU P&R practice examples

1. Germany: Fragmentation of services weakens the efficiency of a comparably well equipped LTC system (Report section 5)

The German case shows how strong competitive incentives affect LTC delivery in a comparably well financed and accessible, but rather fragmented care system with weak local steering capacities. Although Germany invests a comparably high level of its GDP in health and social care, the LTC system's efficiency is weakened by a lack of coordination and integration in combination with a strong competitive environment. Also, its capacity for innovation and integration is challenged by the implementation of a rigid system of narrowly calculated task elements.

In Germany, community and institutional LTC are delivered by a multiplicity of competing private or non-profit care services. They act (primarily) as private enterprises. There is almost no regulation regarding regional planning of service development by local authorities or bottom-up coordination of catchment areas, so that local coordination is difficult in a competitive environment. This is because the enactment of the LTC insurance prioritised private provision and weakened existing regionalised social care structures provided by great German charity organisations. In the following period, the developing structure of mainly small scale providers as well as the scarcity of funding caused an underdevelopment of specialisation and high-quality efforts (SVR, 2009), leading to a bias towards traditional care and a neglect of P&R potentials.

For institutional care this means that local authorities have almost no influence over whether and where care homes are built; in some cases they do not even know about such building projects. Against this background, intermediate care services in particular are as yet underdeveloped. There are some services in the realm of respite/intermediate care which are increasingly funded by the LTC insurance. Their purpose is, however, often badly communicated and they are underused, while approaches such as crisis intervention or intermediate care services to support hospital discharge or to prevent inadequate hospital admissions – all of which would bear preventive and rehabilitative potentials – are very rare.

Similarly, medical services are increasingly provided under a competitive regime. An explicit goal of recent health care reforms was the decentralisation of service planning. New selective contracting options allowed local insurance companies to implement innovative 'integrated care' programmes for their insured clients, where only selected providers (physicians, hospitals etc) are contracted. Given that these insurance companies only offer these programmes to their insured subset of the local population – the programmes serve as distinction criterion between the companies to compete for clients – new fragmentation effects can be observed. Local service providers have to adjust patient care in each particular case and choose different care pathways according to a complex variety of 'integrated care programmes'.

Innovative approaches to strengthen local governance are just beginning to react to these coordination problems:

- Currently, community-based LTC support centres for case management, advice and coordination of LTC services ('Pflegetützpunkte') are being implemented (BMG: LTC Further Development Act (2008)). Support by a case manager has recently become a statutory right (central point of access, counselling and advice, coordination of the entire spectrum of care, (LTC Further Development Act (2008)). Community-based round tables, inviting local geriatric-gerontopsychiatric and social care providers to develop comprehensive regional care networks, are pilot-tested. Under-supply of medical services for inhabitants of care homes is to be addressed by new legal options for providers to contract physicians (either cooperation or employment).

2. The Netherlands: Fragmentation of services overcome by strong local steering capacity (Report section 5)

The Dutch case presents an example of how fragmentation problems can be overcome by strengthening local steering capacities within a co-governance of local authorities and insurance agencies.

Basically LTC is paid by the National LTC Insurance (AWBZ). Eligibility of an individual patient's care is assessed and decided by the National Care Need Assessment Organisation (CIZ). Allocation of care to individual patients is done by Care Offices (Zorgkantoren) on the basis of eligibility established by CIZ. These offices (32 in total) operate on a regional level. They represent the AWBZ and can perform their task of allocating care by purchasing care from providers. The providers have to deal with their regional care office. This is also the case with patients, even if they have different health care insurances (to which AWBZ insurance is automatically connected). The interdependencies between purchasing, funding and provision of LTC are thus regulated in a non-fragmented way.

Additionally, the regional care office is a key actor of unifying care provision, thanks to its power that follows its purchasing potential. However, two other features add to that. One is that the care office has a duty to consult with local providers, patients' organisations and local authorities about developments in demand and supply of care. The office can thus diminish fragmentation of care and promote new – more integrated – forms of care. The other feature is that the administration of such a regional office is commissioned by the Ministry of Health, Welfare and Sports to the largest health care insurance in the region. The advantage of this delegation is enhanced continuity of care services that are partially paid by AWBZ and partially by the health insurance, in particular when it comes to integrated types of care: cancer care, diabetes care, stroke care, dementia care. In fact, care offices have explicitly accepted the extension and improvement of integrated care as one of their genuine tasks.

