



THE SOLID FACTS

HOME CARE IN EUROPE

Edited by Rosanna Tarricone & Agis D. Tsouros



Keywords

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Abstract

Demographic, epidemiological, social, and cultural trends in European countries are changing the traditional patterns of care. The next decades will see increasing rates of care-dependent older people and noncommunicable diseases as the leading cause of chronic illness and disability. The break-up of the traditional large family group and urbanization will also lead to gaps in the care of older or disabled family members. These changes in needs and social structure require a different approach to health and social sector policy and services since a disease-oriented approach, alone, is no longer appropriate. An answer to these issues could be home care, a sustainable approach to prevent the need for unnecessary acute or long-term institutionalization and maintain individuals in their home and community as long as possible. Technological innovation together with new and modern forms of service delivery organization can represent a viable solution to developing home care in Europe provided that health care systems can further enhance integration and coordination. This publication is part of the work of the WHO Regional Office for Europe to present evidence for health policy- and decision-makers in a clear and understandable form. It explains why health and social services should provide high-quality and targeted home care for disabled and older people. It provides evidence for the effectiveness of home care, shows how it can be improved and explains the need to ensure equitable access. The publication also explores the varied cultural and care contexts in different countries and reveals how to educate professionals and the public about these issues. This booklet seeks to broaden awareness, stimulate debate and promote action.

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There is an intrinsic appeal to the term home care that has caught the imagination of politicians, professionals and the public. "Back to the future" is an expression that could accurately reflect the potential to explore, exploit and implement an old idea with today's knowledge and new means. Home care offers the possibility to receive a wide range of services in one's familiar surroundings. Home care emerges now as an increasingly promising option for providing health and social care for many conditions that are especially associated with older age, disability and chronic diseases.

Many factors drive the need and demand for home care: demographic trends, changes in the epidemiological landscape of disease, the increased focus on user-centred services, the availability of new support technologies and the pressing need to reconfigure health systems to improve responsiveness, continuity, efficiency and equity.

Home care is understood and practised differently around the European Region. Similarly, the evidence about the appropriateness and effectiveness of home care is complex and diverse and hence poses an inherent challenge to gather and to analyse and make informed decisions. This publication was produced with the primary aim of offering a systematic overview of the various aspects of home care based on the best available evidence relevant to the special features of the European Region. It is meant to broaden understanding of the multiple facets (organizational, service delivery, funding and health systems stewardship) of home care and to stimulate debate and action. I am convinced that home care is a term that will increasingly become an indispensable and integral part of health systems development in the future, and I therefore feel that this timely publication will fill an important gap in our knowledge base on this important topic.

Enis Bariş

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There are several good reasons for home care. Many people prefer home care to any other option. Home is a place of emotional and physical associations, memories and comfort. Although many people can be happy in assisted-living facilities, retirement communities or nursing homes – and for many people these are better options – leaving home can be disruptive and depressing for some people.

Home care is delivered at home. When people are not feeling well, most want to be at home. Home care keeps families together, which is particularly important in times of illness. Home care prevents or postpones institutionalization. Home care promotes healing. Home care allows maximum freedom for the individual, in contrast to institutions, which are regulated environments. Home care is personalized – tailored to the specific needs of each individual.

Responding to these simple and human needs requires substantial public commitment. This requires both a social and a political impetus, entailing changes in culture, attitudes and widespread education of all professionals, in both the community and institutions, in both the health care and social sectors as well as informal carers involved with people who need home care. It demands human commitment and flexible organizations more than expensive drugs and interventions and should be a concern for all governments.

There are a few fundamental questions about the development of home care services. In many cases these would compare favourably with institutionalized forms of care in terms of cost-effectiveness, but organizing a network of services could be more challenging than running facilities such as nursing homes. Does this explain the path of service development?

Moreover, who is the right caregiver at home? The people requiring care – empowered and well trained – informal carers, nurses or physicians? Wandat is the right combination of them in any given circumstance? Who is the appropriate case manager: the one who designs the care programme and controls it, trying to manage the different caregivers?

This publication presents these challenges with exemplary clarity, providing a concise overview of the best available evidence on home care, and a series of spotlights briefly describe some enlightening policies and programmes from cities around Europe.

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1. Home care in Europe: an overview

Home care aims at satisfying people's health and social needs while in their home by providing appropriate and high-quality home-based health care and social services, by formal and informal caregivers, with the use of technology when appropriate, within a balanced and affordable continuum of care (1,2).

Life expectancy has risen sharply in the WHO European Region in the last few decades. The proportion of older people in the general population is increasing steadily in many European countries and is predicted to rise still further in the coming decades. This will mean increasing rates of care-dependent older people (3). The next decades will also see dramatic changes in the needs of those with noncommunicable diseases, as the leading cause of disability and death. A variety of people with chronic conditions may stay at home given difficulty in mobility, and dependent children with severe health problems or people with mental disorders may also require home care (4–6).

Sociodemographic change and mobility trends affect home care needs. The break-up of the traditional large family group and other sociological trends, such as urbanization, complicate the situation. Family groups are often intact in rural areas, with many generations living in a household and family members taking care of the older or disabled family members.

Urban communities are different, with small family units, limited living space and the younger generations often moving away from their families because of work commitments. All these factors increase the likelihood of today's and future generations needing additional care that their relatives are unlikely to provide and place a major responsibility on all levels of government: national, regional or district and especially municipal, where home care is applied in practice (7).

These changes in needs and social structure require a different approach to health and social sector policy and services, since a disease-oriented approach alone is no longer appropriate. Evidence suggests that disabled and older people tend not to want institutional care, and families and other informal carers prefer strongly



to continue to care for their dependent family members in a friendly environment such as their own homes and local communities (8).

In the present and in the future, decision-makers would envision home care as a sustainable approach to prevent the need for unnecessary acute and/or long-term institutionalization and maintain individuals in their home and community as long as possible.

References

- Home-based and long-term care: home care issues and evidence. Geneva, World Health Organization, 1999 (http://www.who.int/chp/knowledge/publications/Chronic_conditions/en/index.html, accessed 25 July 2008).
- 2. Community home-based care in resource-limited settings: a framework for action. Geneva, World Health Organization, 2002 (http://www.who.int/chp/knowledge/publications/Chronic_conditions/en/index.html, accessed 25 July 2008).
- 3. Eurostat. *Europe in figures: Eurostat yearbook 2008*. Luxembourg, Office for Official Publications of the European Communities, 2008.
- Thornicroft T, Tansella M. What are the arguments for community-based mental health care? Copenhagen, WHO Regional Office for Europe, 2003 (Health Evidence Network report; http://www.euro.who.int/HEN/Syntheses/mentalhealth/20030903_8, accessed 25 July 2008).
- 5. Moise P et al. *Dementia in 9 OECD countries: a comparative analysis.* Paris, Organisation for Economic Co-operation and Development, 2004 (OECD Health Working Paper 13).
- Moon L et al. Stroke care in OECD countries: a comparison of treatment, costs, and outcomes in 17 countries. Paris, Organisation for Economic Co-operation and Development, 2003 (OECD Health Working Paper 5).
- 7. The impact of ageing on public expenditure: projections for the EU-25 Member States on pension, healthcare, long-term care, education and unemployment transfers (2004–50). Brussels, Economic Policy Committee and the European Commission, 2006 (Special Report Number 1).
- 8. European Commission. *i2010: independent living for the ageing society.* Luxembourg, Office for Official Publications of the European Communities, 2006.

2. An emerging need for home care in Europe

Although the particular history, drivers of change and subsequent policy responses vary across Europe, all countries are similarly facing a set of common demographic, social, technological, epidemiological and political pressures that influence both the demand and supply of home care demand and provision (Fig. 2.1) (1).

Demographic shifts

Demographic changes are leading to an increased demand for home care. The population structure within European Union (EU) countries is set to change dramatically in the near future. In particular, the proportion of old and very old people is set to increase (Fig. 2.2), while the number and relative proportion of children, young people, young adults and adults will decline, as fertility rates are falling sharply.

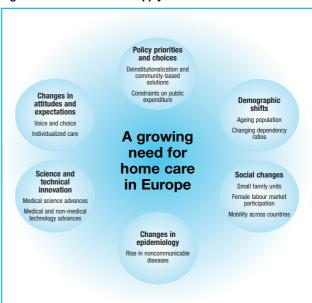
Although the rates vary by country, they are set to fall further, resulting in an ageing population profile and reducing the dependency ratio of carers to dependents. This will affect the tax base for funding public services and the available pool of formal and informal carers (2).

