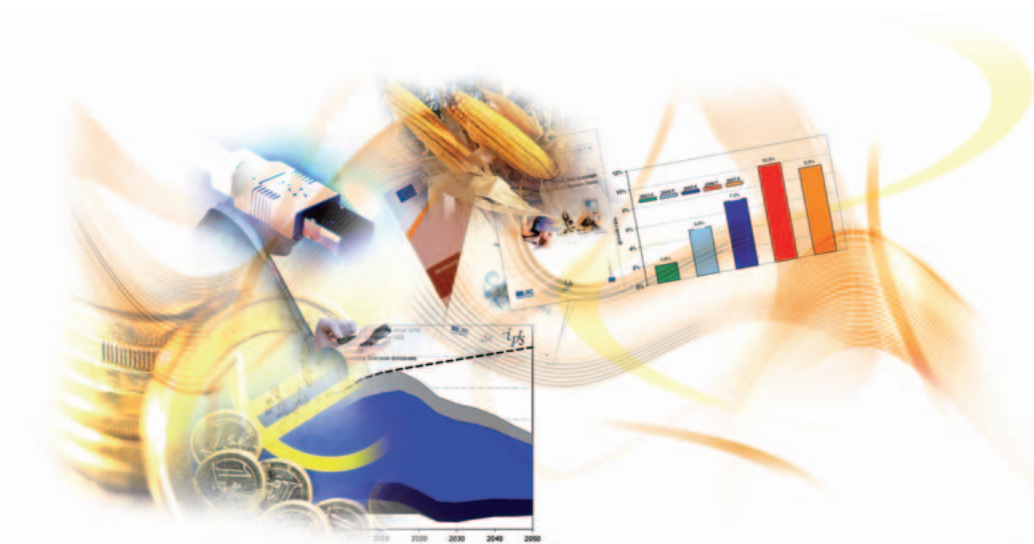


The Potential of ICT in supporting Domiciliary Care in Spain

**Authors: Christine Redecker, Juan Reig, Trinidad Carrión,
Sara Martinez, Manuel Armayones,
Desmond McCarthy and Manuel Fernandez**



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However, as ever, the views and conclusions expressed in the report, together with any errors or omissions, are the responsibility of the authors.

■ Preface

Launched in 2005 following the revised Lisbon Agenda, the policy framework 'i2010: A European Information Society for Growth and Employment' has clearly established digital inclusion as an EU strategic policy goal. Everybody living in Europe, especially disadvantaged people, should have the opportunity to use information and communication technologies (ICT) if they so wish and/or to benefit from ICT use by service providers, intermediaries and other agents addressing their needs. Building on this, the 2006 Riga Declaration on eInclusion¹ defined eInclusion as meaning "both inclusive ICT and the use of ICT to achieve wider inclusion objectives" and identified, as one of its six priorities, the promotion of cultural diversity in Europe by "improving the possibilities for economic and social participation and integration, creativity and entrepreneurship of immigrants and minorities by stimulating their participation in the information society."

In the light of these goals, and given the dearth of empirical evidence on this topic, DG Information Society and Media, Unit H3 (eInclusion) asked the Institute for Prospective Technological Studies (JRC-IPTS)² to investigate from different angles the adoption and use of ICT by immigrants and ethnic minorities (henceforth IEM) in Europe and the related policy implications. In response to this request, IPTS carried out the study "The potential of ICT for the promotion of cultural diversity in the EU: the case of economic and social participation and integration of immigrants and ethnic minorities", the results of which are available at the URL: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html>.

In Summer 2008, as part of this research effort and following a pilot study performed a few months earlier in Italy, IPTS issued three tenders for parallel, linked studies to be conducted in Germany, Spain and the UK on the "The potential of ICT in supporting the provision of domiciliary care, with particular attention to the case of migrant care workers and informal carers". Given the widespread presence of migrant workers in both formal and informal long-term care services and also the growing diffusion of ICT-based tools and services in the provision of care in domiciliary settings, the studies aimed to broadly assess the current level of ICT diffusion in those settings and the current and potential support they provide to the diverse range of carers involved (paid and unpaid, qualified and authorised or not), including those from a migration background.

This document is the final report on the research carried out between January and May 2009 in Spain. The reports on the other three countries and a cross-analysis of main findings stemming from them are all available at the URL:

<http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html>.

1 Available at http://ec.europa.eu/information_society/events/ict_riga_2006/doc/declaration_riga.pdf.

2 The Institute for Prospective Technological Studies (IPTS) is one of the seven research institutes of the European Commission's Joint Research Centre (JRC).

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■ Executive Summary

One of the key challenges in long-term care in Spain, as in the rest of Europe, is the increasing tension between the growing number of older people in need of care, and the decreasing number of available carers, together with a preference for domiciliary over residential care. There are almost 8 million people aged 65 or older living in Spain, accounting for 17% of the total population. 2 million of them are 80 years old or older. Today, 65 year olds living in Spain can expect to live another 20 years. However, on average, only half of these years will be spent in good health. In particular, disability rates increase with age. In 2008, 2.2 million people aged 65 and above (30% of this age group) were affected by a disability.

Family care, provided predominantly by women, has a long tradition in Spain and reflects the preferences of both care recipients and carers. Although public support to long-term care provision at home has grown over the past few years, informal care, predominantly given by family members, still represents the bulk of care provided to the elderly in Spain. Nearly 90% of dependent people are cared for in their homes. Of those aged 65 and above, 75% – about 1.4 million people – are exclusively cared for by family members and friends, or, in 14-17% of cases, by privately employed caregivers. In roughly two thirds of cases, the caregiver and the care recipient live under the same roof. The majority of family carers are women between 45 and 64 years old. 43% are daughters, 22% are wives and 8% are daughters-in-law of the care recipients. The majority of carers are married (75%) and do not work outside the house (73%).

Since the implementation of the Dependency Law of 2006, a higher share of disabled people benefit from public services. In 2009/10, more than one million people of all ages were

recognised as being dependants. However, only in two thirds of cases some service or payment was awarded, with the result that around 450,000 people aged 65 and older received some public service to support their care needs. Public domiciliary care services were granted in only 16% of the cases of home care provision, whereas a financial compensation for family care was awarded to 70% of dependants who were not in residential care. Thus, public long-term care provision, though it only reaches a minority of older people in need of care, further reinforces informal care provision at home, and sets incentives for families to privately organise assistance, if needed, to complement and supplement their care engagement.

Recent trends, if they continue, could challenge the sustainability of the current family-based care arrangement. Firstly, the number of female caregivers in gainful employment has been increasing over the last few years, accounting for 25% in 2004 as compared to only 19% in 1994. Furthermore, due to the fact that women now tend to give birth later in life, carers increasingly have to take care of their children and parents at the same time. In parallel, the rise of diseases and chronic health conditions among the older population is reflected in an increase of care tasks and demands. Most notably, the share of care recipients needing assistance in all areas of their daily life increased from 44% in 1994 to 68% in 2004. Furthermore, the frequency and intensity of care demands have grown: more carers assist their relatives permanently (77% in 2004; 73% in 1994) and 57% (53% in 1994) spend more than 5 hours a day on care. In 2004, on average 11 hours a day were spent on care.

Moreover, 90% of carers are not trained and, in 84% of cases, carers do not receive any support from outside their family network. Assistance

provided by municipalities (5%) and other public and private service providers (in total below 3%) is not available to the vast majority of carers. As a consequence, 85% of family carers feel that caring negatively affects their daily lives; 80% are affected in their leisure and family life; 61% face consequences for their professional or economic situation and up to 66% report that they suffer health problems because of their caring duties.

In response to a situation in which the family network increasingly lacks the capacity to meet the care need, care assistants (many of them of migrant origin) are more and more frequently employed privately by the care recipients and their families to substitute or supplement family care. The exact number of care assistants and their personal profiles are unknown. Some sources speak of 200,000 to 600,000 migrant care assistants, whereas more cautious estimates calculate a total of less than 100,000 care assistants, 40% of them of migrant origin.

Combining findings from different rigorous data collection exercises indicates that between 12% and 20% of elderly people in need of help are assisted by a “domestic employee”, at least in some of their daily tasks. In over 100,000 households, care assistants are employed to live in elderly disabled people’s homes to act as the main caregivers. Between 40% and 68% of these care assistants are migrants, predominantly from Latin America and, to a lesser extent, from Eastern European countries. The vast majority of care assistants are women. Their salaries are very low, not only in absolute terms (€600 to €800 per month for full-time work), but, in particular, when considering the activities that care assistants are expected to perform. They accept these terms for lack of alternatives and are welcomed by families, irrespective of their level of competences and training.

There are marked differences between native and foreign care assistants, indicating that immigrants tend to be more intensively involved in care tasks. 85% of those living with

the care recipient were of foreign nationality. 90% of migrant care assistants are giving care on a daily basis, as compared to 74% of native care assistants. Reflecting the different living arrangements for migrant and native care assistants, 32% of migrants compared to only 1% of native care assistants work 24 hours a day. 60% of migrant care assistants are employed for continuous care, covering morning, afternoon and night, compared to 11% of native care assistants. Moreover, migrant caregivers are employed as the main caregivers more frequently than their Spanish colleagues. 87% of migrant care assistants considered themselves to be the main source of care provision, in 48% of cases their assistance was the only help the care recipient received (as compared to 69% and 29% for natives). Only 17% have a binding contract with social security benefits and, in the remaining 73% of cases, there are no plans to legalise the work relationship.

Looking at ICT take-up and usage patterns in Spain, it becomes clear that old people in need of care and their caregivers are affected by multiple digital divides (i.e. gender, age, and nationality) and possibly by educational and economic divides as well. As a consequence, ICT tools and services are currently not widely exploited to support home care. However, a number of trends indicate that care recipients and caregivers are becoming aware of the benefits offered by ICT and are starting to seize these opportunities.

Most significantly, the public telecare programme, which was implemented in 1992, has become a huge success and reaches increasing numbers of dependent people in their homes. In 2008, almost 400,000 dependants used this tele-alarm system, which thus reached 4.7% of the population aged 65 and older. Furthermore, there are a number of pilot projects and research trials for different assistive technologies, which could benefit dependants and their caregivers in the future.

In parallel to these efforts to mainstream telecare solutions, mobile phones have become a key tool for elderly and disabled people in ensuring their safety and keeping in touch with family and friends. Similarly, family carers and care assistants use mobile phones to facilitate their work and improve communication and coordination among the different actors involved in home care.