3. United Kingdom: English World Class Commissioning – separating planning and provision (Section 5)

In England, Primary Care Trusts (PCTs) (local health bodies) have historically been responsible for providing and/or purchasing health services (primary, community and hospital) on behalf of their local populations. Often, they provided many of these community services themselves and funded local GP practices to provide primary care and local hospitals to provide acute care. More recently, however, PCTs have been recast as *commissioning-led organisations*. While they may continue to provide a range of community services, their main tasks are to assess the needs of the local population and to secure relevant services from a more mixed economy of public, private and/or voluntary providers. Where they still provide some of their own services there must now be a clear organisational separation between their commissioning and provision functions and a clear commissioning plan/process in place. This trend

towards lead commissioning organisations is in its early phases and its specific effects on LTC in P&R remain to be seen.

To support this change in emphasis, the government has developed a national 'World Class Commissioning' agenda, with each PCT undergoing an annual assurance process in order to demonstrate its progress against a series of organisational competences. Technical and development support for improving commissioning systems is also available via a national list of preferred providers, and many regions are exploring formal opportunities for continuing professional development. In many ways, this agenda has been prompted by the recognition that previous reforms tended to strengthen health service providers and that health care commissioning has often been very under-developed as a result. There has also been a series of rapid organisational restructures of commissioning organisations over the last twenty years, which has tended to create significant instability. One potential barrier to integration is that the WCC agenda has been introduced for the NHS but not for social care. The WCC agenda covers LTC but is not specific to LTC services.

While 'world class commissioning' is a significant attempt to redress this imbalance, concerns remain about the level of clinical engagement, transaction costs and the availability of the necessary skills at local level. In the longer-term, there are also questions about the extent to which a commissioning-led approach may be the right way forward for a 'product' as complex and difficult to specify and monitor as health and social care (see Smith et al, 2004; 2006 for a UK review; see Ham, 2008 for an international review of the evidence).

4. Denmark: Implementation of competitive instruments (Report section 5)

In Denmark, strong public services already have a long tradition within the care system. A nationwide local government reform came into force in 2007. Since then, P&R services in Denmark have been undergoing a major change process in terms of organisation, management and delivery. Regional and local authorities now have overall responsibility for providing and commissioning comprehensive care (including P&R) and thereby can exert strong local/regional steering capacity. The aim of the reform was to provide a better basis for ensuring cohesive patient treatment and care, and simplified access to prevention, examination, treatment and care. Local authorities became the gateway to the public sector and thereby took on a considerably stronger role in health and social care. Five new regions became responsible for the health sector, i.e. hospitals, psychiatric treatment and the Danish Health Security. The regions provide a platform for planning and enhancing quality. Local authorities are at time of writing (2009) still in a phase of transition. They now play a more frontline role, as they have become responsible for all health promotion, prevention, training, care activities and rehabilitation not performed at hospitals. In the field of LTC, they are now responsible for home nursing offered to citizens free of charge, and social services to older people as there are personal or practical assistance, transport to rehabilitation appointments, meals-on-wheels, etc. In particular with regard to retraining and rehabilitation, one of the overt reasons for assigning sole responsibility to local authorities was to reduce the occurrence of 'grey zones' when patients move from the secondary to the primary sector (Christensen/Hansen, 2006: 43).

The 2007 local government reform was also intended to encourage collaboration and multidisciplinary working between different stakeholders, thereby ensuring more efficient use of resources, and greater focus on prevention at the local level. Additionally, it was intended to contribute to greater coherence between the administrative levels.

Within this system, although services are predominantly delivered by public providers, competitive instruments are also used to enhance efficiency and quality of care provision. Firstly, rules on free choice have led to transparency in the use of resources. Secondly, local LTC is exposed to competition from private providers, with the intention of contributing to more efficient task solving. Thirdly, specific incentives were set to stimulate the development of innovative care concepts. A specific target of the 2006-8 LTC policy was, for example, better and more flexible home help. Local authorities could apply to a central fund to carry out projects under three themes: Increased activity – more time for home helpers at home with individual older persons; Digitalisation – to free up human resources so that home helpers can spend more time with older people, and to increase flexibility and continuity; More choice and flexibility – to improve quality and effectiveness of care.

It would be interesting to see what long-term effects this reform might have on the public service system.