The demand for home care is known to increase with age, even if individuals become dependent at a later stage than previous generations; the lat-

ter is due, for example, to improvements in lifestyle, Fig. 2.1. Influences on the supply of and demand for home care food, personal hygiene and housing. Improvements in disease prevention, standards of living and self-care activities will also influence the level of assistance required and overall levels of dependence (3).

Social change

Changes in social attitudes, values and behaviour contribute to increasing the demand for formal home care services. The fragmentation of the traditional large family group into small family units in an urbanized context reduces the number of people who can provide care to dependent family members. In addition, female labour market participation has risen steadily, and greater emphasis is placed on facilitating paid work and enhancing career opportunities for women. Increased female labour market participation and tighter regulation of labour markets results in the availability of a smaller pool of family care. In countries where labour



market incentives and active labour market policies seek to raise the participation of women further, this has serious implications for the provision of both informal and formal care. These policies are part of the muchbroader Lisbon strategy for growth and employment of the EU that addresses measures to delay retirement and discourage early retirement to increase labour market participation among all sectors of the European population. Thus, since the peak age of the people caring for an older person is between 45 and 60 years, these would result in a global shortage of informal carers (4,5).

Greater internal mobility across Europe at all points in the life course (working and retirement age) can give rise to considerable distances between family members. In countries recently joining the EU, younger and professional groups have migrated significantly, contributing to not only brain drain but also potentially a widening care gap (2).

% 20 Year 65 years and older 0-14 years Year Women 80 years and older Total 80 years and older Men 80 years and older

Fig. 2.2. Projections for the proportion of the population in various age groups in the European Union (27 countries), 2005–2050

Source: Eurostat (2). © European Communities, 1995-2008.

Changes in epidemiology

Improvements in public health have contributed towards changing epidemiology. A rise in noncommunicable diseases influences the demand for home care, including the following (6–8).

- Mental illness is being increasingly recognized and treated, and community care is preferred to institutionally based care.
- The pattern of disease is changing. Some diseases such as Alzheimer's disease and dementia are becoming more prevalent in an ageing population. There is also greater awareness and understanding of such conditions and how effective treatments and support may be offered within a home setting by using a range of home care services.
- More people are living with the consequences of diabetes, heart diseases, respiratory diseases, stroke and cancer: these could be effectively and efficiently taken care of at home with appropriate and targeted support.

Science and technical innovation

Developments in science and technology (both medical and non-medical) are affecting the demand for and the supply of home care. Medical advances including pharmaceuticals, devices and surgical technologies have contributed towards increasing life expectancy and enhancing the quality of life for many disabled people, older people and children with complex care needs. Simple home modifications (such as adapted toilets, showers and baths and lifting equipment) more easily match residential settings to the needs of people with impairment. The development of technology and innovation promises to deliver a range of opportunities and solutions for population groups wishing to remain in their home, and both high- and low-technology home care solutions are supplementing and complementing traditional home care services (9).

Changes in attitudes and expectations

There are rising expectations around consumer choice and citizen voice within the organization and delivery of services (10,11).

- In some settings, such as for home care, a discourse of entitlement or user rights has grown up around the importance of individualized and customized care and has emphasized the importance of user choice, control and self-determination in the funding and provision of services.
- The appropriateness of institutional provision is increasingly questioned, and home- and community-based solutions and services are preferred. Almost 90% of respondents in one European survey felt that social and health care systems should help older people to remain in their homes for as long as possible (10).

With increased population mobility and migration, all European countries have to address the needs of diverse populations. The public expects services to be culturally sensitive and to better reflect the needs of ethnic minority groups, which in turn generates new demands for home care provision.

Policy priorities and choices

A range of policy changes and priorities create pressure on home care. There is policy support for the idea that home-based solutions benefit individual users, their families and society more broadly (11,12).

- In most European countries, deinstitutionalization and community living are accepted as general principles underpinning the formulation of policy, including: (1) closing long-stay mental institutions, (2) individuals with learning disabilities living in community and small-scale settings and (3) older people experiencing better quality of life under community care rather than long-stay nursing and residential homes.
- There are concerns about the pressure on public expenditure associated with the ageing population, particularly around pensions and health care costs. Health spending grew faster than gross domestic product in virtually all countries in the Organisation for Economic Cooperation and Development (OECD) from 1990 to 2004.
- Home-based solutions are advanced not only for health, social and emotional benefits but also because of the potential reduction in public expenditure, as home care provision has been demonstrated to be more effective and efficient than institutionalized care.
- Primary care (such as home-based nursing services, hospital and hospice-at-home care) is seen as central in ensuring the quality of life, and this has been coupled with a shift of resources from acute and long-stay beds to community care within the health and social service systems.
- Recognition of the pivotal role of informal care (both family and friends or neighbours) in contributing towards providing care has led to increased demands for policy and service providers to recognize and sustain these fundamental actors.

References

- Home-based long-term care: report of a WHO study group. Geneva, World Health Organization, 2000 (WHO Technical Report Series, No. 898; whqlibdoc.who.int/trs/WHO_TRS_898.pdf, accessed 25 July 2008).
- Eurostat. Europe in figures: Eurostat yearbook 2008. Luxembourg, Office for Official Publications of the European Communities, 2008.
- Andrews GR. Promoting health and function in an ageing population. British Medical Journal, 2001, 322:728–729.

- Vlasblom JD, Schippers JL. Increases in female labour force participation in Europe: similarities and differences. Utrecht, Tjalling C. Koopmans Research Institute, University of Utrecht, 2004 (Discussion Paper 04-12).
- Facing the challenge: the Lisbon strategy for growth and employment. Report from the High Level Group chaired by Wim Kok. Luxembourg, Office for Official Publications of the European Communities, 2004.
- Thornicroft T, Tansella M. What are the arguments for community-based mental health care? Copenhagen, WHO Regional Office for Europe, 2003 (Health Evidence Network report; http://www.euro.who.int/HEN/Syntheses/mentalhealth/20030903_8, accessed 25 July 2008).
- 7. Moise P et al. *Dementia in 9 OECD countries: a comparative analysis.* Paris, Organisation for Economic Co-operation and Development, 2004 (OECD Health Working Paper 13).
- 8. Moon L et al. Stroke care in OECD countries: a comparison of treatment, costs, and outcomes in 17 countries. Paris, Organisation for Economic Co-operation and Development, 2003 (OECD Health Working Paper 5).
- 9. Heaton J et al. *Technology-dependent children and family life*. York, Social Policy Research Unit, University of York, 2003 (Research Works, 2003-02).
- European Foundation for the Improvement of Living and Working Conditions. Health and care in an enlarged Europe. Luxembourg, Office for Official Publications of the European Communities, 2004.
- 11. The impact of ageing on public expenditure: projections for the EU-25 Member States on pension, healthcare, long-term care, education and unemployment transfers (2004–50). Brussels, Economic Policy Committee and the European Commission, 2006 (Special Report Number 1).
- 12. Shepperd S, Iliffe S. Hospital at home versus in-patient hospital care. *Cochrane Database of Systematic Reviews*, 2005, (3): CD000356.





3. The supply side of home care in Europe

Organization of home care solutions and services

History of home care

There is no single, uniform history of the evolution of home care services policy and provision across Europe. The development of home nursing and home help are bound up with the emergence of complex systems of welfare, social security and health care that have followed different trajectories and given rise to different patterns of funding and provision within each country. Adding to this diversity, prevailing social and cultural institutions at the national level colour the welfare reforms and policy mix. The result is a rich mix of approaches and strategies for funding, organizing and delivering home care services, tax-based provision, municipal, regional and national levels of responsibility, differences in health and social service boundaries and greater or lesser policy support for informal care (1).

Home care provision across all European countries has relied historically on informal care (primarily family) and voluntary or church provision. The central place of the family and extended kinship networks in delivering support to older and disabled people is a consistent theme across all European welfare regimes. Only during the late 19th century did growing state involvement in health and social welfare begin to augment, but not displace, this form of provision (2).

During the 20th century, large-scale institutions and hospitals became the dominant forms of provision for supporting a range of groups including older people, children, disabled people and people with mental disorders. Nevertheless, professional and consumer criticism of the place of these institutions grew from the 1950s across western Europe and the Nordic countries. There have been moves since the 1960s to reduce the number of long-stay beds for older people and children in hospitals, to improve nursing homes and residential homes for older people, children and people with disability and to close long-stay mental institutions. Policies known variously as deinstitutionalization, community care, continuous care, integrated care and home-based



care were promoted as an alternative to or replacement for institutionalized and acute provision. A major push was to acknowledge the key role and enhance the provision of informal and family care across these groups. In such countries as the Scandinavian countries and England, there was not a direct policy shift from institution-based to family care but a shift from institutional care to community-based formal services and only subsequently to a greater emphasis on family-based care.