Furthermore, the internet is becoming a valuable resource for information and training for informal caregivers, which, in the future, could become a key tool for facilitating and improving home care provision. There already are a number of websites and online services, from both public and private institutions, offering support and guidance to people in need of care and their caregivers. Although older people, family carers and migrant women use the internet less frequently than other population groups, access and skills levels have been constantly increasing over the last few years and those who are connected display similar usage patterns as more privileged population groups. More than half of older internet users already use the internet to gain information on health issues and female internet users enquire about health issues more frequently online than men (59% compared to 49%). If the reliability, usefulness and appropriateness of this information were ensured, the internet could become a powerful tool for information and knowledge exchange, as well as for medical, psychological and emotional support.

Moreover, the internet is a rich, but under-exploited resource for training. Given the situation of caregivers, in particular those living with an older person, online courses and training materials could be an interesting way for them to upgrade their skills without neglecting their care responsibilities. Online training courses can

contribute not only to improving the quality of care provision, but also to increasing caregivers' prospects of making their care experience relevant for the labour market, thus opening up (future) job opportunities for them.

At the moment, the widespread use of internet-based services in home care is hampered by the still low level of internet access and skills among elderly dependants and their informal caregivers, and also by the lack of targeted, reliable, easily understandable and open information and training resources, which clearly address caregivers' needs and yield visible benefits for them.

To realise the full potential of ICT in improving the quality of home care provision and contribute to making long-term care sustainable in the future, policy action should focus on:

- Supporting the development, implementation and mainstreaming of ICT solutions for home care; in particular, for internet services providing information, training, support and guidance to informal caregivers;
- Raising awareness among caregivers and families who employ care assistants of the opportunities offered by ICT in improving the quality of care provision;
- Promoting internet access and skills of dependants and their caregivers;
- Improving access to training programmes for all caregivers, including (migrant) care assistants, and implementing qualification and certification schemes that allow them to make their caring experience relevant for their professional development;
- Legalising and regulating informal care provision, with a view to improving the status, work conditions and salary of privately employed care assistants.

1. Introduction

This study was commissioned by the JRC-IPTS³ in Seville and carried out by Consultores Euroamericanos Asociados (CEA) in partnership with Instituto de innovación para el bienestar ciudadano (I2BC). It is part of a comparative study that includes two other countries; namely Germany and the UK. The main objectives of this research are, firstly, to perform a prospective study on the current situation in Spain of (family) carers (i.e. unpaid and voluntary caregivers) and informally (and often illegally) employed care assistants who perform care tasks in the homes of elderly people, a great majority of whom are immigrants or belong to ethnic minority groups (IEM). Secondly, the research tries to identify how

Information and Communication Technologies (ICT) can contribute to improving the quality of caregivers' lives and of their work, with a particular focus on caregivers from migrant backgrounds.

Four research themes were derived from these principal objectives:

- To provide an overview of the organization of domiciliary social care provision and the role of carers and care workers;
- To explore the contribution of ICT to domiciliary care provision;

Table 1: IPTS definitions of different caregiver groups involved in home care

IPTS definition	Job contract/ declared to social security	Payment	Description	OECD definition ⁴
Care workers	Yes	salary/pay	Qualified and authorized (geriatric) nurses, usually employed by public and private care providers.	Practicing nurses
	Yes	salary/pay	Nursing/geriatric assistants and other care workers, without recognised qualification/certification in nursing.	Personal care workers
Carers	No	No	Family members, friends, volunteers not receiving any monetary compensation.	Uncompensated informal caregivers
	No	cash benefits / allowances	Family and friends who receive some monetary compensation for their care activities.	Compensated informal caregivers
Care assistants	No	salary/pay	Caregiver receiving a salary/pay by care recipient or his/her family but without a formal contract declared to social security	Undeclared caregivers
	No	salary/pay	As above but without residence and work permits	Undocumented migrants

Source: Kluzer et al. 2010.

³ The Institute for Prospective Technological Studies (IPTS) is one of the 7 research institutes of the European Commission's Joint Research Centre (JRC).

⁴ See Fujisawa & Colombo (2009).

- To examine the impact of ICT applications and the roles of the people providing the care in a domiciliary setting;
- To consider the ways ICT can improve the competencies and performance of IEM care workers.

To address these research objectives, a literature review was undertaken on the organization of domiciliary social care in Spain (Chapter 2), the contribution and situation of different caregivers groups (Chapter 3) and also on the contribution of ICT to domiciliary care provision (Chapter 4). A range of information sources were consulted and synthesized; an overview of the main data sources used is provided in Box 1:. Furthermore, I2BC conducted systematic research on caring organizations on the internet, and websites were chosen as representative case studies (Chapter 5) and conducted interviews with thirteen randomly-chosen migrant care assistants in Malaga to investigate in depth the situation of migrants who are informally employed as care workers, including their use of ICT (Chapter 6). Finally, CEA carried out interviews with experts

in the field of ICT and domiciliary social care to better assess the potential of ICT in supporting domiciliary caregivers, addressing the fourth research theme (Chapter 7).

Thus, the second chapter presents an overview of the social care system in Spain. In the third chapter the situation of family carers and informal care assistants, in particular those from migrant backgrounds, are outlined. The fourth chapter is devoted to a review of the current state of ICT usage and take-up by elderly people, immigrants and in support of domiciliary care. The fifth chapter presents an overview of ICT initiatives to support dependants, carers and care workers. Chapter 6 summarizes the results and analysis of interviews conducted with a random group of IEM care workers in Malaga. Chapter 7 provides a discussion on the applications of ICT to support carers and migrant care assistants, based on interviews with experts in long-term care. Chapter 8 offers conclusions and recommendations, including a considerations of the opportunities offered by ICT for supporting informal care assistants.

Box 1: Main Data Sources

INE: The National Institute of Statistics, INE, (www.ine.es) is a rich data source for statistical figures on population indicators, including, in particular, demography, nationality, immigration and also ICT use.

INE-EDAD (2008), the disability survey (“Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia 2008”): This rather comprehensive survey investigates the situation of people with disabilities, including the type and level of disability, their living conditions, the kind of care they receive and the situation of their caregivers. While the EDAD survey is a household survey, in 2008, for the first time, a special module (EDAD-centros) administered residential care centres was added. The data of the INE-EDAD survey is available from the INE website and has been published in INE (2009a), INE (2008a) and IMSERSO (2009).

IMSERSO: Publications by the Institute for Older People and Social Affairs (IMSERSO), which is affiliated to the Ministry of Employment and Social Affairs. These include a comprehensive report on the situation of elderly people in Spain, summarizing the wealth of data available in 2008 (IMSERSO, 2009) and statistical data on the number of applicants and beneficiaries of long-term care services (SAAD-IMSERSO, 2010). Furthermore, IMSERSO commissioned a series of surveys, in particular, the 2004 survey on informal help to elderly people in Spain (IMSERSO 2005a and 2004), which also investigated the role of privately employed care assistants, and a survey on the living conditions of elderly people, conducted in 2006 (IMSERSO, 2006; Abellán et al., 2007). Additionally, IMSERSO conducted an exploratory study on immigrants in domiciliary care (2005b).

■ 2. The Context of Long-term Care in Spain

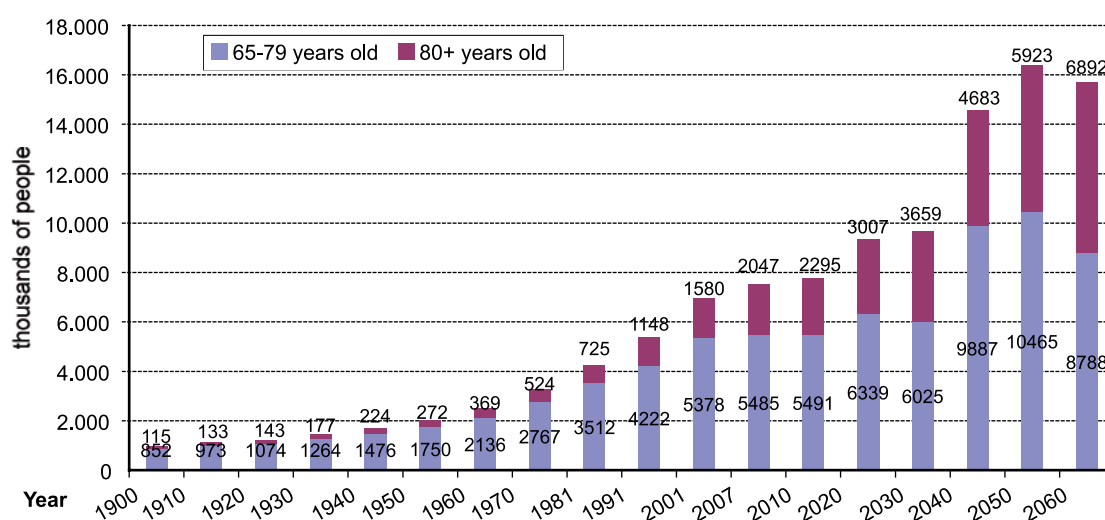
2.1 Demography, Dependency, Disability

According to preliminary figures for January 2010 (INE, 2010), the total number of residents in Spain is just below 47 million, 87.8% of which (41.2 million) have Spanish nationality. Thus, today there are 2.5 times more people living in Spain than at the beginning of the twentieth century (18.6 million). In the same time period, the numbers of older people, i.e. those 65 years old or older, has increased by eight. Today there are 7.9 million people aged 65 or older registered in Spain, accounting for 16.9% of the total population, whereas in 1900 this age cohort accounted for only 5.2% of the population. Projections by the national statistical office (INE) predict that in 2020-2050 the older population will grow eight times faster than the total population, so that, in 2060, 15.7 million people will be older than 65, accounting for roughly 30% of the total population (IMSERSO, 2009).

A further important aspect of ageing in Spain is the “Ageing of the Aged”, as expressed in the high rate of people aged 80 and above. In the years 2003 to 2007, the senior population increased at a rate of 4.9% whereas the cohort of the people aged 80 and above increased by 21.1%. According to the official data for the year 2007, 2 million people were 80 years old or older, representing 4.5% of the total population and 27.2% of old people (i.e. aged 65 and above). Projections estimate that, in 2060, 13% of the total population will be in their eighties or older, accounting for 44% of the senior population.