5. Denmark: preventive home visits to over 75s (Report section 6)

While several countries have developed a system of preventive home visits for older people, all Danish local authorities have been required by law since 1998 to offer two annual preventive home visits to all citizens aged 75 years or older. The overarching aim is to help older people better to use their own resources in order to maintain their independence for as long as possible, as well as to facilitate the early detection of signs of illness, the provision of health promotion advice and signposting to relevant support services. The visits are usually carried out by district nurses, but an obligatory health check is not included and GPs are rarely directly involved. As an example, the Odense 'Walk and Talk' project seeks to combine preventive home visits with greater health promotion in order to increase physical activity, detect unmet support needs, encourage older people to join with others in walking groups and/or to set up their own and to enable older people to broaden their social networks. Thus, in spring-summer 2009, home visitors were trained as exercise consultants for older people. The home visit takes the form of a walk, where health and social issues are discussed along the way and signs of tiredness, dementia, etc are observed. Of 25 people offered a walk-and-talk, 10 said yes, of which 8 requested another walk-and-talk at the next visit. Qualitative evidence – feedback from participants – showed general satisfaction and funding has been sought to employ an exercise consultant and to broaden walk-and-talk to all sections of the local authority (Rosenlund/Mikkelsen, 2009). However, further evaluation is required to understand the potential impact of such an approach on future service use, including a more general need to ascertain the value of preventive home visits as a mainstream service, in terms of the extent of its impact on prevention among recipients, and in order to inform future development of the service.

6. Greece: Open Care/Protection Centres for Older People (KAPI) (Report section 6)

KAPIs are multidisciplinary centres (>1000 throughout Greece) which, from their outset in the early 1980s, offered locally provided, combined social and health programmes, with the aim of supporting older people to remain independent in community-based settings and avoiding the need for more intensive LTC, including family-provided care and admission to institutional forms of care. They typically consist of a social worker (who is the team leader and co-ordinator), a nurse or health visitor, a physiotherapist, an occupational therapist and a family assistant. The service aims to detect any unmet medical, social or mental health needs and to promote independence. The Help-at-Home services, which are usually associated closely with the local KAPIs, provide a range of essential services to support depend-

ent older people at home, focussing on those with limited financial means and no family help. However, recent studies have shown that their insecure funding has seriously undermined their capacity to function effectively. Nevertheless, with a planned policy for operation and adequate funding, the combined KAPI and Help-at-Home network could provide a model for the integrated provision described in a recent systematic review by Lionis et al (2009).

7. England: Intermediate care (Report sections 6 & 7)

From 2000, the English government pledged some £900 million (€1,021 million) to develop new intermediate care services (to prevent unnecessary hospital admissions, facilitate swift and timely hospital discharges and prevent premature admissions to permanent residential and nursing care). Although this can include a range of services (such as rapid response nursing, hospital at home, step-up and step-down care home places, supported discharge, and residential/day rehabilitation), the aim is to create a network of services which:

- are targeted at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute inpatient care, long-term residential care, or continuing NHS inpatient care,
- are provided on the basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery,
- have a planned outcome of maximising independence and typically enabling patients/users to resume living at home,
- are time-limited (normally less than six weeks and often as little as 1-2 weeks or less),
- involve multidisciplinary working, with a single assessment framework, single professional records and shared protocols.

Crucially, intermediate care should include intensive and active rehabilitation – to prevent older people upon leaving acute hospitals from being ‘warehoused’ in non-acute or residential settings and eventually needing permanent institutional support. This seems to be in contrast to some Slovenian non-acute hospitals for older people, with some national experts questioning the extent to which these provide active and fully structured rehabilitation.

Although intermediate care is a relatively new concept in England, the growing evidence base identifies a number of key themes (see, for example, Martin et al, 2007; Regen et al, 2008; Kaambwa et al, 2008; Godfrey et al, 2005; Green et al, 2005), including:

- conceptualising a working model of intermediate care. Overall, one of the defining aspects of intermediate care may be that it is a ‘bridging’ service – between locations (home/hospital), between individual states (illness to recovery or management of chronic illness) and between sectors (acute, primary, social care and housing),
- there is a need to move beyond ‘services’ alone when developing intermediate care to concentrate on the intermediate care ‘system’ (including issues such as eligibility criteria/referral processes, accessibility and workforce development),
- within intermediate care, provision has tended to concentrate on supported discharge (rehabilitation in residential settings), with fewer services addressing admission avoidance (preventative services in non-residential settings).

