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Abstract

How to care for those who are dependent and disabled, whether because of age or sickness, is a recurring theme in today's world. As a result, most countries throughout the world are introducing programmes to provide home-based care for those with reduced autonomy.

The stakes are high: life expectancy and consequently the proportion of old people within the population are steadily increasing. The result is increased dependency, often combined with fundamental changes in traditional care structures and in particular the family, foremost among them.

Last but not least, it represents an economic issue which all countries are obliged to resolve.

Hence the need to ask what the role of social security, taken in its broadest sense, should be in the provision of home-based care.

The problem is identical everywhere, but responses vary depending on whether the national traditions are based on Beveridge or Bismarck, or are closer to those of Southern Europe. It is true that all of them seem to be in favour of home-based care; the main differences lie in their understanding of what it involves.

One fact is obvious: social security is involved everywhere. However, its degree of involvement varies from one country to another and this has a major influence on the provision of such care, and in particular on its financing.

A further element is the multifarious nature of social security activities. It may at one and the same time, be involved in promoting home-based care (supplying benefits, training professionals to meet this new type of need), assessing the degree of dependence (involvement in the design of assistance programmes), coordinating the various actors involved (particularly in networking), monitoring the quality of the care provided and providing support for families (family benefits in kind or in cash to assist families to take care of those with reduced autonomy).

Social security, however, in spite of its praiseworthy efforts, cannot manage without the other actors involved in providing social protection; the responsibility for dependency, in particular, must be global in order to be effective. In other words, it is essential that such care must include not only medical treatment (where the role of social security is vital) but also social factors (where the role of social security is, at best, passive).

Most countries are now introducing reforms to keep dependents with reduced autonomy, at home. Some are more advanced than others, for cultural and/or structural reasons, but the fact remains that all of them share the same philosophy. Finally, it is worth

emphasizing that in spite of the remaining divergences, there is consensus on the key role of social security organizations; as the cornerstone of this system, they constitute the essential interface between all those involved in providing home-based care.

Introduction

Home-based care is directly related to the concept of dependence. Ageing, the development of chronic and disabling diseases, the AIDS pandemic and family isolation are among the factors which combine, at the dawn of the twenty-first century, to ensure that social protection systems cannot afford to ignore it.

One of its main characteristics is that dependents, either because of their state of health or in addition to it, need help to perform the essential acts of day-to-day life (eating, personal hygiene, dressing, mobility, etc.).

This means that the concept of home-based care will involve a complex pattern of assistance combining medical and technical assistance and possibly surveillance, which are the responsibility of sickness insurance, as well as day-to-day help which will be provided mainly by the family with the support of specialized services. Many actors will be involved: health professionals and specialists in home-based care, hospitals, the social services, associations, local communities ...

This complexity makes the financial implications difficult to estimate but in most cases home-based care is less expensive than placement in an institution. How then can the long-term survival and financial independence of such a system be guaranteed, in the face of increasing demand?

While dependence is almost inevitable its effects may, if appropriate steps are taken, be reduced or retarded. This being so, what can be done to guarantee the efficiency and quality of the global network of medico-social care?

Social security, defined by the International Labour Office (ILO)[1] as the "protection provided by a community for its members by means of a series of public measures", clearly has a role to play in this equation; the question is what that role should be.

The first section of this report will concentrate on defining the issues involved in the participation of social security institutions in providing home-based care for individuals with reduced autonomy, before moving on to examine their role in providing financial support, and finally in providing treatment.

[1] ILO. 2000. *World Labour Report 2000*, International Labour Office.

1. The issues involved in home-based care

1.1. Demographic and epidemiological issues

By the year 2025, 11 per cent of the world's population will be over 65; the fastest growth will be in the oldest age groups: there will be twice the present number of people over 80 (2 per cent of the world population) and two and a half times the number over 85[2]. However, this rapid acceleration in the ageing of the population as a whole hides wide regional differences, with countries divided into three main groups. For this same period, average estimates concerning the population over 65 years of age, vary between:

- 4 per cent for more than 70 countries, half of them in Africa;
- 9.4 per cent for about 40 countries, mainly located in Asia and Latin America, which are in demographic transition; and
- 20.9 per cent for countries which have reached an advanced level of demographic transition (Europe, United States, Canada, Japan and certain countries in Asia and Latin America).

In the European Union alone, the number of highly dependent old people is estimated at 9 million; over 3.1 per cent of the population in France will be over 85 in the year 2025.