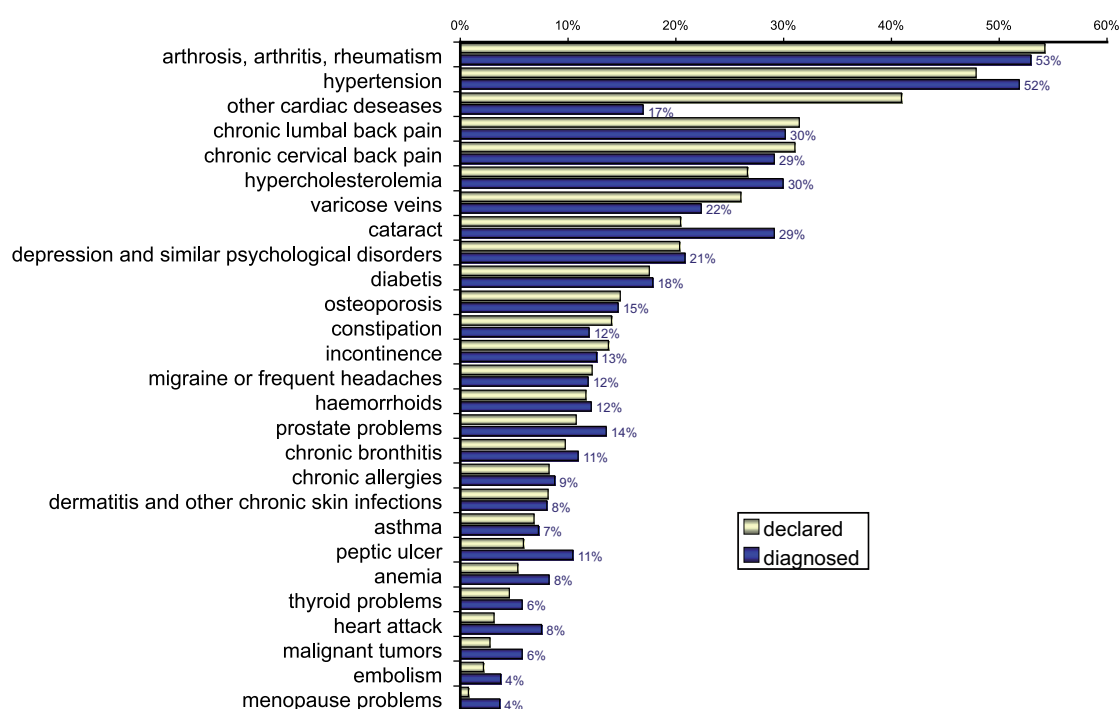
These increases in absolute and relative terms reflect decreasing fertility and increasing life expectancy rates. The mortality rate in Spain has fallen considerably during the past century. In 1900, only a third of the population was still alive at the age of 65; in 2000 almost nine in 10 people lived beyond this age. Today, at the age of 65, people living in Spain can expect to live another 18 years if they are male and

■ Figure 1: Number of people aged 65 and above, 1900-2060, in thousands



Source: adapted from IMSERSO, 2009, p. 44; for 2010-2060: estimation; 2008 data.

Figure 2: Incidence of different chronic or long-term diseases as declared by respondents aged 65+ and as officially diagnosed in the 65+ population, 2006



Source: Illustration of table 2.18 and 2.19, IMSERSO (2009), p. 99 and 100.

another 22 years if they are female (Eurostat data for 2008). However, on average, only 10 of these years will be spent in good health (Eurostat data for 2007). These figures indicate one of the major consequences associated with the growth of the older population, namely an increased incidence of chronic diseases and of disabilities, leading to a higher share of dependent people.

While people live longer, the incidence of different chronic diseases among those at retirement age is high. The most recent National Health survey (INE-MS, 2006) revealed that 53% of people aged 65 years old and older have been diagnosed as suffering from a rheumatic disease; 52% from hypertension; 30% from chronic pain in the lower back. High cholesterol values are diagnosed in 30% of cases and depression affects 21% of the older population. In 2006/07, the percentage of people aged 65 and over who deemed their

health to be good or very good was 48.4% in the case of men and 33.2% in the case of women. That same year, 22.8% of women and 13.2% of men considered their health to be poor or very poor (Ministerio de Sanidad y Política Social, 2010). In other words, 66.8% of women and 51.6% of men aged 65 and above considered themselves not to be in good health. Compared to 2001, in 2006/07 the positive assessment of health in people aged 65 and over increased in men and decreased in women.

One further consequence of the ageing of the old population is the increase in the number of elderly dependents, i.e. those who cannot live independently anymore but rely on the help of others for their survival and wellbeing, in many cases because their health status evolves and different disabilities manifest themselves.

Box 2: Disability and Dependency

Disability is defined as any type of limitation that prevents the realization of the basic activities of daily living.

Dependency: A dependant is a general term for a person who relies on another person for help and support. The elderly form a part of the total population of dependants in Spain.

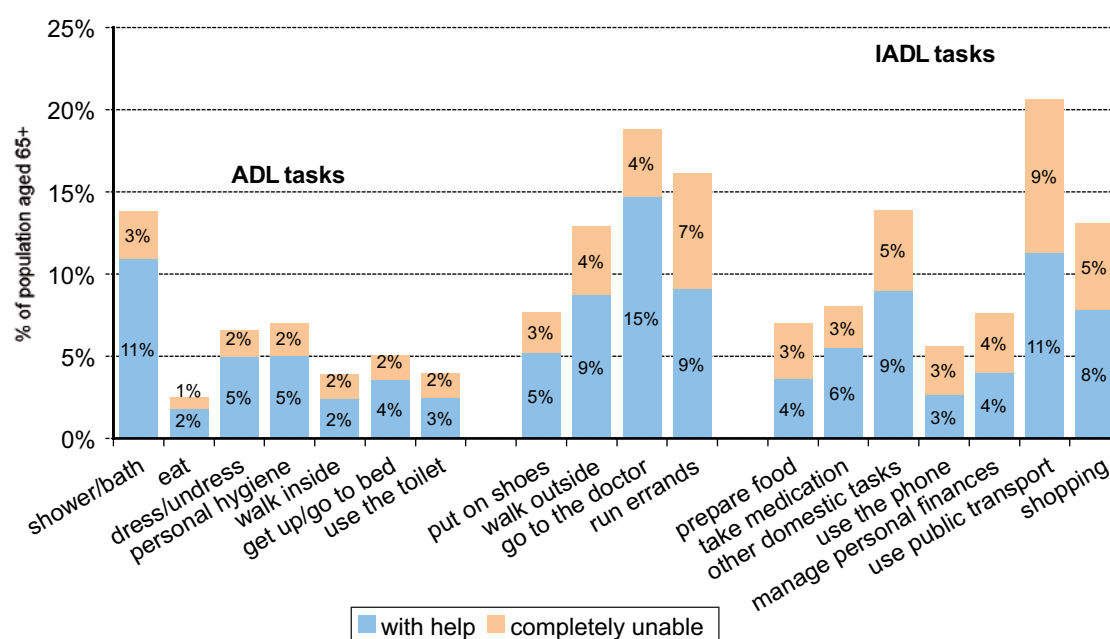
Two types of classification of dependency commonly used in Spain are Katz's Basic Activities for Daily Living (ADL) and Lawton-Brody's Instrumental Activities of Daily Living Scale (IADL) (See Annex II). These are two ways of measuring and classifying the extent of the disability, based on a set of different criteria.

Disability is a descriptive term, referring to a physical or factual limitation, whereas *dependency* is a normative concept associated with certain legal rights. As a consequence, not every person who is in need of care or receives care, is considered legally to be a dependant. Likewise, disability is usually considered a necessary, but not sufficient, condition for dependency.

According to the survey on the living conditions of elderly people of 2006 (IMSERO, 2006), the dependency rate increases substantially with age and differs significantly between men and women. Among those aged 65-74, 90% of men and 78% of women claim not to need any assistance in performing normal activities of daily

life. However, among those aged 85 and older, 54% of men and even 86% of women report they need help (IMSERO, 2009, p. 106). Mobility problems are the most frequently encountered limitations: 1.6 million people aged 65 and above (468,000 males and 1,141,200 females) have mobility problems (IMSERO, 2009). In

■ Figure 3: Share of the population aged 65 and above who are unable or need help to perform different activities of daily life, 2006



Source: IMSERO (2009), Table 2.25, p. 106, based on data from the survey of living conditions of elderly people, IMSERO (2006).

fact, over 20% of this population group cannot use public transport without help, 19% cannot go to a doctor on their own and 16% need help for running errands.

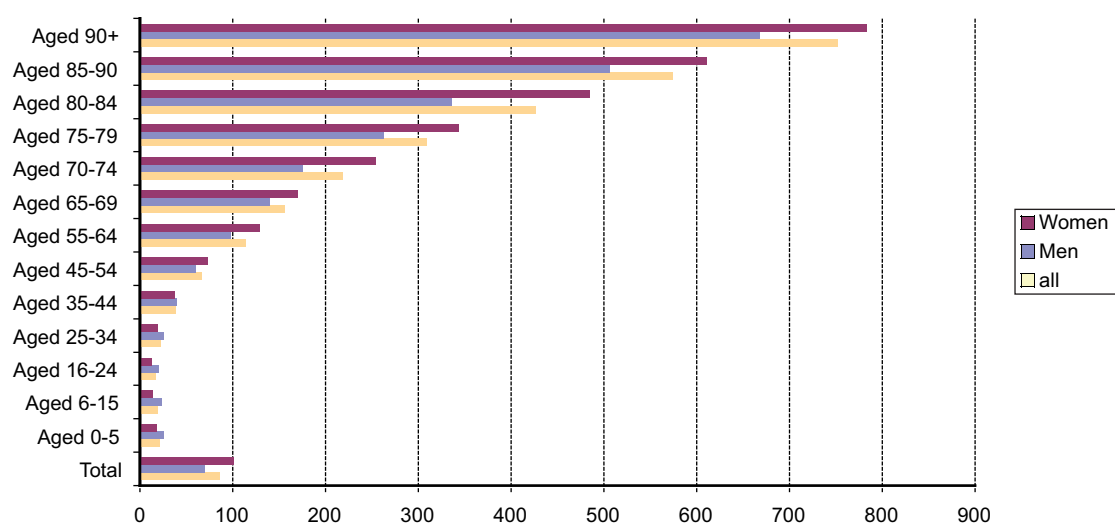
On the whole, the share of older people encountering difficulties in performing these instrumental activities of daily life (IADL) is roughly twice as high as the rate of seniors failing to perform basic activities linked to personal hygiene and health (ADL). However, nearly 14% of older people are unable to shower or bath without help, 7% cannot take care of their personal hygiene and 6.6% have problems in dressing.