Institutionalization and deinstitutionalization processes took place at very different times and paces across Europe. Both were much more recent phenomena in countries in southern and eastern Europe. In countries in eastern Europe, for example, institutional care persisted as a dominant form of provision until the early 1990s (3).

Adding to traditional forms of home care, hospital and hospice-at-home schemes, home nursing and home help are more recent and complex forms of intervention that reflect developments in medical and information technology. All European countries currently emphasize the importance of providing a spectrum of care for vulnerable groups, but the precise meaning of this and the policy challenges vary within each country according to the contingencies of history and context. In many southern European countries, for example, formal home care has still not been developed fully, whereas some Nordic countries have comparatively underdeveloped voluntary sectors. These differences are explained in part by the differing histories, inherited levels of provision, traditional roles of state and civil society and evolving expectations about where responsibility for home care should lie (1,4).

Professions and providers involved in delivering services

Home care is necessarily a labour-intensive activity that relies on a variety of providers to deliver an array of formal clinical and social services, as well as informal services, in the home setting. These providers include a mix of professional and non-professional personnel, including nurses, therapists (physical, occupational and speech), home care assistants, social workers, physicians, dietitians, homemakers, companions, volunteers and others.

Nurses represent the largest group of professional home care employees. Frequently, nurses evaluate people who receive home care, develop care plans, provide skilled nursing care and determine whether other services are required. They also make the best use of the available care assistance for the people receiving home care and their family members through education. The home care setting would require nurses to increasingly work independently, to exercise independent judgement, to coordinate and manage care teams and to provide more sophisticated and advanced procedures. Nevertheless, in most European countries most nursing and other health care services are funded and organized separately (such as at the national, county or regional level) from home care services (which are more likely to be a municipal responsibility – see the next paragraphs) (4).

Home care assistants, or aides, are the foundation of the home care workforce because of the wide variety of services they provide. These services can range from assisting with therapy and the activities of daily living to preparing food. Home care assistants typically visit most frequently and spend the most time with the person receiving care. Although these workers are considered critical to home care, there are growing concerns of a severe global shortage in the supply of home workers. Trends indicate that, in the absence of successful plans for expanding this workforce, the crisis will increase in the future. Immigrants are seen as a plausible answer to this problem. There are significant flows of care workers from low- and middle-income countries to high-income countries within Europe - for example from Slovakia and Hungary to Austria: from eastern European countries to the United Kingdom; and from Albania to Italy (5). In Italy, for example, the proportion of workers employed in domestic positions who were born outside Italy increased from 20% in 2001 to 83% in 2006. However, most of these caregivers are not licensed and work outside the oversight of regulatory bodies, and concerns about the quality of care have thus been raised. At the local level, governments are beginning to implement programmes aimed at matching the demand for home care workers with an adequate supply of trained nurses and aides. Better training and accreditation programmes can guarantee a constant supply of qualified caregivers (6).

As a drawback, in eastern European countries that export labour, the current transnational migration phenomenon is contributing to a drain of the young active workforce and a potential care gap for the older generation of these countries (7).

Other home care workers include social workers and therapists. Social workers can support people receiving care and their families in seeking and gaining access to community assistance, overcoming red tape and financial concerns and considering social aspects that can influence the home care plan for treatment. Therapists such as physical, occupational and speech consider therapy needs, develop care and rehabilitation plans and have oversight for any assistants involved in providing therapy (5).

Box 3.1. Integrated primary care teams in Catalonia, Spain

Since the gap between social and health services persists in Catalonia, with both networks depending on different administrations and different budgets, the national health system has intended to solve this problem. Primary care teams have been responsible for actively looking for and identifying people at risk, both from the clinical and social viewpoints. Family doctors and, mainly, primary care team nurses are responsible for any house calls for care: this may include both acute and chronic care. Domiciliary programmes are determined to look proactively for these people at risk. At the home of the person receiving care, nurses evaluate not only physical needs (nutrition assessment and the existence and control of chronic conditions) but also independence in daily activities, communication and mental needs. Nurses also evaluate the informal carer situation. If social needs are identified, nurses contact referral social workers. This group of professionals might be integrated in primary care teams in some cases or depend on local authorities. To avoid gaps in coordination, a "linking nurse" from primary care daily contacts referral hospital services to prepare hospital discharges in advance and allow both the person receiving care, the family, primary care teams and social services to be ready for any new needs that may arise at home. On the other hand, primary care teams develop specifically a case manager strategy among skilled nurses, who can take care of all special clinical needs once a person with multiple conditions who is receiving care has been discharged. Finally, to reduce the gap between social and health services, a primary care trust that includes local social services and government health primary care services has been set up (11).

Informal care

An informal carer is traditionally defined as "a carer that looks after family, partners, friends or neighbours in need of help because they are ill, frail or have a disability; the care they provide is unpaid" (8). Historically, informal care has provided the bulk of home care and still remains the largest source of home care. It is only since the mid-20th century that formal care began to represent an important adjunct to informal care in the home care setting. Spouses, children and their spouses or other family members usually provide informal care (9).

The balance between informal and formal care differs substantially from country to country and changes over time within countries as it is connected to particular political, economic, demographic and cultural factors. In southern European countries, informal care remains the dominant source of home care. Without the work of these unpaid carers, home care would be totally unsustainable and many acute needs would remain unattended. The situation is different in northern European countries where informal care is less common, because municipalities provide extensive personal care and domestic services (such as home help in Denmark, although private organizations may provide this with municipal funding), and informal care tends to focus on providing companionship and social support. The same is true, for example, in Scotland, where municipality-funded personal care has replaced some of the intimate personal care formerly provided by close relatives, reducing strain. Research has also shown in other Scandinavian countries (such as Norway) that older people do not want their close relatives to provide their intimate personal care but prefer to have their care and support needs supplied formally by employed care workers. The range of tasks, types and levels of activities that informal carers undertake varies widely both within and between European countries (Box 3.1) (10).

Even if informal care continues to deliver a relevant part of home care for disabled and older people, certain trends must be taken into account.

- The ageing population and the increasing proportion of the oldest old: an increasing proportion of informal carers (particularly spouse carers) are themselves likely to be older, and the tasks they are able to undertake may be limited.
- The participation of women in the labour market, reflecting active government policies: the conflict between the demand of European economies for new workers and the need for informal care should not be underestimated.

• Cash-for-care schemes are blurring the boundaries between formal and informal care. For example, some schemes (such as in the Netherlands) allow relatives, including close co-resident relatives – to be paid for the care they provide. In some countries (especially Austria, Greece and Italy), relatives use the cash payments to purchase live-in grey labour care workers for older people (7,12).

Home care services: organizational designs and structures

In almost all EU countries, home care is located at the intersection between the health care system and the social system and has its own peculiarities within each. Traditionally, the separation between health care and social systems relies on the nature of the service provided at home (health- or socially related).

Home care services provided by health care systems often include:

- rehabilitation, supportive, health-promoting or disease-preventive and technical nursing care, both for chronic and acute conditions (the latter are better known as hospital-at-home schemes), occupational therapy and physiotherapy (13); and
- home health care recipients would be mostly older people, people with complex illnesses and people with terminal illness.

Home help services, traditionally provided by the social service sector, instead, comprise:

- household duties, such as shopping, cooking, cleaning and administrative paperwork (such as filling in forms and paying bills), activities such as socializing or going for walks and delivering personal care (help with bathing and dressing, etc.);
- these services commonly substitute for informal care; nevertheless, they could also stimulate it (help for family members, neighbours or friends) and provide moral and psychological support (counselling and advice); and
- once again, most people receiving home help services are older people, many of them living alone.

Many countries, such as Belgium, France, Italy, Portugal, Spain and the United Kingdom, have an organizational model in which the "health" component of home care is part of the health care system and the "social" component is part of the social system (Table 3.1) (1,4). In other countries, especially Denmark, Finland and Sweden, policy-makers recognized the advantages of providing home care within a single organization under the responsibility of one institution: the municipalities.