The issue of home-based care is particularly acute in developing countries, as a result of increased chronic diseases (respiratory insufficiencies, for example) or disabling pathologies (Alzheimer's disease) connected with age. However, it applies equally to the development of other diseases which also induce a state of dependency, particularly the AIDS pandemic.

In this context, a recent report of the World Health Organization (WHO) estimates that between 34 and 46 million individuals are HIV-positive throughout the world; two-thirds of them are concentrated in Africa, where one person out of twelve is infected. In Botswana, for example, a programme of home-based care was introduced for AIDS sufferers in 1990, because available institutional care was insufficient to cover the needs of patients, and also because the family is most effective target in terms of AIDS prevention.

1.2. Sociological issues

The impact of demographic factors is further heightened by sociological issues arising mainly from changes in family structure and in the structure of rural societies, which are affecting all countries.

[2] *Source:* INED (*Institut national d'études démographiques*), *www.ined.fr*.

In Asian countries in particular, problems connected with ageing are compounded with those created by a massive rural exodus, an increase in the number of working women, and housing problems. In China, for example, 90 per cent of the population over 60 was in the care of descendents in 1987. In 1997, ten years later, less than 25 per cent of Chinese households included a dependent.

Although it is less obvious in rural areas, the same trend is apparent in Thailand, where 44.6 per cent of households cared for dependent relatives in 1997, in the Philippines, India, Malaysia and the Fiji Islands.[3]

In sub-Saharan Africa, however, it is the AIDS pandemic rather than ageing, which is responsible for changes in family structure.

1.3. Economic issues

The third argument in favour of the development of home-based care is its comparatively low cost, when the only alternative for dependents is placement in an institution. The cost of the latter often places a heavy burden on families as well as on communities. In addition, few countries have the infrastructure needed to cope with increased needs in coming years. It is therefore essential both for the well-being of the individual and for the community, to encourage home-based care in order to maintain its quality.

As an indication, the cost of care for dependent persons amounts to between 1 and 3 per cent of gross national product among members of the European Union.

1.4. Care quality

Home-based care for dependent people avoids breaking down their social networks and destroying their individual frames of reference, and thus provides a better quality of life. The effects of the heat wave which swept Europe in the summer of 2003 highlight this; the death rate was lower among those living in their own homes (24 per cent for those living at home, compared with 76 per cent for those in institutions).

All these factors indicate that there will be an increasing need for home-based care in coming years and that the time has come for government action to forestall the economic and financial consequences on the one hand, and to create an appropriate care network, on the other. We will examine the role of social security in the development of home-based care from these two angles.

[3] ISSA. 2000. *Social security issues and research capacities in Asia and the Pacific – A six-country study*, Social Security Documentation, No. 24, Asia and Pacific Series, International Social Security Association.

2. What is the role of social security in the financing of home-based care?

Home-based care for those who are ill and/or dependent, as described above, relies on the availability of the technical and medical care required by their state of health, as well as assistance in their day-to-day lives. It is difficult, when trying to develop a funding model, to distinguish between the responsibilities which should be borne by sickness insurance and those which should be covered by a special system dealing with dependency.

Examination of the main existing models, reveals that although the solutions adopted to provide funding are related to the social protection systems previously adopted by the various governments and their "generosity", they are also characterized by the systematic participation of national and geographical communities (provinces, regions, local municipalities …) and that the models tend to overlap.

Generally speaking, care systems in the more developed countries fit into one of three categories: in the "Beveridge" countries, most home care is covered by the community through local services and benefits financed mainly through taxation. In "Bismarck" countries, dependency is recognized as a "risk" in its own right and is therefore covered by special insurance financed through contributions from employers and staff. Finally, the last group of countries, most of them in Southern Europe, prefer a system of social assistance which exists alongside the social security scheme and is incomes-based.

2.1. The Beveridge model

The Northern European countries (Denmark, Finland, Sweden and the Netherlands) pioneered the development of this type of care in the 1970s: home-based care is integrated in public health measures; it is mainly decentralized, with the local communities taking on the major responsibility, and nursing care and medical appliances are often provided free of charge (Denmark).

In Sweden, the social protection system replaces the family to enable dependents to retain their autonomy. 80 per cent of the funding is provided through local taxation, the remaining 20 per cent being provided by central government (2 per cent), individual contributions (9 per cent) or supplementary income.

The "liberal" systems which exist in the Anglo-Saxon countries are less generous. In the United Kingdom, funds provided jointly by the local authorities and the National Health Service (NHS) are used to purchase services from suppliers who are frequently privately-run. Since April 1993, the social services of the local authorities have been responsible for managing these funds. All costs are covered from global budgets which include both

placement and maintenance in the home environment, which creates an incentive to avoid placement in institutions. The cost of treatment is covered entirely for those over 60, but other benefits (in the form of a "care package") are few and are income-related.