The living arrangements of older people reflect, to a certain extent, the level of their dependency: 77% of those living on their own and 83% of those living as a couple claim not to have any problems in performing IADL/ADL tasks; only 1% of those living alone and 2% of those living as a couple state that they are severely or completely dependent. For those whose children live with them, these rates change slightly with 71% being completely independent and 5% being severely dependent. However, of

those living with their children in the house of their children, only 34% are not limited in their daily activities, while 15% are heavily dependent (IMSERSO, 2009, figure 5.19).

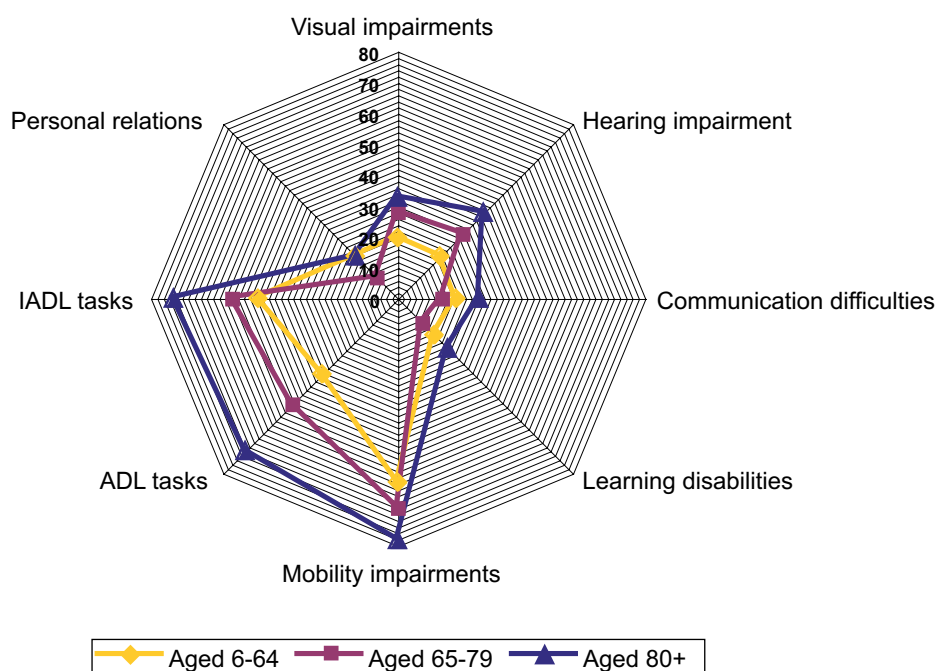
Disabilities are one of the main factors accounting for the dependency of an older person. In Spain, the incidence of disabilities among the older age cohorts is particularly high when compared to Northern European countries (Pommer, 2007, p.18). According to the “Survey of Disability, Personal Autonomy and Situations of Dependency in 2008” (INE-EDAD, 2008), 58% of the 3.8 million people with disabilities in Spain are 65 years old or older: 2.2 million (30%) of people aged 65 and above, have been affected by a disability in the reference year 2008. This figure is some 2 percentage points lower than the figure established in the previous survey, conducted in 1999. The overall rate of disability of the whole population is situated at 8.5% (9.0% in 1999) with an absolute number of 3.8 million disabled people (IMSERSO, 2009). Disability rates increase with age: 51% of those 80 years and older and 75% of those 90 years or older suffer from some disability.

Figure 4: Disability rate in the Spanish population per 1000, by age and gender 2008



Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008.

Figure 5: Types of disabilities by age groups (in % of disabled people), 2008



Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008.

According to the EDAD (2008) survey, the main types of disabilities that affect older people are mobility impairments which affect 68% of people aged 65 and above and 78% of those in their eighties or older, a figure which is well above the incidence of other disabilities, followed by problems in conducting IADL tasks (54% of the 65+ cohort; 73% of those above 80) and in conducting ADL tasks (49% of the 65+ cohort; 70% of those above 80) (for definitions, see Annex II).

Whereas up to the age of 50, disability rates are higher among men, among those aged 65 and older, disability rates are 24% for men and 35% for women. This finding is corroborated by studies such as the one undertaken by Jordi Amoros (2006) which investigates specifically women with disabilities. It states that women over the age of 50 show a significantly increased disability rate when compared to men. Official data from the national EDAD (2006) survey confirms that especially for the three major disability types, there are significant differences between men and

women. The incidence of disabilities in old age is far higher for women than for men, varying by 6.6 percentage points for those aged 65-79 (25.3% compared to 18.7% of the population) and by 15 percentage points for those aged 80 and older (57% of the female and 42% of the male population). Also among those who are disabled, the incidence of restrictions which are the main causes for dependency is significantly higher among women: 83% of disabled women aged 80 or older, compared to only 67% of disabled men, suffer mobility restrictions, 73% of them (62% of men) are affected in conducting ADL tasks and 79% (57% of men) in IADL tasks. This trend can be seen both nationally and regionally, although there are regional variations as concerns the levels of disability (Jordi Amoros, C., 2006, p.9). In 2008, a regional study was conducted to identify the number of disabilities per age group in Andalucía. As a general tendency, it was confirmed that disabilities increased with old age, but women were found to suffer more disabilities than men after 60 years of age.

Regarding the level of severity of their impairments, 56% of people over the age of 65 consider themselves to be completely disabled, i.e. unable to perform the corresponding activity without help, and 35% consider themselves to be severely disabled, i.e. declare that they receive help in performing the tasks in question. However, only 33% of disabled people aged 65-79 and 36% of those aged 80 or above claim to be in a bad or very bad state of health.

2.2 The Long-term Care System in Spain

Long-term care covers a wide range of services provided by local authorities and the independent sector to elderly and/or disabled people either in their own homes – as “domiciliary care” (“ayuda a domicilio”) – or in a residential home. The Spanish long-term care system is complex and fragmented. There is no single integrated social care system that addresses the elderly, people with disabilities and other dependants at the same time. The social security system, the social services system, the health system and many other organizations are responsible for care for elderly people. They are divided into a decentralized structure of 17 autonomous regions, 50 provinces, and more than 8,000 municipalities in charge of providing services. This fragmentation is also reflected in the diversity of services available that include personal support (physical and emotional help), domestic help (household chores), technologies, and rehabilitation, to name a few. Many different professionals work in this arena from nurses to social workers to domestic helpers (Moretón Sanz, 2007, p.46).

The recently enacted Law for the Promotion of Personal Autonomy and Care for Dependent People (“Dependency Law”, 2006) has led to substantial changes, improving the entitlement to care of elderly and dependent people. However, the Dependency Law leaves the implementation

of care to the autonomous regions, which have the mandate to organize its caring network in a way that is most suitable to the region in question. This division of tasks was already brought about by “II Plan de Acción para las Personas con Discapacidad (2003-2007)”, in 2003, which allows each autonomous region to make decisions concerning the organization of long-term care provision within their respective regions. Consequently, the service implementation differs substantially in the different autonomous communities and provinces in Spain.

2.2.1. Services provided under the Dependency Law

The “Act for the Promotion of Personal Autonomy and Care for Dependent Persons” (LEY 39/2006, núm. 299) configures a new citizenship right. This law, implemented in 2007, acknowledges the right for the elderly or disabled to carry out their basic activities of daily living (ADL) see (Annex II and Glossary). People that are accredited as being dependent – based on their inability to perform the basic activities of daily living – are entitled to receive care by means of a set of different services (domiciliary care, telecare, day centres, night centres or residences) that are matched to their degree and level of dependency. When the competent administrations are unable to offer these services in kind, the dependent person is entitled to receive financial benefits. This financial assistance can be used to obtain care through private networks or through the family itself.

The decision of whether assistance is awarded depends on the level of disability and how this affects the basic activities that are needed for daily life. The lack of access to financial or physical resources that would overcome such obstacles to daily life is also a prerogative in establishing the allowance for dependants, which could be used to contract an accredited private service from outside the family (Díaz, A.F., 2006, p.11).

The “System for the Autonomy and Attendance of Dependents” (SAAD)⁵ deals with all applications and entitlements connected to the Dependency Law. It combines direct service provision to dependent people with a system of economic compensation for services needed, with the former taking precedence over the latter. All benefits and services foreseen by the Dependency Law and other legal acts, whether on national or regional level, are implemented through the network of social services established in the different autonomous communities.

Eligibility is determined by the degree and level of dependency (ranging from Grade I (levels 1 and 2 to Grade III (levels 1 and 2)) and, to the same extent, by the applicant's financial capacity. Reflecting the specifications laid down in the Dependency Law, the service catalogue of SAAD includes as in-kind services: measures for the prevention of dependence and the promotion of personal autonomy; telecare service (“teleasistencia”), home care service delivery; day centres and night centres; and residential care centres. Cash benefits are granted (a) exceptionally, when the corresponding in-kind service is not available; (b) as an allowance for home care undertaken by the family in the home environment; and (c) as an economic benefit allowing a person with a high level of dependency (i.e. Grade III) to employ a personal assistant.

The amount of the economic benefits depends on the economic situation of the dependent and on his or her level of dependency. In 2010, the maximum monthly amounts for economic benefits related to services ranged from €401.20 for Dependency Grade II (level 1) to €833.96 for Dependency Grade III (level 2). For family care, maximum benefits ranged from €300.90 (Grade II level 1) to €520.69 (Grade III, level 2) in monthly payments and for personal assistance, which is only awarded at Dependency Grade III,

€625.47 were paid for level 1 and €833.96 as a monthly maximum.⁶

The implementation of measures is left to the municipalities, provinces and autonomous regions. Hence, 17 autonomous regions, 50 provinces, and more than 8,000 municipalities are jointly in charge of providing the service the law allows for (Vazquez, 2007, p.117).

According to official statistical data published by SAAD-IMSERSO (2010) in June 2010,⁷ in the course of the annual period 2009/10, 1,317,982 persons applied for services provided by SAAD, which corresponds to 2.8% of the Spanish population. Andalucía had by far the highest applicant rate (28.3% of the population), followed by Cataluña (15.5%), whereas in Ceuta y Melilla (0.3%), La Rioja (0.9%) Navarra (1.5%) and Catabria (1.6%) application rates were very low, reflecting demographic differences across regions (SAAD-IMSERSO, 2010). Compared to the previous year (2008/2009), 27,016 more applications were registered, an increase of 2.1%. 78.7% of applicants (1,036,711) were 65 years old or older, two thirds of those (689,253) 80 years old or older. 64.4% of applicants aged 65-79 and 71.7% of applicants aged 80 or older were female.