Based on evidence from randomised controlled trials, rehabilitative care in community hospital locations is associated with greater independence for older people than care in district general hospital settings.

Overall, however, the jury is still out as to whether intermediate care, although a welcome concept, will be sufficient to rebalance the current health and social care system for older people (with a danger that it becomes something of an 'add on' to existing services, rather than a lever for transforming the system as a whole).

8. Austria: Facilities for Geriatric Acute Care and Remobilisation (Report section 7)

Type, Scope

Implemented clinical structures with policy commitment and defined plans for nationwide expansion.

Background

Specific needs of geriatric patients with complex needs are not yet sufficiently met within acute health care structures in Austria. Therefore, in 1999 the decision to establish a nationwide network of Geriatric Acute Care and Remobilisation Units was taken. The Austrian Federal Institute for Health Care (ÖBIG) determined the framework conditions for the planned facilities in the Austrian Structural Plan for Health (ÖBIG, 2009).

Content and method

The Austrian Structural Plan for Health (ÖBIG, 2009) defines the official quality standards for Acute Geriatric Care and Remobilisation facilities. These criteria comprise minimum personnel requirement, adjustment of hospital infrastructure to the needs of older people (technology and room equipment, size), and the services required. The most recent revision of this plan was performed in 2006. As there is no professional specialisation in Geriatrics established in Austria to date, Geriatric Acute Care facilities are usually established under the lead of a specialist in Internal Medicine or Neurology. In general, services are directed towards older people who have complex chronic conditions, who are limited in their autonomy due to functional or mental health needs and, last but not least, towards those who are in need of rehabilitative and reintegrative measures (ÖGGG, 2008). A multidimensional treatment regime is offered to patients in primary (admission from the community) and secondary (transition within the health care system) Geriatric Acute Care and Remobilisation Units.

A core element and tool of all AG/R facilities is a standardised and comprehensive geriatric assessment. The geriatric assessment can be described as a multidimensional and multidisciplinary diagnostic process intended to determine a frail older person's medical, psychological and functional capabilities, resources and problems. A complete assessment allows for individual counselling of the patient and a thorough planning of treatment, rehabilitation, reintegration process and LTC measures.

Target group

Older patients admitted to (or transferred within) hospital with multiple and chronic health problems and in need of multidimensional treatment and care.

Results, evidence

The comprehensive geriatric assessment has been standardised and results are used for systematic benchmarking of Geriatric Acute Care since 2008. Initiated by the Austrian Society for Geriatrics and Gerontology, currently AG/R units in four Austrian provinces (K, OÖ, St, W) are fully participating in the related benchmarking process guided and evaluated by “Joanneum Research” in Graz (Styria).

Current state, Contact

So far approximately 40 Geriatric Acute Care and Remobilisation units have been established in six of the nine Austrian provinces. By the year 2010 there will be around 3,700 beds dedicated to AG/R integrated into existing hospitals in 61 locations (ÖBIG, 2009).

<http://www.geriatrie-online.at>

9. Germany: Rehabilitative short term care (Report section 7)

Type, scope

Caritas Bremen is a short term respite care unit with 15 places in a northern German city with about 500,000 inhabitants. The rehabilitative approach of the programme aims to support people to move back home, with the help of a bridging-person (“Pflegeüberleitungsperson”).

Background / aims

The project is one of the few initiatives since the last health care reform to pilot test new contracting options of integrated care for the target group of frail older people. The main innovation is the provision of a defined pathway for patients. A problematic side-effect generated by this vertical integration might be stakeholders’ interest to maintain patients within the reach of their own organisation and to restrict their choice thereby (new barriers at horizontal level).

Content and method

The care unit is located in a care home, close to the department of physiotherapy, logotherapy and ergotherapy. Following the programme, home care is available for up to 7 days after discharge.

Target groups

An innovative integrated care contract with two health insurance funds provides extended rehabilitative training to mobilise older people, e.g. after an acute hospital admission to regain autonomy and better cope with disabilities. The programme is aimed exclusively at older people insured by the involved insurers, with care needs exceeding those met by home care and part time care (day care) services.

Results, evidence

Quality management is in place, though not published. Evidence not published.