2.2. The Bismarck model

A new branch of social protection was created in Austria in 1993, in Germany in 1994, and Luxembourg in 1998 and in Japan in 2000, to provide insurance cover for dependency.

However, although in Bismarck models, cover for the sickness risk is based on contributions paid by employers and salaried workers, the emergence of the dependency risk seems to have brought about a change in the distribution of responsibilities.

In Germany, dependency insurance, which is intended to cover only part of the needs, is financed by a contribution of 1.7 per cent of gross salary, divided equally between employers and employees; retired workers contribute in the same way, sharing contribution premiums with their retirement organisms. 90 per cent of the population subject to compulsory sickness insurance, is covered. The remainder, who are covered by private sickness insurance, are also obliged to cover the dependency risk through a private organization.

In Luxembourg, the compulsory dependency insurance scheme relies on mixed funding: the government assumes 45 per cent of the expenditure while the actively employed and pensioners pay a special contribution of 1 per cent of their gross income.

Japan also has a mixed system: 50 per cent of the funding is provided from incomes-based contributions from beneficiaries (33 per cent) and pensioners (17 per cent). The other 50 per cent is provided by the national government and local authorities. This system provides all dependents with access to a wide range of benefits (home calls from nurses, assistance with personal hygiene …)

2.3. The "Southern European" model

In the Mediterranean countries, there has been far less discussion about the need for insurance cover for "long term support", mainly because of a strong tradition of family-based models of informal care as well as major budgetary constraints. In these countries, benefits are allocated under both contributory protection systems (for instance those covering sickness, disability, work accidents and old age) and the social welfare system. The benefits provided for dependent persons are paid mainly on the basis of disability or old age, with a higher pension rate for the latter.

In Italy and in Spain, the governments provide funding for the *indennità di acompagnamento* and the *ayuda de soporte*.

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In Spain, for example, home help is provided free of charge for minimum pension holders and paid for in full, by those who have double the minimum income. Payment is based on income for those who fall between the two extremes. Spain has only half the amount of communal housing available in other countries, because the tradition of it being the family or close relatives who provide care, continues to predominate. Ambitious projects to modernize the way in which care is provided for dependents are being implemented within the framework of the "Plan of Work 2000-2005" for old people. Their main characteristics are the widespread decentralization of the services provided and the participation of users in the definition of the programme, but there are no changes, as far as we are aware, in the financial equilibrium.

Greece and Italy also have a certain number of special programmes which are administered locally.

France is a special case because it is going through a transition period. It provides a personal autonomy allowance *(allocation personnalisée à l'autonomie* (APA)) which resembles the allowances paid in the countries following the "Southern European" model, financed by a tax of 0.1 per cent taken from all household income and by a contribution from all the compulsory old age insurance schemes. It consists of a cash benefit, allocated on the basis of income and the degree of dependency of the individuals concerned.[4]

In addition, at the time of writing, the system was moving towards the creation of a National Solidarity Fund for Dependency (*Caisse nationale de solidarité pour l'autonomie* (CNSA)) funded through the APA described above, plus a contribution of 0.3 per cent from state and private employers, balanced out by the introduction, as in Germany, of a day of solidarity, and a contribution of 0.3 per cent on income from property and investments. In the draft legislation currently under discussion, the *départements* (provinces) would be in sole charge of the care programmes for dependents and responsible for pricing and financing establishments (including treatment) while expenditure on out patient care would remain the responsibility of the sickness insurance. The CNSA would act as a monitor for local policies and its mandate would be to "supervise and assist in guaranteeing equal treatment throughout the national territory".

Examination of the different methods of finance clearly reveals that governments have been obliged, over a relatively short period, to adapt to the increasing burdens of home-based care, by helping those concerned and/or their families to assume them beyond the initial scope of social assistance. They have had to provide substitute financing, which is more or less generous and based more or less on solidarity, depending on the approach of the government.

[4] "L'allocation personnalisée d'autonomie au 30 septembre 2003", *Etudes et Résultats*, No. 281, December 2003, Direction de la recherche, des études, de l'évaluation et des statistiques (DREES), ministère des Affaires sociales, du Travail et de la Solidarité/ministère de la Santé, de la Famille et des Personnes handicapées.

However, while the measures described above indicate that the financing of home care is guaranteed for several years to come, it remains to be seen whether it will be sufficient to reach the desired the desired objectives in terms of equity, efficiency and quality. Among others, these include:

- coordination of health and social aspects, out patient and hospital care;
- neutrality of financing based on the best solution for the individual;
- efficient needs assessment;
- move towards professional treatment;
- support for families.