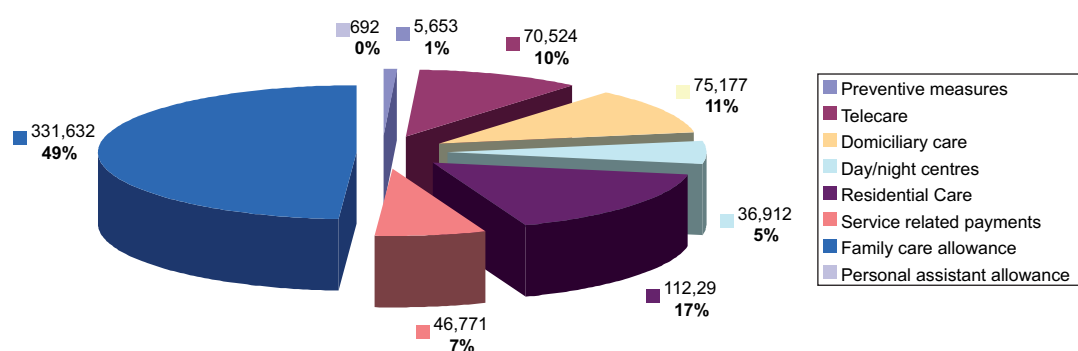
In 90.6% of cases, the dependency was recognised, leading to a total number of 1,194,603 officially recognised dependent people, i.e. 2.5% of the population. In 10.6% of cases, no dependency level was awarded and in 20.7%, Grade 1 was granted, with the consequence that only 67.8% of officially recognised dependants were eligible to services provided under the Dependency Law: 29.1% of dependants at Grade II and 39.6% at Grade III.

5 http://www.imsero.es/dependencia_01/saad/index.htm

6 http://www.imsero.es/dependencia_01/saad/prestaciones_sistema/prestaciones_dependencia/index.htm

7 <http://www.imserodependencia.csic.es/documentos/estadisticas/indicadores/saad/2010-06/estadisticas-saad-jun-2010.pdf>

Figure 6: Number of services awarded to dependants in Spain, 2010 (in % of services)



Source: SAAD-IMSERSO, 2010.

Thus, in 2009 to 2010, 578,953 dependent people (70.5% of those eligible) were awarded some kind of service, accounting for 1.2% of the overall population, 65.2% of them women. 55.3% of all beneficiaries were 80 years or older; 76.8% (444,636) were 65 years or older. A total of 679,652 services were granted, on average each beneficiary received 1.17 services. By far the most frequently granted service was the financial reimbursement for family care: this service was awarded 331,632 times, thus accounting for roughly half of the services awarded and applicable to 57.3% of all beneficiaries. Discounting the 112,291 cases in which residential care was granted, one can say that in roughly 70% of cases where a person with an elevated or high level of dependency is living at home, the family is recognised as the main provider of care and a financial compensation is paid.

Among the other services offered to dependants living at home, domiciliary care services (“ayuda a domicilio”) were awarded to 16% of beneficiaries not living in residential settings, day and/or night centre provision was granted to 8%, and, most notably, telecare services were awarded to 15% of beneficiaries living at home.

2.2.2. The implementation of public long-term care

IMSERSO (2009) divides the officially supplied care provision into three different categories: (a) Public home care services (including, in particular, domiciliary care (“ayuda a domicilio”) and telecare); (b) Private and public day care services, including pensioners’ clubs and day care centres for the dependent population; (c) Private and public residential homes (including sheltered housing and residential apartments). In 2008, a total of 753,995 elderly people, accounting for 9.4% of the population 65 and older received home care services; 358,078 of them in form of domiciliary care and 395,917 as telecare. Clubs and other open day care services had a total of 3,562,576 members. However, (public and private) day centres for dependent elderly people offered only 63,446 places distributed among 2,258 centres. In 2008, public and private residential care arrangements offered 339,000 places, 97% of which were located in one of the 5,100 residential homes. The remainder accounted for alternative housing projects, which offered just below 10,000 beds. 72% of the places in residential homes (i.e. nearly 200,000) were reserved for dependants. 724 centres offered temporary placement; in total 4,561 beds were reserved for this service, which covered 4.4% of the population 65 and over.

The distribution of users of these services, shows a predominance of women in all services. 67% of domiciliary care recipients, 76% of telecare users and 71% of people attending day centres for dependent people are women. In the case of residential centres, women account for 66% of residents. For day centres and clubs, the rate of women is lower, accounting for only 54% of users. Regarding age, those aged 80 years and above represent 59% of users of day centres and telecare services; they account for 62% of users of residential centres and 50% of users of domiciliary care, and one of every two users are aged 80 or older.

According to IMSERSO (2009), the average monthly price for domiciliary care (“ayuda a domicilio”) is €213.29 (€12.71 per hour), the price of the public telecare service is €21.16 per month; a price for placing a dependant in a day centre is at €656.11 per month. A place in residential care costs as €1294.25 per month, €1441.3 if the person is dependent. Services are co-financed by public funds and by the individual user, according to rules that depend on the kind of service and the regional legislation.

There are profound differences between the autonomous communities in the administration of domiciliary care services. The figures vary in terms of the intensity and coverage of care, the type of service and the cost per hour of the service (Andrés-Pizarro, J., 2004). These differences lead to a high variability in respect of the access to services, financing, allowances, costs etc. In absolute terms, the autonomous community of Madrid had the highest number of users of domiciliary care services, with more than 70,000 beneficiaries of domiciliary care and more than 100,000 users of telecare services, whereas Cataluña had the highest number of places in day care centres and residential homes, accommodating 12,700 and 58,000 elderly people, respectively. However, when looking at the coverage rate, i.e. the number of people over the age of 64 who benefit from the services offered, Extremadura ranks highest for domiciliary

care (covering 10% of the older population) and day centres (covering 1%); Madrid remains the leader for telecare services which serve 12% of older people; and Castilla y Leon is leader in residential care, offering beds for nearly 7% of the older population. Galicia is one of the regions lagging behind in all categories, with coverage rates of 1.6% for domiciliary care, 1.2% for telecare, 1.6% in day centres and 2.8% for residential homes (IMSERSO, 2009).

However, when looking at long-term care provision from the perspective of the user, it becomes clear that these services only reach a very small proportion of those who are in need of help.

2.3 The Reality of Long-term Care

According to Pommer (2007), there are three typologies of care in Europe: the Scandinavian model, based on the individual; the Continental model, supported by the nuclear family; and the Mediterranean model, which relies on the extended family network. Spain clearly falls into the third category. In Spain, the family does not only have the moral obligation, but also the legal duty to support their relatives and the authorities can enforce this. At the same time, it reflects cultural and individual preferences: 77% of people aged 65 and older would like to be cared for in their homes, 11% would prefer to be cared for in the home of a son or daughter, while only 5% would like to be taken care of in a residential home. 81.4% of elderly people think that the family should be caring for dependent people, either as the only (5.5%) or the main source of care (42.6%) or in combination with public (domiciliary) care provision (33.3%) (IMSERSO, 2006).

As a result, home care is by far the most frequent form of long-term care in Spain. Nearly 90% of dependent people are cared for in their homes and three in four dependants receive informal assistance exclusively from

family members and/or friends (Table 2). When differentiating between dependants who primarily need assistance for the basic activities of daily life (ADL) like washing and dressing and those whose main problems lie in instrumental activities (IADL) like cleaning, cooking and shopping, numbers change slightly. In cases where there is a need for assistance in ADL tasks, public and private domiciliary care provision is sought more frequently than in cases where IADL tasks are the main concern – an effect that might reflect the more complex and rigorous criteria for granting service provision for IADL needs. Similarly, the rates for residential care change from 8.6% to 13.7% when comparing dependants with IADL and ADL problems. However, of those living at home, very few rely exclusively on domiciliary care services, less than 7% of those needing assistance in ADL and only 4% for those needing help in IADL.

In both, domiciliary and residential care, public care provision is notably lower in comparison with private service providers, being the only resource of help for only 1% of the dependant population living at home and reaching only 4.2% of dependants who are also cared for by their families (cf. Jimenez Martin-2, 2007, p.13). These data illustrate recent policy incentives promoting the decentralization

and privatisation of public services, a private management of services that is matching an increased care demand from society (Rodríguez Cabrero, 2004, p.39). This trend is reflected in the residential care sector, where private residential homes account for 75% of the market as opposed to 25% of publicly run institutions. Also in the home care sector, private home services and day centres have grown substantially since 1990, in particular in urban areas, to the detriment of voluntary services (Rodríguez Cabrero, 2004, p.28).

This relatively low level of public and private service provision, reaching only 25% of dependants, is confirmed by the disability survey (INE-EDAD, 2008) and the survey on the living conditions of elderly people (IMSERSO, 2006). According to the survey on the living conditions of elderly people (IMSERSO, 2006), only 3.4% of all people aged 65 and older who were in need of help received assistance through the public social services. For ADL activities, the majority relied on the help of their daughters (around 40%, differing across activities) or their spouses (in around 20-25% of cases). 15.5% of older people employed a domestic help on an hourly basis and 1.7% employed a domestic help to live with them in their homes.

Table 2: Sources of help used by the elderly and the respective percentage for ADL and IADL in Spain, 2004

Type of care	%dependants	%ADL	%IADL
Informal help only	74.4	64.8	79.3
Private domiciliary care	4.0	6.3	2.8
Public domiciliary care	1.0	0.4	1.3
Private domiciliary care and informal assistance	6.2	10.2	4.2
Public domiciliary care and informal assistance	4.2	4.8	3.9
Private residential care	5.9	7.7	4.0
Public residential care	4.4	6.0	4.6
Total	100	100	100