Current state, Contact

Ongoing. Sustainability of the project might depend on economic success of integrated care contract for the insurance funds involved. <http://www.caritas-bremen.de/51408.html>

10. Germany: Support centres for older people and family carers in Berlin-Tempelhof (Report section 7)

Type, scope

These local community-oriented initiatives were initiated in 1999 by the federal government and the federal association of social welfare providers League of the Head Associations of Voluntary (= Non-Statutory) Welfare Work) as a reaction to demographic change and increasing demands for advice on issues concerning LTC.

Background and aims

The concept involves a combination of counselling and case management services with the development of a care network in an inner city area. Employed social workers are supported by volunteers.

Content and method

The centres are dedicated to helping older people with care needs to stay at home as long as they wish (supporting autonomy), to facilitate return home after a hospital admission and to provide systematic information about regional service options for home care and rehabilitation. In addition, the centres are assigned to initiate and build up a local network between existing LTC organisations.

Target groups

The services are available free of charge to all older people and their relatives in the respective region. Special focus is placed on intervening in critical care situations (crisis in home care arrangement, acute hospital admission), to prevent avoidable referrals to a care home.

Results, evidence

The centres are mostly well established in their regions and in many cases have successfully facilitated better cooperation between care organisations. However, evidence in terms of patients' outcomes is largely unmeasured/unmeasurable, since the interventions are complex and financial means for evaluations are scarce.

Current state, Contact

Ongoing. The centres have been an important pilot project for the recommendation of the LTC Further Development Act (2008) to build up community-based LTC support centres for case management, advice and coordination of regional LTC services.

<http://www.koordinierungsstellen-rundumsalter.de/>

11. Health Centres in Denmark (Report section 7)

In line with the new national drive for improved P&R services in Denmark, since 2006 the majority of local authorities have established 'health centres'. The general concept is to set up an organisational unit that offers patients who have been referred by their GPs targeted health promotional, preventative and rehabilitative support, training, guidance and/or treatment, co-ordinated and delivered by a multidisciplinary team. Within this umbrella concept, local authorities are free to create their own centre model,

and consequently centres vary greatly in terms of target groups, aims and range of services. Some are general centres for all citizens, some focus on rehabilitation and re-training after hospital discharge, while others have health promotion and prevention as their aim, or are targeted at those with chronic illnesses, including older people.

All health centres have in common the need for strong partnership and joint working between GPs, hospitals, patient associations and training and exercise providers. Early evidence from evaluation (Hansen/Jørgensen, 2008) indicates that GPs have not referred as many patients as expected, which is thought to be due to lack of knowledge about the centres, lack of continuity in the services offered by the centres or lack of routine in the referral process. In some local authorities the communication and joint working between the practice sector and the local authority, in relation to patient education and rehabilitation, has been seen to have improved (Campbell/Wagner, 2009).

12. Denmark: Integrated health care for older people (Report section 8)

The background to any study of LTC for older people in Denmark is the major change in housing and care for older people that began in the 1980s. The Skaevinge Project (Wagner, 1997) fundamentally and radically shifted Denmark's entire approach to LTC, and the principles have since been adopted in countries as culturally varied as Japan and the US. At the centre was the dismissal of the concept of traditional nursing homes, where care and accommodation were provided as a package. With the separation of housing and care functions a raft of changes were introduced: rooms were converted into homes, older people retained their individuality and the notion of self-care became central, 24 hour care by inter-disciplinary teams was adopted and crucially, instead of receiving pocket-money, older people could now keep their pensions and make decisions about the kind of care they preferred. All developments since then have been based on these earlier self-care initiatives.

In the Skaevinge local authority a three year project (1984-87) mobilised all its health resources for the improvement of the health of its residents. The implementation of an action research programme not only managed to reorganise the structure of the health services, but at least equally importantly, it achieved an alteration in the perception of people's needs and led the way to a national prevention-orientated care policy for older people.

In its original aims, the Skaevinge Project included equal access for all residents, focusing on prevention by supporting the individual to maintain and strengthen his/her own health status and quality of life. By using the concept of prevention instead of treatment and care, both with health providers as well as with older people, significant results continued to be achieved even ten years after the initiation of the programme.

A mixed methods approach was implemented to investigate both quantitative and qualitative data. Demographic and social status were found to be similar after ten years of implementation of the project, however subjectively-assessed health status and quality of life were improved. Although the overall use of health services was almost the same, there was a significant reduction in the number of home visits by GPs and in the number of consultations by telephone. The marked positive trend of the activities of daily living, although small, enhanced self-determination and self-care for people that could accept this change. The societal analysis of the project showed that the average hospital bed occupancy declined by 6% and overall health expenditures were decreased, despite an increase of the older age group.