3. What is the role of social security in home-based care?

Since this involves the implementation of global care, both medical and social, the term "home-based care" includes both the treatment provided by health professionals and the services provided for the individual concerned by the family or any other specialized service, in the current document.

Even if, as you will see, the social security is not the only actor involved in providing home-based care, it has a primary role to play in organizing the provision of quality care adapted to the needs of the individual.

3.1. Access to appropriate benefits

Its first task is to provide the necessary benefits for home-based care. These are:

- Benefits in kind: house calls, nursing care or kinesitherapy, personal hygiene, hours of home help, medical appliances and technical support, adapted housing and vehicles …; Japan for its part supplies only benefits in kind in order to encourage the use of specialized professionals; in Germany, for the same reason, benefits in kind are of more value than their equivalent in cash. However, the amounts provided in the form of cash benefits are the same whatever the location of the beneficiary, in order to guarantee their neutrality.
- Cash benefits: although certain countries such as Austria, for example, provide only cash benefits, in most cases cash benefits are provided in addition to benefits in kind; they finance certain additional benefits (home help, tele-assistance …) but above all, as in Sweden or in Spain (*ayuda de soporte*) they provide compensation for the support provided by the family.

The volume of such benefits has risen steeply (11 per cent per annum in Canada between 1991 and 1997), so it is essential to ensure that they are distributed appropriately on the basis of reliable criteria.

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3.2. Assessing individual needs

Most countries have introduced measures for needs assessment to make it possible to monitor that benefits are in line with individual needs:

- Luxembourg has set up a multi-disciplinary unit (doctor, nurse, psychologist, physiotherapist, ergo therapist, social assistant) to assess and provide instructions, which is independent of the dependency insurance; based on a medico-social table, it determines the care and assistance required in the form of weekly credit hours.
- "Case Management" as used in the United Kingdom, is a means of ensuring that benefits are suited to needs and to overcome obstacles of the institutional type which may exist between the various suppliers of benefits.
- The French AGGIR (*Autonomie gérontologique Groupes iso-ressources)* table comprises six levels of dependence and is used to establish the programme of support linked with the APA.
- In Japan, the amount of support which will be provided is determined with the help of a computerized "care needs certification" system.
- In Germany, assessment is carried out by medical doctors from the funds together with social workers.

3.3. Coordination of the various interveners

Alongside the health professionals and medical auxiliaries who intervene as decided under the above-mentioned programmes, the social security funds have recognized the need to coordinate activities in order to ensure better provision of home-based care and keep the individual as the "focus of attention".

Coordination networks have been developing in France since 1996, within an experimental framework, in order to facilitate the global provision of home-based care for patients suffering from major or chronic pathologies. General practitioners are at the heart of this network which combines local (sector) hospital care, self-employed medical auxiliaries and home nurses (*services de soins infirmiers à domicile* (SSIAD)), social services and domestic services (home help, home delivery of "meals-on-wheels" and medication).

The Social Agricultural Mutual Benefit Society began an experiment directed towards the rural population in March 2000, which is now showing positive results. The number of old people benefiting from this network is increasing, its satisfaction rating, including among health professionals, is high and the experiment has changed their perception of both sickness insurance and social work.

In Canada, local community health centres (*Centres locaux de soins communautaires* (CLSC)) are responsible for running home-based care programmes.

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3.4. Encouragement and monitoring of high-quality care

Social security also monitors the quality of the care provided.

In France, for example, certain health professionals have signed "good practice and public health" contracts which emphasize prevention and improved quality of care; they enable follow-up files to be created and transmitted for monitoring to sickness insurance funds medical services.

Germany has 13,000 out-patient care units; the latter have been obliged to introduce an internal quality control mechanism, and external monitoring is carried out by the medical services of the sickness funds: more than half of these units have been monitored in this way since 1997.

These controls enable the training needs of health professionals to be assessed. In this context it is worth noting that France will recognize geriatrics as a medical specialization in its own right as from the beginning of the academic year 2004, in order to provide a better understanding of the particularities of providing care for old people through medical training. The old age insurance funds are also taking steps to ensure that prevention training is given to paramedical auxiliaries providing home-based care.

3.5. Sharing the responsibility with other actors

Alongside the medical and health care provided by health professionals, a whole range of personal services to the individual are indispensable as part of the global provision of medico-social care. A large number of social security thus interact with the individuals concerned and their families to supply them.