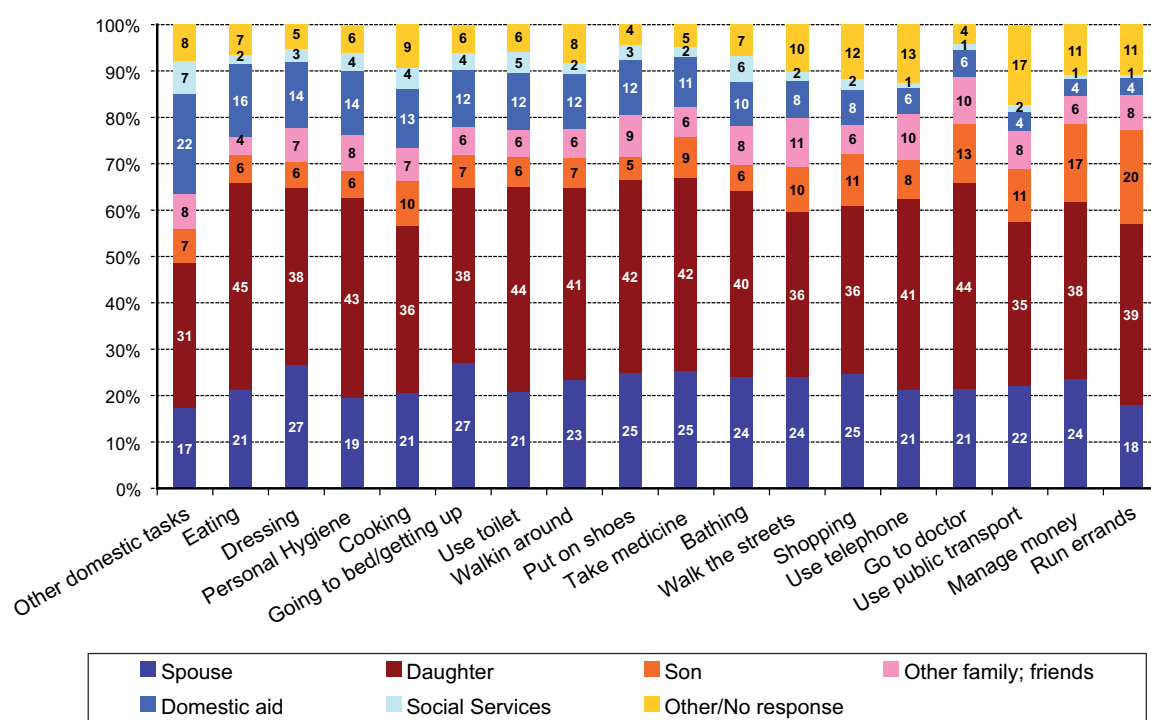
ADL: Basic Activities for Daily Living

IADL: Instrumental Activities for Daily Living

Informal help refers to care provided by family members and/or informally employed caregivers

Source: Jiménez-Martín, S., *Aspectos Económicos de la Dependencia y el Cuidado Informal en España*, Universidad Pompeu Fabra, 2007, p. 13.

Figure 7: Main caregivers' profile, by task, for people aged 65+ who receive care, 2006

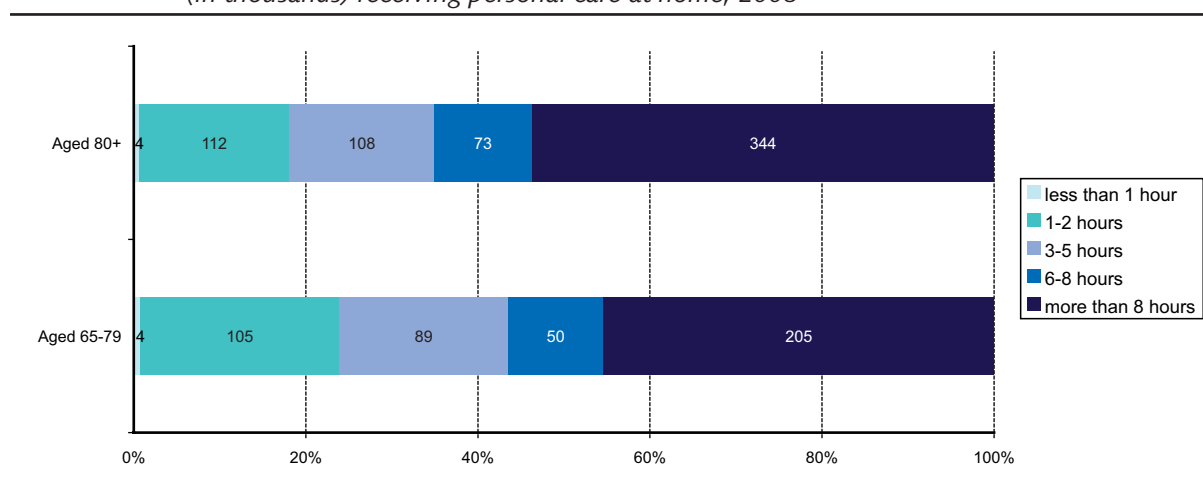


Source: IMSERSO (2006), question 19b, p. 37-42.

As Figure 7 indicates, spouses and daughters are by far the most important sources of assistance for older people in need of care, irrespective of the activities for which assistance is sought. Sons are more active in administering money, running errands, accompanying their parents to the doctor or assisting in other instrumental activities of daily life (IADL). They are less involved in basic activities, such as bathing, feeding, and dressing. The contribution of care assistants privately employed as household helps supersedes that of sons or other family members in tasks connected with ADL, such as feeding, dressing, bathing and personal hygiene. In these areas, 12-16% of respondents are assisted by a personal employee, while only 4-7% are helped by their sons and 4-9% by other family members or friends. 22% of elderly people who receive help are assisted by household employees in "other" domestic tasks: presumably tasks such as cleaning, laundry and ironing. The contribution of (private and public) social services in this sample is minor, exceeding 5% only for "other" domestic tasks.

According to the INE-EDAD (2008) survey, in 2008, 20% of disabled people over the age of 64 did not receive any aid – either in the form of technical assistance or personal care – and some 13% used only technical assistance. Roughly two thirds of elderly disabled people living at home, i.e. 1.4 million people, received personal care, either exclusively (31% of cases) or combined with technical aids (36% of cases). There are significant differences between men and women. While 61% of disabled women over the age of 64 receive personal assistance, only 48% of men do so, and 32% of disabled men over the age of 64 do not receive any help compared to only 23% of women (INE, 2008a). Just over one million disabled people aged 65 and above received personal assistance on a daily basis, roughly 80% of them for more than 3 hours a day. More than half a million elderly people in Spain received personal care for more than eight hours a day (see Figure 8). The time spent on care tasks is used mainly for ADL activities: dressing and undressing, cleaning or showering the

Figure 8: Intensity of care provision, indicated by the number of disabled people aged 65 and above (in thousands) receiving personal care at home, 2008



Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008.

individual. In second place come IADL activities, in particular preparing meals, shopping and cleaning (INE, 2009a).

The INE-EDAD (2008) survey also investigated, for the first time, the situation of disabled people in residential centres. The survey revealed that, in 2008, there were 269,400 people living in residential care, 82.6% of them over the age of 64, three quarters of these aged 80 or above. 92.7% of people in residential care had some kind of disability; the number of women with disabilities was, at 175,700, nearly twice as high as that of men, who accounted for 93,700. 216,400 people with disabilities lived in centres exclusively for older people, 63,000 of them men and 153,400 women (INE, 2008a). Nearly 80% of these people were over the age of 80 (INE, 2009a). Considering that there are 2.2 million disabled people over the age of 64,

residential care therefore accommodated roughly 10% of the older population.

In conclusion, one can say that public long-term care provision, while offering services to a substantial number of elderly people, falls short of accommodating the needs of the vast majority of them. Rather, public services are designed, on the one hand, to be a last resort for those who have no family network to fall back on or whose family is not able to respond to their increasing care needs; and, on the other, to be an incentive for home care, offering a minimum of services to assist family carers and compensate them for their work. While under the Dependency Law, the entitlement to long-term care is improved, the importance of family care is strengthened by the fact that the family allowance is by far the most frequently awarded care service.

■ 3. Caregivers in Spain

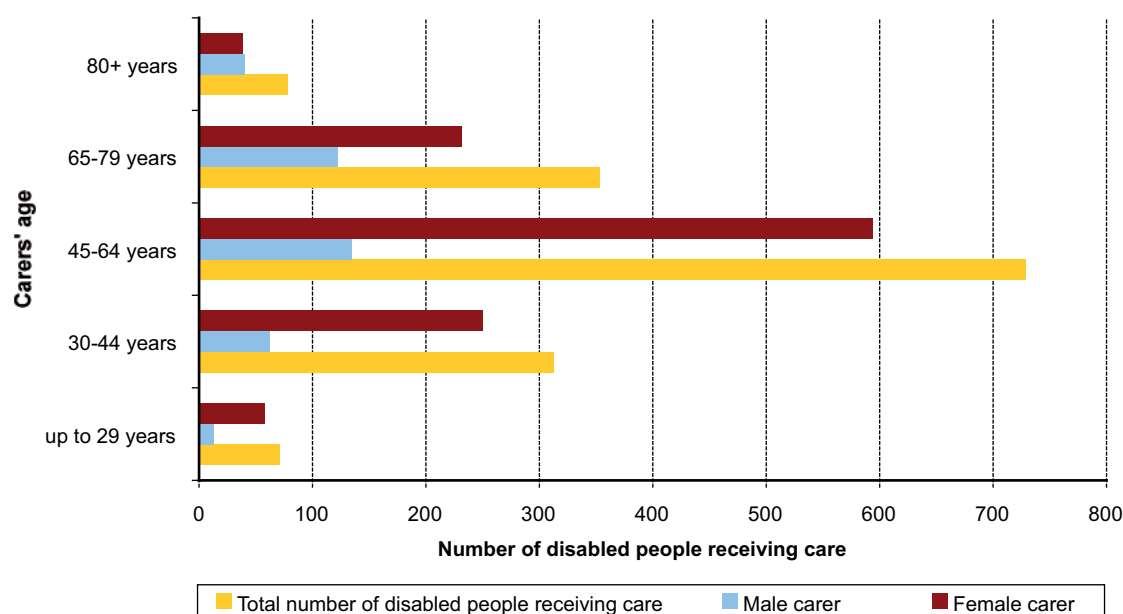
As outlined in the previous chapter, the majority of the home care given to elderly dependants in Spain is undertaken by families, mostly by spouses and daughters, in some cases assisted by privately employed assistants. However, it is very difficult to provide comprehensive and sound data on the number and profile of these informal caregivers.

According to SAAD-IMSERSO (2010) data, 128,778 people are registered officially as family carers, i.e. are recognised non-professional caregivers of a dependent person – in the majority of cases an older person – and receive a family care allowance under the public long-term care scheme. 99.5% (128,088) of them are subject to a special agreement with the social services, which includes certain tax and pension benefits.⁸ Of

those, only 7,581 are men, i.e. 94% are women; 45% are under the age of 50, 33% aged 50-60 and 22% older than 60. The region of Andalusia had by far the highest level of registered family carers, with over 48,000 carers.

However, the actual number of informal caregivers is far higher, even if projected numbers do not completely coincide. The INE-EDAD (2008) survey estimates that, in 2008, in total, 1.4 million disabled people aged 65 and older received personal care in their homes; in about 850,000 cases, the main caregiver was living in the same household as the care recipient (INE-EDAD, 2008). In total, there are at least 1.7 million family carers supporting disabled people (of all ages), nearly a million of them living with the care-recipient. Three out of four main carers

■ Figure 9: Number of disabled people (of all ages) by age and sex of main caregiver, 2008



Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008.