Table 3.1. Country-specific organization of home health and social care in selected EU countries

Country	Health care at home	Social care at home	
Belgium	Central or regional government	Local government or municipality	
Denmark	Local government or municipality	Local government or municipality	
Finland	Local government or municipality	Local government or municipality	
France	Social insurance and local government or municipality	Local government or municipality	
Germany	Social insurance	Social insurance	
Ireland	Central or regional government	Central or regional government	
Italy	Central or regional government	Local government or municipality	
Netherlands	Social insurance	Social insurance	
Portugal	Central or regional government	Local government or municipality	
Spain	Social insurance	Local government or municipality	
Sweden	Local government or municipality	Local government or municipality	
United Kingdom	Central or regional government	Local government or municipality	

For example, municipalities have provided home care in Denmark since 1992. In contrast to local government-oriented single-agent solutions, Germany and the Netherlands, for example, have a single funding stream (insurance-based) that covers home nursing and social care services. In addition to these institutional actors, voluntary, charitable and for-profit providers of home care services have extensive roles.

Home care delivery: the onset of needs and needs assessment

Crucial aspects influencing the nature, the intensity and, ultimately, the organizational structures of home care services are:

- the definition of eligibility criteria for home care services;
- the early detection of eligible people; and
- proper needs assessment.

Country-based eligibility criteria for home care services may vary considerably. Not only do they vary between countries but may vary within countries as well: this is, for example, particularly the case in England and Finland.

Countries with very different funding regimes and assessment arrangements, such as England and Germany, have clear thresholds below which people are not eligible for home care services: these thresholds ration demand and reflect resource constraints for home care. Individuals eligible for home care should be identified in an early stage of need for home care, as people are frequently only included in programmes once their condition has deteriorated further from previous chronic conditions, such as dementia, ageing or, simply, social isolation (14).

Although the needs assessment processes in many European countries remain fragmented and based solely on medical expertise, in some other countries single-point assessment or interdisciplinary assessment teams and/or agencies are responsible for guiding the citizen through the variety of service providers (Table 3.2).

Assessing users only may not be sufficient to effectively and efficiently provide home care services. In addition, the needs of family and informal carers should be taken into consideration at an early stage.



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Assessment of direct supportive services to help carers facing problems they encounter should target the following areas: (1) quality of information, allowing informed choice in endorsing a carer role, (2) supportive action to prevent and treat a carer's physical problems, mental and emotional challenges, including easy access to respite care and to professional care and (3) education and training in practical caring and skill in coping emotionally with caring (15).

Nevertheless, this does not always actually happen; indeed, home care services are more likely to be provided to older people who do not have family carers. If there are family carers, home care services are much more likely not to be provided. Home care services are not normally responsible for financial benefits to reduce the costs experienced by informal carers, but home care services can directly reduce the financial losses experienced by informal carers if they enable carers to maintain paid work.

Table 3.2. Examples of needs assessment in selected European countries

Country	Method of needs assessment
France	Centres locaux d'information et de coordination
Italy	Multidimensional geriatric assessment units
Netherlands	Care needs assessment centres
United Kingdom	Single assessment process

Policy implications

- Home care policies should be targeted for both direct users of services and informal caregivers.
- Policies should tackle the scarcity of resources for nurses and home assistants that would possibly alleviate the burden of informal carers.
- As foreign-born caregivers have filled this void in some countries, an initiative to qualify these younger migrant cohorts intensively is needed to compensate for their educational and social disadvantages.
- Local governments should also integrate these foreign-born caregivers into the formal network, minimizing the share of irregular work participation in private households.
- Resource constraints may shape assessment processes and restrict access to and the levels of home care services provided. These restrictions may also inhibit the provision of low-level, preventive home care support to people whose needs are not yet severe.

References

- 1. Hutten JBF, Kerkstra A. Home care in Europe. A country-specific guide to its organization and financing. Arena, Aldershot, 1996.
- 2. Twigg J, ed. Informal care in Europe. York, University of York/SPRU, 1993.
- 3. Risse GB. Mending bodies, saving souls: a history of hospitals. Oxford, Oxford University Press, 1999.
- 4. Ehrenfeld M. Nursing and home care in Europe. International Nursing Review, 1998, 45:61–64.
- 5. Stone R. Long-term care workforce shortages: impact on families. San Francisco, Family Caregiver Alliance, 2001 (Policy Brief No. 3).
- Lamura G, Polverini F. East to west: the migration of informal caregivers. Washington, DC, AARP International, September 1, 2005 (http://www.aarpinternational.org/gra_sub/gra_sub_show.htm? doc_id=556115, accessed 25 July 2008).
- 7. Eurostat. Europe in figures: Eurostat yearbook 2008. Luxembourg, Office for Official Publications of the European Communities, 2008.
- 8. White paper: together for health: a strategic approach for the EU 2008-2013. Bunnik, the Netherlands, European Association Working for Carers, EUROCARERS, 2007.
- 9. Mestheneos E, Triantafillou J. Supporting family carers of older people in Europe the pan-European background. Hamburg, University Medical Centre Hamburg-Eppendorf, 2005.
- 10. Penning MJ. Hydra revisited: substituting formal care for self and informal in home care among the older adults with disabilities. *The Gerontologist*, 2002, 42:4–16.
- 11. Aranzana A, Cegri F. Home care program structure. In: *Home care guidebook*. Barcelona, Catalan Family and Community Medicine Society, 2003.
- 12. Vlasblom JD, Schippers JL. *Increases in female labour force participation in Europe: similarities and differences.* Utrecht, Tjalling C. Koopmans Research Institute, University of Utrecht, 2004 (Discussion Paper 04-12).
- 13. Shepperd S, lliffe S. Hospital at home versus in-patient hospital care. *Cochrane Database of Systematic Reviews*, 2005, (3): CD000356.
- 14. Nies H, Berman PC. *Integrating services for older people: a resource book for managers*. Dublin, European Health Management Association, 2004.
- 15. Thomé B, Dykes AN, Hallberg IR. Home care with regard to definition, care recipients, content and outcomes: systematic review. *Journal of Clinical Nursing*, 2003, 12:860–872.

Funding home care

General issues related to funding home care

Fundamental issues around home care include what is provided, to whom and how it is best funded. The mechanisms for resourcing and purchasing home care are closely related to the principles of eligibility for health and social services: universalism or targeting, entitlement and/or budget constraint and systems of assessment, boundary-setting and cost-shunting (1).

Funding issues include how resources are raised (such as via taxation, user contributions, individual payments and market-type mechanisms) and how these are allocated to the individuals, such as services, vouchers with restrictions on how they are spent and cash payments without restrictions on how they are used. The consistency and sustainability of current systems for funding home care across Europe varies considerably, with evident disparities in terms of fundraising and distribution, access and quality of services, reimbursement mechanisms, public versus private delivery mix, degree of population coverage and satisfaction. Nevertheless, although funding arrangements across Europe are diverse and variable, there is a widespread trend to seeking greater sustainability in the light of increased demand. Common mechanisms include:

- withdrawing some types of publicly funded home care services, such as help with cleaning and other household tasks; and
- providing cash-limited cash payments or vouchers rather than professional services (market mechanisms).

The widespread and growing use of market mechanisms (such as cash payments, care allowances, personal budgets and vouchers) is variously intended to stimulate a diverse, flexible and responsive supply of home care services and/or to encourage a shift from formal services to informal care. These mechanisms have several consequences.

- They involve a different set of policy levers than those used by (local or national) welfare states in relation to their own in-house services.
 In particular, they may require different mechanisms to regulate the quality of services.
- Information, advice and brokerage services become much more important in helping potential users to choose appropriate providers and negotiate individualized service options.
- They blur the boundaries between formal home care services, greymarket care and informal care: remember that, in some systems, it is

Box 3.2. Denmark - integrating services through a single funding stream

In Denmark, a single resource stream from municipal taxation funds home nursing and personal care services. These services also work across the boundaries between older people's own homes, sheltered housing and nursing homes. Community health centres form the base for home help and home nursing services, often working in integrated teams and caring for both very frail older people and those living independently in the community.

Box 3.3. Germany - funding dignity, choice and independence

A key aim of statutory long-term care insurance in Germany is to reduce reliance on social assistance. When a person is eligible for long-term care insurance and her or his care dependence needs have been assessed, the person can choose between receiving a payment in cash, having a package of care services in-kind delivered by an agency or a combination of the two.

perfectly possible for care allowance or personal budget recipients to pay an informal carer.

As with the ageing phenomenon in Europe, the number of frail people needing home care is likely to rise in the future, and funding home care will imply more choices about resource allocation (such as staff redeployment from hospital to other community services and funding of respite care and informal care) to ensure more effective and efficient services and the delivery of integrated care (Boxes 3.2 and 3.3).