In conclusion, the Skaevinge project is a good practice example having succeeded from both the staff and the policy-makers' perspectives, and being rolled out on a national basis. But most importantly it succeeded from the older people's perspective, giving them the opportunity for self determination and the competence for self-care.

13. United Kingdom: A national system of personal budgets (Report section 8)

In England the disabled people's movement for greater civil rights directly contributed to The Community Care (Direct Payments) Act 1996, which came into force on 1 April 1997. This Act opened the way to social services departments to make cash payments to adult (to age 65) service users, for community care services they have been assessed as needing. The aim was to give users a greater choice in their care, in lieu of direct service provision (Glasby et al, 2009). Despite the initial slow progress, the number of direct payments is continually increasing and the original Act has been extended to include older people, younger people aged over 16, carers, the parents of disabled children. Direct payments are also used as a national performance indicator and became compulsory for all local authorities to offer to those who meet the criteria and want to receive a payment. Direct payments are not considered as an extra income, do not affect other allowances or taxation and cannot be used as payment for permanent residential accommodation.

Since 2003, the concept of direct payment was evolved to the notion of a personal budget, intending to give users greater choice in their care. Personal budgets are similarly allocated to service users post individual assessment. Immediately after a social care needs assessment from the local authority health services, the person in need is informed as to how much money has been allocated to spend on meeting their needs. The personal budget allocation can either be used exactly as a direct payment, or the user can leave the local authority with the responsibility to commission the services – or they can choose to have a combination of the two. They are given the choice on how their money will be spent in direct payments by the local authority, by themselves and how much direct control they have over the money itself.

Currently, there is an option range from having a social worker manage the personal budget on their behalf, right the way through to taking the full amount as a direct payment (with several other options in between). This spectrum of options seems to offer more than self-directed support. There is evidence from both direct payments and personal budgets that service users and their families may achieve better outcomes with either the same (or potentially less) money, because they are enabled to be creative in meeting their own needs and producing more imaginative and effective support (see Glasby et al, 2009; see also www.in-control.org.uk). Although there is still no evidence of misuse, one may argue that these in-cash payments could open the door for paid informal care, subsidising the official local authority services with care from undereducated care-givers, e.g. immigrant women, without any control of the quality of services they provide. On the other hand records of how the money is spent should be kept and a visit at home from the local authority assures that the needs of the person are met (see also www.direct.gov.uk).

14. United Kingdom: Homecare re-ablement (Report section 8)

Re-ablement, although similar to rehabilitation, is a new orientation of nursing home care provision in the UK. Despite the variety of approaches to delivering re-ablement, the common features that remain constant are:

- Support individuals 'to do' rather than 'doing it for them'
- Focusing on real practical outcomes with defined maximum duration
- Implementation of continuous assessment to evaluate individuals' care needs

Evidence shows that the re-ablement approach offers a series of positives. From national monitoring and development work (as well as some independent research), it seems as though there may be over 120 local authorities, out of 150 nationally, who either have or are in the process of setting up/extending a re-ablement scheme (Pilkington, 2009). Re-ablement services have been created due to demographic changes and an increase of demand at all levels of care. Restructured/retrained in-house home help services may offer the lowest appropriate level of intervention in order to cope with the need to extend hospital discharge/intermediate care initiatives, and they are increasingly extending their scope to take on all referrals for home care, whether from hospital or community. Referrals to other services are only made for people with advance dementia or requiring end-of-life care.

One retrospective longitudinal study has also suggested that an average of 60% of people leaving home-care re-ablement did not require a home-care package and, 24 months later, had still never required a home-care package. A local independent evaluation of one such scheme also found that 5% of people without re-ablement required no home-care package and 70% had their home-care unchanged at their first six-week review. With re-ablement, 58% did not require home-care with only 17% having a package unchanged at the six-week review (Pilkington, 2008). While further research is underway to understand the implications of this model in more detail, national trends suggest that such approaches have not yet succeeded in transforming the nature of the system as a whole. There are also some underlying concerns that aspects of current policy may underestimate the social dimension of re-ablement, which can build confidence by improving the ease of daily living and autonomy for older people, as well as reducing hospital admission rates.