8 For the legal framework see: http://www.boe.es/aeboe/consultas/bases_datos/doc.php?id=BOE-A-2007-9690

are women; only 7% of them are foreigners (INE, 2009a). The majority of caregivers are between 45 and 64 years old and only a very few are under thirty or over 80 (Figure 9).

IMSERSO (2005a) estimates that – looking at the whole elderly population – in 5.1% (725,870) of Spanish households, a person over the age of 65 receives support in performing the tasks of daily life. The number of older people cared for by family members is estimated at 1.2 million, i.e. 17% of the population aged 65 and older, a slightly lower figure when compared to INE-EDAD (2008) data. In 4.5% of households this informal care is provided by family members, friends or acquaintances, without receiving payment, in the remaining 0.6% of Spanish households a care assistant is hired. It is estimated that the total number of carers is almost 950,000, representing 6% of the adult population. The White Book on Dependency (IMSERSO, 2004) estimates that about 726,000 informal caregivers of people aged 60+ were living in the same households as these people; 634,000 of them were family carers, while 92,000 (about 14% of the total) were informal care assistants employed by the families.

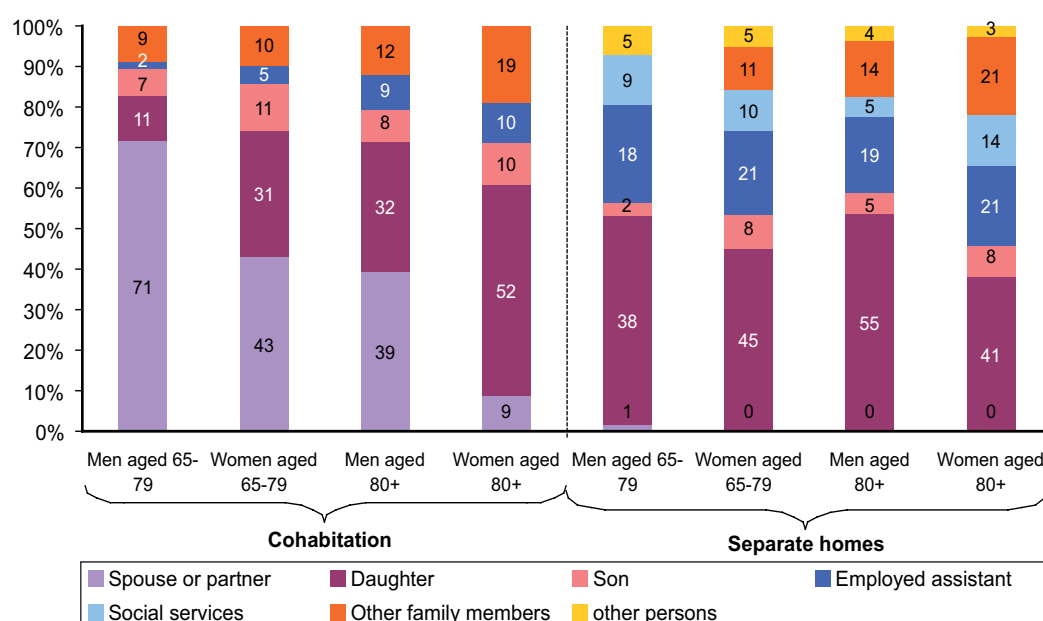
Hence, while the precise figures differ, it can be concluded that between 1.2 and 1.4 million elderly people are informally cared for in their homes, by family members and friends, or by privately employed caregivers. In roughly two thirds of cases, caregivers and care recipients live under the same roof. While the majority of elderly people who need help in performing basic activities of daily life are cared for by their families, in around 14-17% of cases care assistants are employed as the main caregivers.

In the following, the main characteristics of two caregiver groups will be discussed, i.e. family carers (Section 3.1) and privately employed care assistants (Section 3.2), with particular attention to those of migrant origin.

3.1 Family Carers in Spain

All studies concur in the strong presence of women as the main informal caregivers for elderly and dependent people, with little changes over the last few years. IMSERSO (2005a) describes the prototypical carer of elderly people as a 53-year-old woman who

Figure 10: Profile of the main caregiver of a disabled person receiving personal care, according to living arrangement, age and sex of the disabled person, 2008



Source: INE data: Encuesta de Discapacidad, Autonomía Personal y Situaciones de Dependencia, 2008.

is married, has not received secondary or further education and whose main activity is housework. Similarly, they INE-EDAD (2008) survey sketches the main caregiver of older people as a woman, aged 45-64, who lives, in roughly 80% of cases, in the same household as the care recipient; 43% are daughters, 22% are wives and 7.5% are daughters-in-law of the person they care for (INE, 2009a). The majority of them are married (75%) and they do not work outside the house (73%). Regarding their

educational background, 43% have completed primary education, 11% secondary education and 7% have studied a university degree; 17% have not received any education.

However, there are profound differences in the profiles of main caregivers, depending on the age and gender of the care recipient and also on living arrangements. A recent study by IMSERSO (Crespo & López, 2008) sheds light on carers' profiles (Box 3: and Figure 10).

Box 3: Male and Female Carer Profiles

According to a recent study of 209 family carers (Crespo & López, 2008), the most salient difference between male and female carers is that male carers predominantly take care of their partners, while the majority of female carers care for their parents. Over 90% of male carers take care of a woman, in 64% of cases their spouses, and most of them (61%) are retired. The average age of male carers is around 67, while the person they care for is about 76 years old. By contrast, 63% of female carers are daughters who care for their fathers, mothers or both; their average age is 54 while the average age of the people they care for is nearly 80.

Among all caregivers who care for their parents (accounting for 57% of the total sample), half work outside the home, 4 in 10 are housewives, and 6 out of 10 are married. Their average age is around 50 and the average age of the older person cared for is more than 82. In 80% of cases, the care recipient is the mother.

Male and female caregivers differ in their experience and work situation: there are more men who have previously worked outside the home, most of them, retired at the time of data collection (61%), compared to the high incidence of housewives among female carers (42%). These differences remain significant when considering the kinship between the caregiver and care recipient. In the case of spouses, it is observed that most of the men are retired, while approximately one third of female carers are housewives and 17% work outside the home. 73% of the sons who act as carers are in gainful employment, while only 48% of the daughters work and 44% are housewives.

Furthermore, there are substantial differences between men and women in the kind of tasks performed, indicating that women help more often in the more demanding tasks. 89% of female carers, as compared to 54% of men, provide assistance in personal hygiene, 62% of females and 25% of males help in basic activities of daily life, and while 96% of female carers also help in the household, only 63% of male carers are involved in household tasks.

The main carer supporting elderly disabled people are their spouses and daughters: in total 42% of those aged 65-79 are cared for primarily by their spouses and 28% by their daughters. For disabled men under the age of 80 living with their wives, it is the wives who are the main caregivers in 71% of cases. For women in the same situation, husbands only

takes on the main burden of care in 43% of cases. With increasing age, spouses are less able or available to perform care tasks and daughters and other relatives take over. Of those who are disabled and aged 80 and above, 45% are cared for by their daughters, 12% by their spouses, 9% by their sons and 16% by other family members.

Daughters also tend to be the main caregivers for those aged 65-79 if there is nobody living in the same household as the disabled person who could take over the main burden of care. Compared to the prevalence and importance of daughters, sons very seldom step in as main carers; on average in only 9% of cases sons were mentioned as the principle caregiver. The social services play a minor role in domiciliary care at home. Only in 11% of cases, where the elderly disabled people were not living in the same household as their main caregivers, domiciliary care provided by the social services was considered as the main source of care.

The long-standing tradition of women caring for the household has been maintained mainly by the slow entry of women into the Spanish labour market. In 2004, however, there is a slight increase, compared to 1994, in the number of female caregivers who are in gainful employment, 25% in 2004 as compared to 19% in 1994. Also, the share of pensioners among the 16% of male caregivers has risen, from 46% in 1994 to 54% in 2004 (IMSERSO, 2005a), suggesting that caring patterns might be changing. Because women tend to give birth later in life, caregivers increasingly face a double care burden, having to take care of their children and parents at the same time. In 2004, 67% of carers live with their children in the same household and in one third of these cases, the children are under the age of 18.

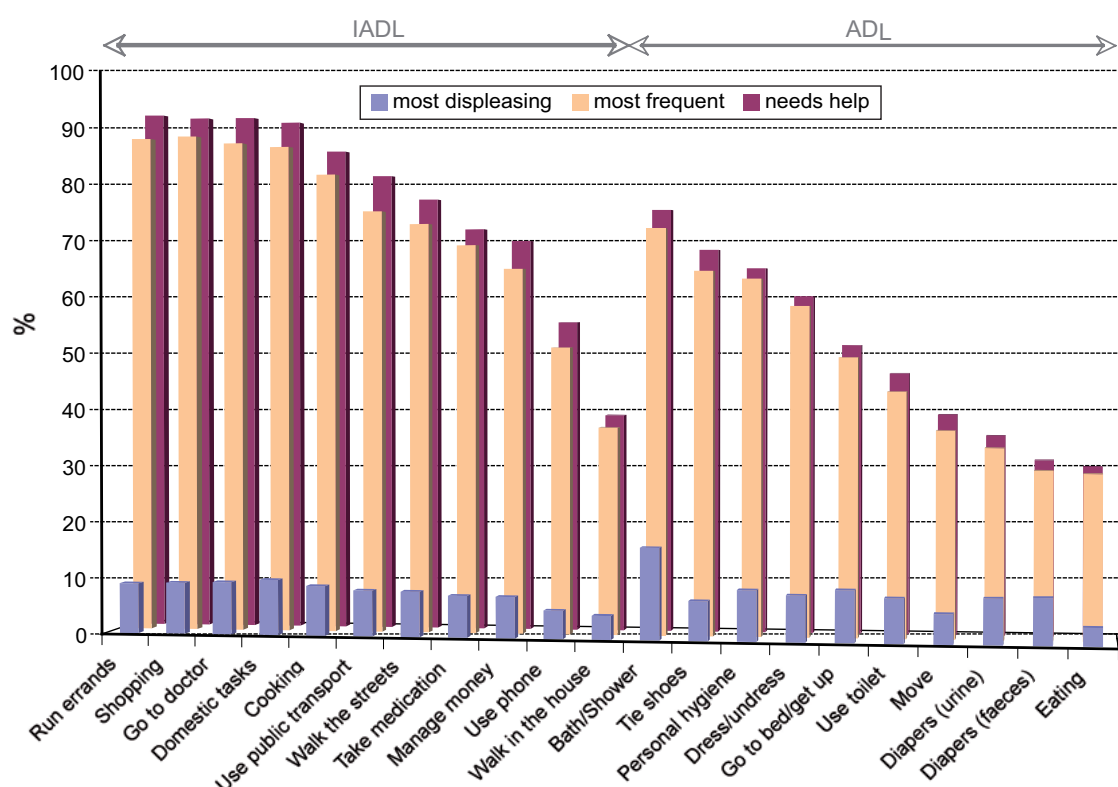
Recently, carers are starting to ask for better working conditions, such as free time, remuneration, collaboration with other family members. They are also starting to look for support from both public and private external resources (Bouzas et al, 2005). Despite the increasing participation of Spanish women in the labour market, there is still little male involvement in domestic tasks, in general. However, during the period 1993-2001, the time spent by Spanish men on domestic tasks grew to 35%, whilst the time spent by Spanish women fell by 5%. Yet, in 2001, the time spent by women on domestic tasks was still twice as high as that of Spanish men (7.22

and 3.1 hours respectively), (Larrañaga et al, 2004). This overall tendency is also reflected in long-term care. Whereas, in 1994, 62% of female carers said they did not receive any help from their families, in 2004, 66% of carers purported to have received some assistance from other family members (Rodríguez, 2004). Additionally, in 1994, 55% of carers were the only caregivers for their relatives, whereas in 2004, only 47% were left completely on their own with the care responsibility.