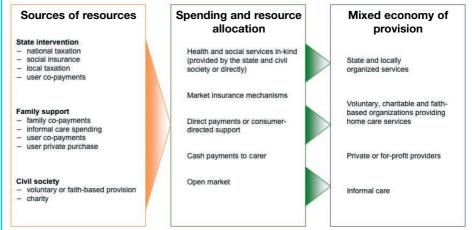
Approaches to funding home care

A range of potential home care funding mechanisms derives from state intervention, market purchases and the contributions of family members and resources of civil society (Fig. 3.1) (2).

Inputs and contributions for home care enter individual systems as services in kind and as various forms of financial resources, such as cash to service users and/or informal carers (3).

The combination of these public, family and private resources shapes the mixed economy of home care, which operates within each specific national setting. Hence, determining the precise quantity of public resources dedicated to home care is not easy, since they are often drawn from across health care, social security and social service budgets, and private purchasing of home care makes a major contribution to the overall levels and quality of home care packages. Public spending on home care accounts for more than 30% of the resources spent on long-term

Fig. 3.1. Funding, allocating and deploying home care Sources of resources

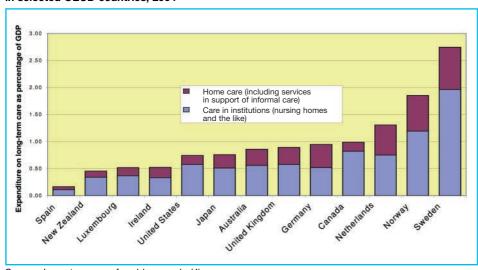


care in many OECD countries, ranging from 0.2% of gross domestic product in Spain to 2.75% in Sweden (Fig. 3.2) (4).

When confronted with a rising demand for long-term care, some countries have been quite prepared to raise taxes or social insurance contributions to fund the basket of services that includes home care (4). Countries with universal long-term care coverage consequently share the concern about the financial sustainability of their systems, especially if the national population is expected to age significantly in the future.

- Some countries have created a single funding stream, such as Germany and the Netherlands.
- Other countries have reduced the scope of public funding: for example, the social insurance-based system in the Netherlands has dramatically reduced the scope of services covered by AWBZ exceptional medical expenses insurance.
- In some other countries, further reforms have been adopted such as developing rehabilitation and disease prevention services: for example, the tax-based system in England is investing heavily in rehabilitation and reablement services.
- Other countries freeze benefit levels for example, the value of home care services for those qualifying for long-term care insurance in Germany – while costs rise, so that an increasing gap develops and is met by individual contributions.

Fig. 3.2. Expenditure on home care as a proportion of gross domestic product (GDP) in selected OECD countries, 2004



Source: Long-term care for older people (4).



 Means-testing has been tightened in some other countries (where benefits had been offered to most of the population) and increased for residential care subsidies.

In addition, relatively little is known about the private market and the grey economy of care across some European states, such as illegal immigrants in southern Europe, who receive an informal salary and do not pay taxes, although they supply substantial home care services. In such countries as Austria and Italy, for example, cash and direct payments to older and disabled people intended to be used to purchase home care have indirectly encouraged grey and migrant care labour. For example, in Italy only about 700 000 of the more than 2 million home care assistants are employed formally (5).

The contribution and opportunity costs of informal care must also be carefully taken into account: this is highly influenced by public expectations about family obligations (6). In the Scandinavian countries, as legally expected obligations are minimal and services are directed mainly towards the individual, exchanges of care and transfers within families are more a matter of choice than prescription. Alternatively, in Mediterranean countries family obligations are placed more on the extended family, whereas in the other countries in western Europe family obligations are directed primarily at the nuclear family: decisions around the public funding of home care

may therefore help shape the respective contributions of families and individuals.

In many countries, such as Austria, England, Germany, the Netherlands and Spain, quasi-market mechanisms have also been introduced to stimulate supply, to increase competition with traditional monopoly providers (public versus private), to promote quality and user-responsiveness and ultimately to reduce costs. Market-type mechanisms may include (7):

- care-managers acting as micro-purchasers (in England);
- cash payments to individual service users (in Austria, England, the Netherlands and Spain);
- voucher-type arrangements (the in-kind service entitlement in Germany and the Lombardy Region of Italy).

In particular, cash payments offer significant opportunities for containing costs: they can be easily capped, and calculations of the level of the

payment often includes a significant discount on the assumption that home care purchased from informal or semiformal providers is less expensive (with lower or no overhead) than services provided by a municipality or county (for example, the personal budget in the Netherlands – see Box 3.4). Nevertheless, there are concerns about the capability of private providers to deliver the best value in home care services by cutting costs or increasing quality under fixed funding, unless they can exploit economies of scale through consolidation and radically improve efficiency by using new technologies (8).

Several fairly different arrangements are used to facilitate more choice for individuals receiving home care, including personal budgets and consumer-directed employment of care assistants, payments to the person needing care who can spend it as she or he likes and income support payments to informal carers. There is a range of approaches to levying co-payments, including flat-rate charges or means-testing; under means-testing, the unit of financial assessment may be individual, household or family, and criteria may include savings or assets such as housing (9).

Current debates on how to improve the funding of home care

Funding home care services is closely interrelated with ongoing debates about the scope of health care provision, the most appropriate health care funding mechanisms and how best to fund long-term nursing and residential care. Inappropriate choice of funding mechanisms for home care may create disincentives, leading to suboptimum provision of care across the different sectors and limiting family and individual contributions (Boxes 3.4, 3.5 and 3.6).

Policy implications

Ideally, policy-makers need to consider several issues for developing effective home care services:

Box 3.5. Italy - vouchers and prospective payment systems for home care services

Home care in Italy is mainly a public service funded based on the capitated budgets of local health authorities. However, regions may also opt for other funding mechanisms. For instance, the Lombardy Region decided to issue home care funding to entitled individuals in the form of a voucher. The voucher-holder chooses among different accredited suppliers (public and private) and pays for services with the voucher. Three different levels of monthly voucher have been defined combining the nature of needs (such as social and health problems, people with complex problems and terminally ill people), the resources to be involved (such as professionals and technologies) and the intensity of care.

Box 3.4. The Netherlands – personal budget schemes as a way to feel less dependent

The Netherlands has extended its personal budget scheme (similar to direct payments in the United Kingdom), enabling older people to avoid waiting lists for services in kind that are in short supply. Personal budgets are allocated, like services, following assessment of care needs. They can be used to purchase any type of intervention covered by the social care insurance scheme, including home nursing, from informal or formal sources. Personal budget funding has led to a modest increase in the number of home care agencies. Users express great satisfaction with their enhanced choice and control, although there is controversy about the administrative burden and lack of support for personal budget holders.

Box 3.6. The United or dis-United Kingdom?

Traditionally, local authorities across England, Scotland, Wales and Northern Ireland operated a range of charging policies for home care services. Some provided services free of charge and others flat-rate charges and administering complex means tests. Since the Department of Health issued guidance on fairer charging policies in 2001, there have been attempts to eliminate what is, in effect, a postcode lottery (6). However, Age Concern Research for England suggests that, while there is more consistency for those on lower incomes, users with additional means are experiencing different approaches to how these resources are taken into consideration. Bordering local authorities may still operate radically different systems, and these systems are complex and not well understood (10). There are also differences within the United Kingdom, with Scotland now providing personal care free of charge for people older than 65 years, whereas most local authorities in England continue to levy charges.

- the availability of reliable information on home care usage and expenditure, both public and private, comparable to acute hospital or residential care;
- clear criteria for deciding how to shift resources among the levels and components of the care package, to make transparent what is publicly funded and for what the user pays;
- the sustainability of current funding arrangements given anticipated increases in demand;
- the potential for improving service efficiency by increasing the integration of services and/or changing the skill mix of home care services; and
- changing the levels of support expected from families and the opportunities to substitute (less expensive) family support for formal home care services.