This includes the municipalities, who often organize meal and medication delivery services as a part of their social welfare centre activities, associations and mutual benefit funds which provide nursing facilities, foundations which organize the work of volunteers who accompanying those who need it …

In Greece, 102 programmes propose a wide range of domestic services: medical care and house calls, nursing care and kinesitherapy, group social assistance for a community or a family, a range of practical services (shopping, administrative formalities …) as well as home help services to do housework; they are managed jointly with the local authorities and the centres for the protection of old people (*centres de protection pour les personnes âgées* KAPI)).

In France, the government and the local communities jointly approve departmental geriatric plans and regional communities are deeply involved in caring for old people. Certain of them, for example, organized or facilitated the creation of *téléassistance* centres to link isolated,

elderly or handicapped individuals with those who can provide help. The most advanced in this domain remain the Scandinavian countries, which gave high priority to tele-assistance for individuals in their plans for assistance to those whose autonomy is reduced.

Local geriatric information and coordination centres (*Centres locaux d'information et de coordination gérontologique* (CLIC))[5] are responsible for providing public information on existing benefits and coordinating all the interveners.

3.6. Support for families

The family plays an indispensable role which is complementary to those of the social security and other actors; the home-based care network must therefore include "support for the supporters" to be considered complete.

- Primary support for families consists of benefits in cash or in kind which are distributed to dependents to enable them to stay at home when the family cannot be permanently present or to provide assistance for a certain number of functions (personal hygiene, handling ...) The presence of nursing assistance, a home-help or a sick-nurse are the most frequent forms of benefit.

- Where members of the family are able to look after the dependent themselves, compensation is provided in the form of cash benefits. They may contribute to pension schemes and receive benefits, either immediately or in the form of capitalization, as in Japan where hours of voluntary work bestow a right to hours of free help later on, for the person who has donated them.

- Another alternative for providing support to families may be provided through part-time day clinics; in Ghana, for example, day care centres have been set up to allow families to share the responsibility for looking after old people, which makes it easier for a family to continue to provide support.

- France proposes an original home-based care structure in the form of rural reception centres for old people (*maison d'accueil rurale pour personnes âgées* MARPA)). These were launched in 1987, and more than a hundred of them exist today. They are small (25 places) and offer their residents living conditions close to those of a private home, with all the benefits of adapted architecture, security, and the company and the stimulation to be found in a communal establishment. In choosing assistance of a "domestic" kind for their residents, the MARPA makes use of nursing facilities available in the area where it is located.

[5] For information, there were 272 CLIC centers in France in 2002, in 87 provinces.

- Along similar lines, "alternative care" services have been set up to provide not only physical rest but psychological respite for those who are looking after dependents in need of constant care. Many countries provide accommodation for old people to take over from the family for a given period of time (holidays, temporary absence of the family).

- In Belgium, the mutual benefit funds organize holidays for old people as well as for the sick and disabled. The aim is to enable them to go on holiday under conditions of optimal security, which provides relief for their families at the same time. These holidays are organized by nurses and trained volunteers.

- Finally, when the family support is not possible, voluntary work, often through associations providing support for patients or charities, is strongly encouraged, particularly in North America. Volunteers go to the homes of the elderly, the dependent, the sick and the handicapped to pay them a visit, provide transport for medical examinations, to go to see a doctor, go shopping, take part in a leisure activity or an association, do odd jobs or provide administrative help, alongside the home-based care provided by health professionals, in order to keep their social lives as active as possible.

Conclusion

In most countries, the objective of the reforms carried out in recent years is to limit institutionalization, through careful and accurate assessment of the needs and competencies of those whose autonomy is reduced, and to develop home-based care.

A certain number of pioneers, particularly among the Scandinavian countries, took early stock of the efforts required to face up to this emerging risk of loss of autonomy. Their experiences revealed the preconditions for meeting this objective while guaranteeing a certain standard of living: stable and neutral funding, a global approach combining preventive medicine and medical care, as well as health and social welfare, access to appropriate benefits, professional training and coordination for all participants and support for families.

Since then, a large number of countries have implanted home-based care programmes, thus demonstrating their growing awareness.

There is no unique model, because the solutions found differ according to the social protection systems already in place; however, all of them depend on their social security institutions, which play a major role whether in terms of providing care or coordination, but which cannot bear the burden of successful home-based care on their own. They must be able to intervene within the wider framework of a policy which incorporates and gives responsibility to local communities, associations and mutual benefit funds, guarantees equal access to benefits, provides attractive working conditions for professionals providing home-

based care and uses both national and family solidarity, local and public service support, including social protection organisms, to reach its objectives.

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