15. The Netherlands: Alzheimer Cafés (Report section 9)

Type, Scope

Informal regular meetings for people with dementia and their carers.

Background

The concept of the Alzheimer Cafés was developed and implemented in The Netherlands in the 1990s, with the aim of information brokering, fighting social exclusion and isolation of people with dementia and their carers, allowing for self help, exchange and thereby developing coping competencies.

Content and method

Alzheimer Cafés are regular meetings, composed of lectures about dementia-related topics by professionals or experienced lay persons combined with time for meeting and exchange with fellow sufferers.

Target group

In general people with dementia (especially at the mild to moderate stages) as well as their carers constitute the target groups. However, in some regions (perhaps where social taboos or paternalism to-

wards people with dementia are stronger), Alzheimer Cafés sometimes focus more, or exclusively, on carers.

Results, evidence

Alzheimer Cafés are found to create knowledge transfer, social support, to prevent isolation and to relieve shame on the part of people with dementia and their carers.

Current state, Contact

The concept was disseminated to other countries, e.g. Austria, Belgium, Germany, UK. There are regular meetings in many towns and cities in these countries, however with slightly different concepts, adapted to national and local understanding and needs.

16. Denmark: The DAISY Study (Report section 9)

The Danish Alzheimer Intervention Study (DAISY) was a major Danish research programme carried out over a five year period (2004-2008) in a number of subprojects. The overall aim was to improve the early social support to patients with dementia and their caregivers. Previous research had shown that being a caregiver was associated with stress and a higher risk of social withdrawal, depression, drug treatments and hospitalisation. Previous studies had indicated that in moderate to severe dementia training, counselling and support to caregivers may reduce the burden and the risk of depression. Social intervention programmes should be redesigned to focus on the needs early in the course of the disease, and to include counselling and support to both caregivers and patients.

The DAISY programme included the following projects:

- A social intervention programme for patients with recently diagnosed mild Alzheimer's disease and their caregivers
- A study of the health-economic aspects of early social intervention in dementia
- A study of the impact of social network and social activities in patients with early phase dementia and their caregivers.
- A study of legal aspects of early phase dementia.

One of the sub-projects was a multi-centre randomised controlled single-blind trial of a social intervention programme with 331 patients. A wide range of quantitative assessments of health status, cognitive performance, quality of life, depressive symptoms, and activities of daily living were included in the efficacy analysis at 6 and 12 months. The intervention programme aimed at combining information and support to patients and caregivers with the objective of preventing or reducing depressive symptoms, impairment of health related quality of life, and loss of social network.

Interim results

Self-assessment of health condition:

- In comparison to women, men assessed their health to be better.
- Patients with dementia assessed their own health to be better than their families/carers did.
- Families/carers assessed their own health to be poorer than the average assessment of health by Danes.

Self-assessment of memory:

- Patients with dementia considered that their memory was slightly deteriorated in comparison to the average self-assessment of memory by Danes.
- Families/carers assessed the dementia patients' memory to be worse than the patient's own assessment.

Level of knowledge:

- 41% of the dementia patients did not know what dementia illness they had been diagnosed with.
- Families/carers had poor knowledge of the services provided by the local authority for dementia patients and their families. Among those who knew of services, only a small proportion used them.

Financial and legal issues:

- Very few patients had set up a power of attorney or a will.
- Almost all the families/carers wished that the patient would look to the future and deal with personal and financial issues.
- Half of the patients and a third of the families did not know what guardianship is, while most of those who did know considered it a good idea.
- General knowledge about laws and social issues was low. Only a few had a broad knowledge of the opportunities available.

Results further showed that as early as the first stage of the illness patients experience a loss of function that leads to limitations in their everyday life and contact with the outside world. This often entails that they take less initiative and families very quickly take over tasks, such as looking after finances, practical help in the home, visits to doctors and dentists, etc. It is recommended that local authorities quickly intervene at the early stage with support, advice and guidance to ensure that social activities are maintained, the patient receives support to continue to be able to travel alone and manage finances, etc. A comprehensive Guidance Model was developed which emphasises that advice should always be in relation to individual needs and wishes. It was further recommended that staff conduct outreach work, as it is not usually the case that the patient or family contact the local authority or doctor to seek help. A Guide to Dementia was developed with sections giving information to patients, families and professionals.