References

- Brodsky J, Habib J, Hirschfeld MJ, eds. Key policy issues in long-term care. Geneva, World Health Organization, 2003 (http://www.who.int/chp/knowledge/publications/policy_issues_ltc/en/index.html, accessed 25 July 2008).
- 2. Wittenberg R, Sandhu B, Knapp M. Funding long-term care: the private and public options. In: Mossialos E, Figueras J, Dixon A, eds. *Funding health care: options in Europe.* Maidenhead, Open University Press, 2002.
- 3. Glendinning C et al. Funding long-term care for older people: lessons from other countries. York, Joseph Rowntree Foundation, 2004.
- 4. Long-term care for older people. Paris, Organisation for Economic Co-operation and Development, 2005.
- Spano P. Le convenienze nascoste. Il fenomeno badanti e le risposte del welfare [Hidden conveniences. The issue of home care assistants and the response of the welfare system]. Verona, Nuova Dimensione, 2006.
- 6. Wanless D. Securing good care for older people: taking a long-term view. London, King's Fund, 2006.
- Lundsgaard J. Consumer direction and choice in long-term care for older persons, including payments for informal care: how can it help improve care outcomes, employment, and fiscal sustainability. Paris, Organisation for Economic Co-operation and Development, 2005 (OECD Working Paper, 20).
- 8. Davies B, Drake P. Strategies for achieving best value in commissioned home care. *International Journal of Public Sector Management*, 2007, 20:206–225.
- 9. Home-based long-term care: report of a WHO study group. Geneva, World Health Organization, 2000 (WHO Technical Report Series, No. 898; whqlibdoc.who.int/trs/WHO_TRS_898.pdf, accessed 25 July 2008).
- 10. Thompson P, Mathew D. Fair enough? London, Age Concern England, 2004.

Integration of home care and other services

Integration and coordination problems in home care

The increasing range of services, interventions, technologies, funding mechanisms and specialized professionals and unspecialized actors in home care has changed traditional patterns of cure and care and altered the relationship within the health care systems and between health and social care facilities.

Service users and their families may experience this increased complexity in terms of problems or crisis: for instance, if they are discharged from hospital with long-term care needs without adequate notice to family members or community care services or if the hospital has not appropriately informed the general practitioner about necessary follow-up. Because of problems of coordination and integration between home care services and the acute hospital sector care, many of the people discharged are thus frequently readmitted, in larger cities perhaps even to another hospital, experiencing the revolving-door syndrome (Box 3.7) (1).

From the perspective of professionals working in hospitals, in nursing care institutions or in community care, the result of poor coordination and integration between home care services and the acute hospital sector care and the lack of capacity in home care services to support safe early discharge from hospital are reflected in increasing waiting lists, inappropriate admissions, bed-blocking, multiplication of diagnoses, tests and procedures as well as medical errors, suboptimal judgement, misunderstanding and delay in rehabilitation (Boxes 3.8 and 3.9). The following issues have repeatedly been identified as key obstacles to coordination and integration (2,3).

• The differentiation between health and social care services emerges in all countries because health matters are usually regulated within the framework of a national health system (such as Greece, Italy, the Nordic countries and the United Kingdom) or a national social insurance system (such as Austria, France, Germany and the Netherlands), while the social welfare systems usually administered by regional or local governments address social care issues. In most countries, the right to health is thus defined quite differently than the right to social care. Different legal arrangements and funding bodies may also produce different accountability and performance management regimens and targets, and these can ultimately constitute major barriers to integration.

Box 3.7. Inappropriate admission to hospitals

Studies have suggested that 20–30% of the people older than 75 years who are admitted to an acute hospital setting are admitted inappropriately. The evidence suggests not only that these people remain in hospital longer but also that, at any one time, 30–40% of the acute hospital beds are being used for people who do not require acute hospital care (1).

Box 3.8. A case study on lack of coordination in home care

Ms B., 70 years of age, was being discharged after a stroke and three weeks in hospital. The hospital staff decided to discharge her on Friday, not feeling responsible for what would have happened after she got out of the hospital. Neither her general practitioner nor the community nurse was informed. Her husband, aged 75, was told that Ms B. would have needed a walker and several prescription drugs, but he could only get the prescription on Monday morning when the general practitioner would be on duty again. Mr B. was also advised that his wife might need rehabilitation, but it was unclear when and in which rehabilitation centre. Further, the hospital nurse did not know exactly how much the rehabilitation copayment would be. She also provided Mr B with a list of phone numbers of providers of community care. Some were providing both home nursing and home help, and some were only providing home help. Ms B. would have to pay for these services, but there was always the opportunity to apply for a care or attendance allowance. Application forms were not available at the hospital, but Ms or Mr B. could perhaps get them at their local office for social assistance.

- The complexity of needs requires the intervention of various professions and organizations with specific professional and organizational cultures. Interprofessional coordination is still scarce due to a lack of awareness, conflicting priorities or professional standards, the lack of skilled social workers or the lack of transparency standards and defined responsibilities. Most importantly, home care services usually involve both professional and non-professional care work, with respective relational and communication difficulties.
- The involvement of private, not-for-profit and charitable home care service providers, fostered by the introduction of cash payments and voucher arrangements that encourage individuals to purchase their own services, further undermines the notion of integrated teams.

Linkage, coordination and networking in home care

The process of integration would link parts within a single level of care, creating multiprofessional teams – between health professionals, between health and social caregivers, and between these actors and informal carers – (horizontal integration) and/or relating different levels of care, such as primary, secondary and tertiary care (vertical integration). Integration within and between care services is especially important for providing services for individuals who require a range of different services over the long term because they are chronically ill, subject to multiple conditions or impaired by disability. What can be found as models of good practice or pilot projects is therefore coordination and networking of professionals who pool their means and resources to develop information, social and health care and disease prevention services designed

Box 3.9. Getting people back home – intermediate care in Peterborough, United Kingdom

Since April 2004, the budgets of two local National Health Service organizations and of the adult social care department of the Peterborough City Council have been fully pooled. Since spring 2005, district nursing and social work staff members have been part of fully integrated teams. These joined-up services are already making a difference to people in Peterborough. At the end of last year, 92-year-old Ms V. was treated in hospital for an intestinal blockage. The treatment was successful, but Ms V. would not have been able to care for herself at home. The integrated transfer-of-care team arranged for her to move to an intermediate care bed at Greenwood House, one of the residential care homes under the Peterborough City Council. "I couldn't possibly have looked after myself," explains Ms V. "I think this was a good idea for me, because I'm on my feet. I've been very well looked after and very comfortable, and the caregivers come to help you if you need them." "It's a small unit and we have more time," says care assistant Herma Whyte. "We can see that they're eating properly and can walk with them for a short distance at a time. They feel more confident and can see what progress they're making. We're here to help them get back home, which is what everyone wants."

Source: Our health, our care, our say: a new direction for community services (4).

to resolve complex or urgent problems based on temporary or permanent collaboration between different organizations. Integrated care can be found in various countries and under various names: seamless care, transmural care, intermediate care, case management (Box 3.10), care management or simply networking (5,6).

Integration in home care cannot be sustained without the active role of informal carers. Informal carers are particularly important as:

- providers of hands-on, direct care; and
- managers and coordinators of a range of different support services received by disabled and older people, such as being responsible for recruiting and employing care workers paid for through cash care allowances.

This is particularly true, as no care system will ever be able to completely cover all long-term care needs through professional services.

The importance of informal care and its complex relationship with professional care constitutes one of the major differences between homebased and institution-based care. What is generally assumed is that, as the needs of the service users grow and they require more complex technical support services, informal care should become more and more complementary to formal care. Research has shown poor evidence that training service users and informal carers in managing complex medical procedures and/or new technologies leads to better outcomes; instead they show the existence of a higher emotional burden of informal carers (but also for the service users). In the opposite case, when less complex care is needed, there is a risk of overlap between informal carers and professionals in delivering specific services that potentially could lead to conflicts (7). Evidence also indicates that one of the most effective means of integrating and supporting informal carers is replacing the domestic duties of informal carers: for example, parents caring for a severely disabled or technology-dependent child will require simple home care services so that they are able to maintain family activities and look after their other children (7).

Professionals should also acknowledge that informal carers need emotional support, technical advice and professional support to help them to deliver good services. Little attention is paid to the fact that the mental, physical and emotional burden of informal carers coupled with anxiety and stress of the service users may sometimes lead to conflict, while one of the most important role of formal services in supporting informal carers is to help them to continue providing hands-on care (8).

Box 3.10. What is case management?

A method of fostering the coordination and integration of different services is case or care management, which aims at matching the supply and demand for people in complex situations. The idea is to build up a network of services and resources over time and across services and to empower the people using these services and their relatives to use them self-reliantly. The methods used are at the level of the individual user and are therefore demand-oriented. The aim is to maximize the benefits derived from a given quantity of resources by coordinating the care delivery, thus avoiding loss of information and double treatment. This instrument is used in many countries, but with different interpretations. In some countries, such as the Netherlands, the Nordic countries and the United Kingdom, case managers might be characterized as a mainstream service, whereas in others, such as Austria, France, Germany and Italy, case management is mainly provided in pilot projects. Differences concern objectives, funding and the organizational setting. For instance, in the United Kingdom, case managers also fulfil a gatekeeping function. In some countries, such as Austria and Germany, case managers are mainly working in projects at the interface between hospital and community care. Case managers should follow the situation of the care user from the initial moment the person needs care. Thus, onestop windows and information centres have been developed in some countries, mostly on a project basis in different organizational settings (municipalities, health care centres and retirement centres). A key issue relates to who the case and care managers are, which professional background they have (nursing rather than social work or even informal carers), which kind of training they get and whether they are given the real means and competencies to manage the processes and to act as an advocate of the service user. In conclusion, the integration of family and informal care remains key to integrated care delivery, because family carers sometimes do not even define themselves as carers and because professionals in many cases see the family of the person who needs care as an opponent rather than as a resource (9). Thus, improvements are difficult to achieve on both sides: by supporting informal or family carers in integrating the various services received by their spouse or older parents (such as information and specific training) and by involving them in formal care systems.

Policy implications

- Creating a single agency responsible for a range of basic home care services (health and social) may resolve one set of fragmentation problems, but the issue of fragmentation between home care and acute health care still needs to be addressed, including preparations for discharge, time continuity between hospital care and home-based services and lack of knowledge of hospitals about the possibilities of aftercare at home, etc.
 - Helping professionals involved in different organizations that operate according to different logics, cultures and have different types of personnel in developing a deep understanding of the other's role and work (especially the health and social sectors) is of utmost importance.
 - An increasing share of integrated home care will certainly boost the importance of management and related tasks. On the one hand, both social and health staff will have to perform more managerial work in addition to direct care, which might also lead to new specializations and new job profiles, such as with respect to case and care management. On the other hand, the necessity of developing steering mechanisms at the national, regional and local levels requires more managerial decision-making in commissioning, contracting, purchasing, planning, evaluating and quality assurance mechanisms.
 - Measures aimed at reconciling the conflicting pressures of paid work and care could be addressed through workplace-based policies that allow flexible work, time off and paid care leave and/or home care and other services that can substitute for informal care so that informal carers can take or retain paid employment.



References

- 1. Foote C, Stanners C, eds. *Integrating care for older people. New care for old a systems approach.* London, Jessica Kingsley Publishers, 2002.
- 2. Leichsenring K, Alaszewski A, eds. *Providing integrated health and social care for older persons. A European overview of issues at stake.* Aldershot, Ashgate, 2004.
- 3. Billings J, Leichsenring K, eds. *Integrating health and social care services for older persons. Evidence from 9 European countries.* Aldershot, Ashgate, 2005.
- 4. Our health, our care, our say: a new direction for community services. London, Department of Health, 2006.
- Gröne O, Garcia-Barbero M. Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. *International Journal of Integrated Care*, 2001, 1:e21.
- 6. Lewis J. Integrated and fragmented care observed from two case studies. *International Journal of Integrated Care*, 2000, 1:e09.
- 7. Penning MJ. Hydra revisited: substituting formal care for self and informal in home care among the older adults with disabilities. *The Gerontologist*, 2002, 42:4–16.
- 8. Klinkenberg M et al. The last 3 months of life: care, transitions and the place of death of older people. *Health and Social Care in the Community*, 2005, 13:420–430.
- 9. Donelan K et al. Challenged to care: informal caregivers in a changing health system. *Health Affairs*, 2002, 21:222–231.



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Effect of technology on the development of home care

New technological advances in home care

Any technology, medical and non-medical, that provides or facilitates care and everyday activities in a user's home can be considered a home care technology. Home care technologies may have distinct advantages over traditional means of care: they could prevent users from going to a physician's office, clinic or hospital to receive care. For people with chronic diseases, for example, these appointments can take up significant amounts of time and can limit their ability and that of informal carers to perform normal professional and social activities (1). Remote systems (such as heart monitors and blood sugar monitors) may allow much more frequent and unobtrusive monitoring than would be possible in more conventional models. Irregularities are much more likely to be noticed early, which could prevent deterioration in the condition of the service users, who can be given quick feedback to allow them to better manage their own condition (2,3).

A few categories are helpful for discussing the attributes and benefits of the technology in technology for home care.

- Active devices perform therapy on users: such devices as home dialysis systems, perfusion pumps, drug delivery systems and oxygen systems (4,5).
- Non-active devices work basically without the intervention of clinicians or the users and do not require electricity or programming: for example, incontinence pads (6).
- General assistance and monitoring devices include such items as fall detectors and pill-minders. Advanced information and communication technology could be also used to locate people with dementia and Alzheimer's disease who wander away from home. Information and communication technology could allow information to be simultaneously shared with the entire home care team and stored for future use (2,3).
- Home modification: to avoid adapting one's lifestyle to the environmental conditions and increasing people's independence in the home, it is fundamental to adapt the residential setting and match it with the needs of residents. This category comprises less sophisticated but essential non-medical equipment for many disabled people, such as special chairs, hoists, rails, ramps into the house, adapted toilets and showers and baths, lifting equipment, special beds to prevent pressure sores and adapted kitchen equipment (7,8).

Numerous studies have shown the effectiveness of technology in home care. Over a wide variety of diseases, technology has shown potential to improve clinical outcomes, reduce the length of stay in hospitals, reduce reoccurrence and readmission rates and improve people's quality of life. Technology can also improve the quality of life of informal carers, making it more likely that the people receiving care and their informal carers can continue to stay active at home and in the community instead of being institutionalized (Boxes 3.11 and 3.12).

Accessing care users through technology

With developments in medical and other technologies, people with very complex conditions may increasingly be able to remain living at home rather than in hospital or institutional care. This means an increasing demand for community-based nursing staff, especially with specialist skills - tissue care, stoma care and palliative care, for example. Nevertheless, while technology continues to evolve, technological restrictions and system rigidity still prevent the diffusion of technology in home care services.

- Size and portability are key for successful home care, and miniaturizing certain devices adequately may still be impractical (10).
- Infrastructure boundaries (such as the communication and electrical systems of the user's home) can also hold back the implementation of home care technologies (10).
- Financial hurdles and administrative rigidity: home care programmes may not be properly funded due to silo budgeting, as funding for home care may be spread among many levels of government and envelopes of public spending (11). In England, health and social care budgets for

Box 3.12. Detecting delirium

Ms P. is 85 years old and has mild dementia. She lives alone at home and receives a home care programme. In the past six months, Ms P. has been admitted twice to hospital because of increasing confusion (delirium). A newly introduced medication caused the first episode and urinary sepsis the second one. After the second admission, continuous home monitoring of behavioural patterns was introduced. One day, the monitoring system recognized that Ms P.'s pattern of behaviour was significantly different than usual and alerted her general practitioner. The general practitioner recognized that this could be a new episode of delirium and arranged an urgent review. The geriatric specialist found that Ms P. was constipated and had urinary retention. Ms P was admitted to hospital and given an enema and was able to void. Her midstream urine microscopy result was clear. She was sent home on the same day, and her behaviour pattern returned to baseline. A possible long hospital admission was avoided by early identification and intervention in a medical emergency (9).

Box 3.11. Home heart monitoring

Mr D., aged 75 years, lives alone on a farm outside a small country town and has known ischaemic heart disease. Because of his remoteness, regular health care consultations are burdensome to him. He had several episodes of angina but never had an infarct. Recently, Mr D. suffered a prolonged episode of chest pain and attended his nearest clinic. This is staffed by a nurse after hours and is located some distance away from the nearest doctor. The nurse recorded an electrocardiogram (ECG) and transferred the information via the Internet to a cardiologist, who made an immediate diagnosis of unstable angina. Mr D. was admitted overnight to a local community hospital, appropriately managed and reviewed by his own doctor the next day. He was instructed on the use of a simple ECG monitoring device capable of transmitting ECG recordings over the telephone. Mr D. returned home aware that his condition would be constantly monitored and would receive instant health care assistance in case of angina attacks (9).



- equipment have been integrated, and all localities now have a jointly funded integrated community equipment service.
- Reimbursement schedules for home care services could be updated relatively to the level of technology on the market: schemes that are not updated may create incentives for clinicians to prescribe more conventional inpatient treatments (11).

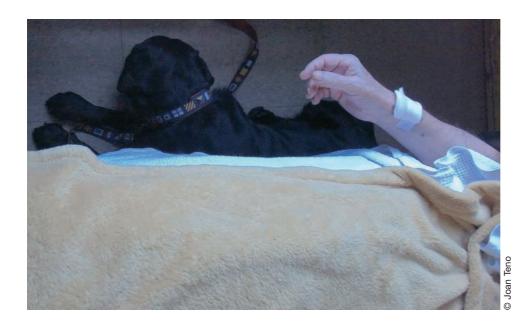
Policy implications

- Policies should be aimed at matching the home and environmental conditions with the needs of the residents with the use of the most appropriate technology (medical, non-medical and information and communication technology), also taking into account the following.
 - Technology should adapt and cope with people's will and culture, and not vice versa.
 - Attention should be given in technology assessment processes to how technologies modify the interaction between professionals, carers and users.
- Policy- and decision-makers should be aware that measuring the performance of home care services, or of the use of specific technologies within the service, is not a straightforward task.
 - Home care comprises a complex interlinkage of services involving multiple health and social problems and decisions: clearly attributing defined outcomes to a given intervention or technology is difficult, even when it is isolated from all the other delivered services and external factors are controlled for.
 - The performance and effectiveness of technologies at people's homes also depends on the level of coordination and integration between systems, organization and reimbursement regimes: a silofree environment is therefore optimal to take full advantage of the benefits of technology.
- Appropriate housing policies would positively affect the proper use of technology in home care, as ownership would influence the responsibility and ability of tenants to adapt homes to their possible needs.

References

- 1. Levy J. Home dialysis can improve quality of life. *Practitioner*, 2007, 251:8, 10–12, 14–15.
- Clark RA et al. Telemonitoring or structured telephone support programmes for patients with chronic heart failure: systematic review and meta-analysis. *British Medical Journal*, 2007, 334:942.
- 3. Jaana M, Paré G. Home telemonitoring of patients with diabetes: a systematic assessment of observed effects. *Journal of Evaluation in Clinical Practice*, 2007, 13:242–253.

- 4. Breitfeld PP. Belief in home chemotherapy. *Pediatric Blood and Cancer*, 2006, 47:237–238.
- 5. Stevens B et al. Children receiving chemotherapy at home: perceptions of children and parents. *Journal of Pediatric Oncology Nursing*, 2006, 23:276–285.
- 6. Reeves P et al. The current and future burden and cost of overactive bladder in five European countries. *European Urology*, 2006, 50:1050–1057.
- 7. Alber J, Fahey T. Perceptions of living conditions in an enlarged Europe. In: *Quality of life in Europe.* Vienna, European Foundation for the Improvement of Living and Working Conditions, 2004.
- 8. Lyons RA et al. Modification of the home environment for the reduction of injuries. *Cochrane Database of Systematic Reviews*, 2006, (4):CD003600.
- 9. Celler BG, Lovell NH, Chan DK. The potential impact of home telecare on clinical practice. *Medical Journal of Australia*, 1999, 171:518–521.
- 10. Farrero E et al. Impact of a hospital-based home-care program on the management of COPD patients receiving long-term oxygen therapy. *Chest*, 2001, 119:364–369.
- 11. Les technologies de la santé à domicile: opportunités et enjeux. Paris, Ministry of the Economy, Finance and Employment, 2006.



4. The challenges for health policy- and decision-makers

Serving the right people at the right time with the right means

Policy- and decision-makers should orient their efforts towards three shared general objectives of every modern health and social system (1,2).

- A good system contributes to improving health and social life throughout the population.
- System responsiveness to non-medical expectations includes safeguarding people's dignity, confidentiality and autonomy and being sensitive to the specific needs and vulnerability of all population groups.
- Fairness in financial contributions to health and social needs requires sufficient funding to enable universal access to services without forcing individuals or families into poverty.

The correct development of home care is directly tied to how well the systems carry out the key functions of service delivery in home care, funding home care, creating resources in home care and roles and responsibilities in home care.

Service delivery in home care

The complex process of delivering home care should focus on the following key aspects.

- Needs assessment: clear eligibility criteria, proper screening, early and multidimensional needs assessment should be part of modernizing home care delivery systems in many European countries. Care would be directed at those for whom it would do the most good, the ultimate clients being both the direct users of the services and the informal carers.
- Integration: individual provider units should be coordinated, which aims at ensuring efficacy and efficiency, improving the quality and increasing the level of satisfaction of both users and providers of care. The means to this end include enhancing continuity, tailoring services and empowering service users.
- Proper management skills: managerial skills are important at all levels of the home care delivery system. Both social and health care staff will have to perform more managerial work in addition to direct care. The same is true for the national, regional and local governments to cope with the necessity of developing steering mechanisms

for commissioning, contracting, purchasing, planning, evaluating, quality assurance mechanisms and producing policies aimed at recruiting and retaining home care workers that include appropriate levels of training and pay.

 A central service point for advice, information and help is necessary to support clients in clarifying their needs and to improve cooperation between different home care professionals and non-professional providers.

Funding home care

Reforms to fund home care services should be based on integrating the funding systems and overcoming institutional barriers, especially between outpatient and inpatient care, between health and welfare services and between professional and informal care. Policy- and decision-makers need to consider several other issues:

- the availability of reliable information on home care usage and current public and private expenditure;
- clear criteria for deciding how to shift resources among levels and components of care to make transparent what is publicly funded and what is privately paid by the user; and
- ensuring the correct use of market mechanisms (such as cash payments, care allowances, personal budgets and vouchers), focusing on sustaining current funding arrangements given the anticipated increase in demand.

Creating resources in home care

Professionals and the public need to be educated in home care. Training of home care personnel is largely inadequate and should be improved if home care is to remain viable with increasing demand, increasing complexity of care and diminishing informal support networks. Specifically (3):

- more training needs to be provided to home care users and their informal support network members;
- training for professional home care personnel needs to become more integrated and multidisciplinary and should include skills training and training in establishing positive interpersonal relationships; and
- home care personnel need to be trained in the use of technologies as part of home care services.

Investment decisions in home care need to be supported and planned, as technological innovation (medical and non-medical) plays an important role in the future of home care.

Roles and responsibilities in home care

The roles and responsibilities in home care involve different levels of government: local, regional or district or central (4). Different levels of government are involved in different types of decisions about funding, allocating and delivering home care and their roles differ between countries. This variation needs to be taken into account in making recommendations about responsibilities at the various levels.

- At the national level, policies are needed to guide planning, legislation and regulation of home care. Central administration should be responsible for setting defined priorities on allocating scarce resources (such as the equilibrium between institutional and primary or community care). In addition, central administration should be responsible for developing human and material resources homogeneously across the country.
- District or regional management is responsible for allocating resources based on clearly defined priorities set by the national administration. National standards should be adapted to meet district or regional and local needs, and district or regional guidelines for home care should be established. The level of administration at the district or regional level and the responsibility decentralized to the community or local level should be decided. In most European countries, the "health" component of home care is part of the health care system, whereas local governments organize and take responsibility for the "social" component of home care. Decisions must be made in the planning stage of home care and guidelines developed so that each level of administration realizes and meets its responsibilities. Such guidelines should help to avoid the problems of duplication, gaps and conflicts in providing services.
- Local government: home care is applied in practice at the community level, regardless of who directs it. The culture of the community organization and its norms, standards and leadership play an important role in the home care programme. Strategies must therefore be developed that promote effective leadership and mobilize community action in planning and implementing home care, consistent with the organizational structure adopted (single provider, separation between health and social care or separation of responsibilities at different government levels). This community involvement includes the participation of carers, service users, health and social service workers, community volunteers, community members and influential leaders. This means that all community members associated with home care should be involved in initiating, ensuring the responsiveness of and sustaining the programme.

References

- Strengthened health systems save more lives: an insight into WHO's European Health Systems' Strategy. Copenhagen, WHO Regional Office for Europe, 2005 (http:// www.euro.who.int/healthsystems, accessed 25 July 2008).
- 2. The Health for All policy framework for the WHO European Region: 2005 update. Copenhagen, WHO Regional Office for Europe, 2005 (http://www.euro.who.int/Information Sources/Publications/Catalogue/20051201_1, accessed 25 July 2008).
- 3. Home-based and long-term care: home care issues and evidence. Geneva, World Health Organization, 1999 (http://www.who.int/chp/knowledge/publications/Chronic_conditions/en/index.html, accessed 25 July 2008).
- 4. Community home-based care in resource-limited settings: a framework for action. Geneva, World Health Organization, 2002 (http://www.who.int/chp/knowledge/publications/Chronic_conditions/en/index.html, accessed 25 July 2008).



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