However, at the same time there has been an increase in the incidence of diseases and chronic health conditions among the people cared for, which is reflected in an increase of care tasks and demands: In 2004, 95% of older people cared-for suffered from some disease or received some type of treatment, compared to 79% in 1994. Correspondingly, 76% of carers assisted in basic ADL such as bathing, dressing and eating in 2004, as compared to only 60% in 1994; 89% of carers supported domestic IADL such as cleaning, washing, and cooking (80% in 1994); and 92% assisted in other IADL activities, such as walking in the street (77% in 1994) (IMSERSO, 2004). Most notably, the share of people needing assistance in all three areas (domestic IADL, other IADL and ADL) has increased from 44% to 68%. Furthermore the frequency and intensity of care demands has grown. More carers assist their relatives permanently (77% in 2004; 73% in 1994) and 57% (53% in 1994) spend more than 5 hours a day on care; on average 10.6 hours a day are spent on care.

In 84% of cases, family carers do not receive any assistance (other than possibly within their families); in 7% of cases, privately employed care assistants help them in their tasks. Assistance provided by municipalities (5%) and other public and private service providers (in sum below 3%) is not available to the vast majority of carers. In general, family carers do not receive training or targeted preparation for their tasks. Only 10% of caregivers have undergone any training, mainly in interaction with the medical staff attending their

Figure 11: Main care needs and most frequently performed tasks by family carers, 2004



Source: IMSERSO (2005a), p. 207.

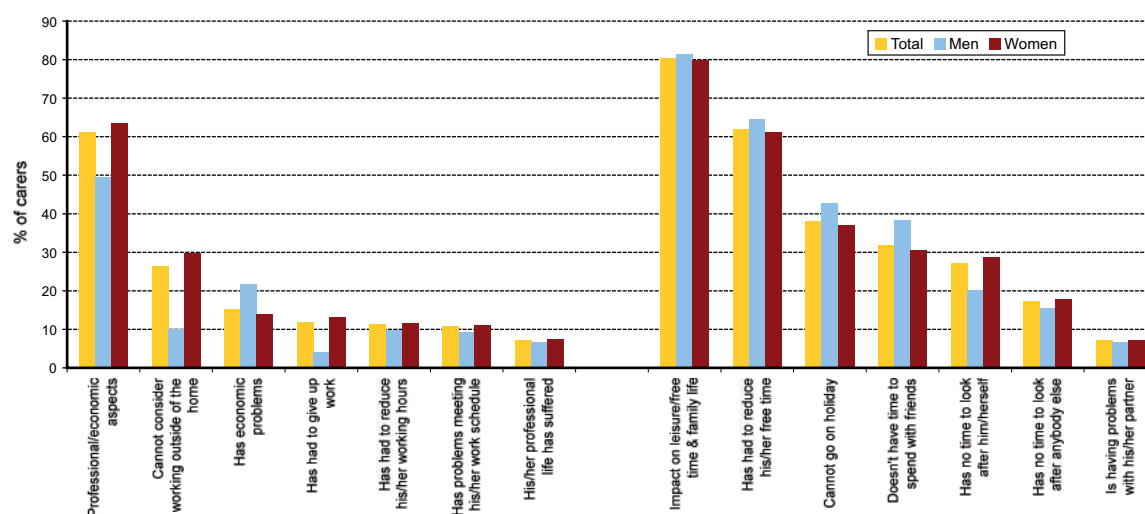
dependent relatives, through books or information events. One third of carers believe that, to care for an elderly person, some preparation and training is needed, while 26% consider that training is only needed to care for a highly dependent person or a person with dementia. Thus, although training opportunities are scarce, the majority of carers do not feel ill prepared for the caring tasks.

Looking more in detail at the care needs and most frequently performed tasks (Figure 11), four different levels of frequency of care needs emerge. Almost all care recipients (i.e. more than 90%) need and receive care for activities connecting them with the outside world: going to the doctor, shopping, running errands. A very high majority (70-80%) needs assistance for instrumental tasks in their homes, such as cleaning, cooking, taking medication, managing money, and, to a lesser extent, walking around the house. Thus mobility, expressed in different ways, is the predominant factor driving the care need. Furthermore, there

are cases in which dependency is higher and more complex and intensive care needs take precedence over mobility restrictions. This is the case for more than half of care recipients, who need some help in basic ADL such as bathing, dressing, getting up and going to bed. A fourth group of 30% to 40% of care recipients are even more severely dependent, i.e. are incontinent or need to be fed.

Carers assist in all of these tasks to roughly the same extent (more than 90%). In general, the carers' satisfaction with their tasks is high: 69% did not find any of the tasks required as distressing. While some of the tasks are considered more difficult and demanding than others, 10% of carers consider that none of them is disconcerting, with the exception of bathing/showering their relatives, which 16% dislike. Similarly, when asked about which kind of behaviour displayed by their relatives they find most annoying, 66% declared they were not upset by any of the typical

Figure 12: Impact of caring on the professional, economic, leisure and family aspects, 2004



Source: IMSERSO (2005a), p. 219.

mannerisms. Traits that were considered most irritating were physical (18%) and verbal (17%) aggression, incontinence (15%) and refusal to wash themselves or be washed (14%).

Despite the overall satisfaction with the care situation, caring affects carers' lives in many ways and, although family carers are not dissatisfied with their situation, their lives and wellbeing suffer. A study carried out in Andalucía concludes that for 68% of the carers studied, caring affected various different aspects of their lives, such as: health, work, relationships, and social life among others (García-Calvente et al, 1999).

85% of family carers questioned in the IMSERSO (2005a) survey feel that the assistance they provide negatively affected their daily lives. Though there are no significant differences by gender, there are by age: with increasing age, the share of those who are impacted by their caring activities rises from 64% for those under the age of 30 to 90% for those over the age of 89. Older carers more frequently face consequences for their health and leisure life than younger carers, whereas economic and professional difficulties are more frequently encountered by those aged 30-60 (65%) than by those who are younger or older (in less than 50% of cases).

In total, 80% of carers are affected in their leisure and family lives; 61% face consequences for their professional or economic situations (Figure 12) and 56% say they suffer health problems because of their caring engagement (Figure 13). These findings are confirmed by the INE-EDAD (2008) survey, according to which 64% of caregivers living in the home of the disabled person had reduced their leisure time in order to care for the disabled person and for 54% caring had an impact on their working lives or economic situations (INE, 2009a).

The private life of the carer is most substantially affected by the reduction of free time, which was mentioned by 62% of respondents. In general, negative impacts on personal life are connected with a lack of time for other activities and people: 38% of carers report they are not able to go on holiday, 32% miss spending time with friends, to look after themselves (27%) or other people (17%). While leisure time and family life are affected for men and women alike, female carers tend to be more impacted in their economic and professional situations (63% of women compared to 49% of men). While economic problems are more prominent among men (22% of men compared to 14% of women), problems to join and stay in

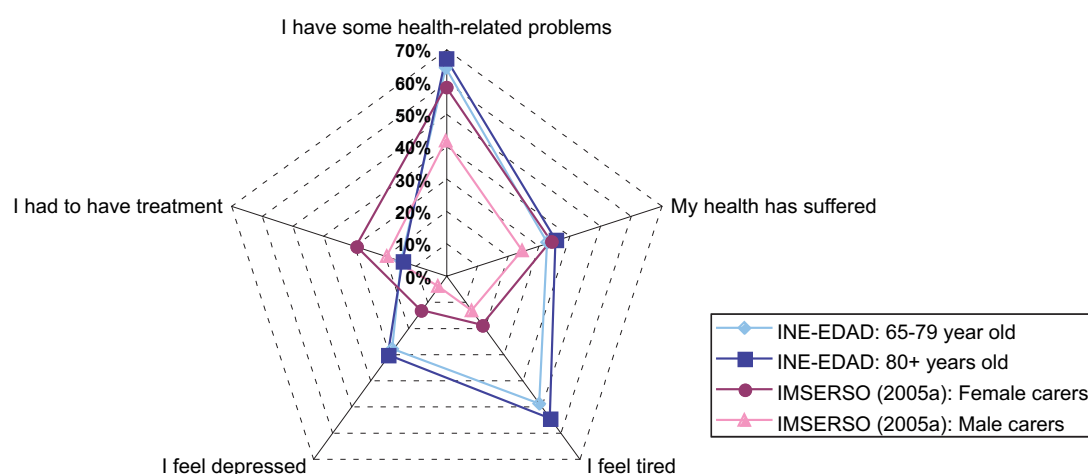
the labour market are more relevant in the case of women: 30% of women (compared to 10% of men) are concerned because they cannot take up work, which reflects the higher proportion of female carers who are not employed, and 13% of women had to give up work (as compared to only 4% of men) (IMSERSO, 2005a).

As concerns health status, women are also more frequently affected (58% of cases) than men (41% of cases). In total, one third of respondents say they are tired, 28% feel their health has deteriorated, 18% feel depressed and 12% had to undergo some kind of treatment (see Figure 13). When asked more in detail about their health conditions, 32% say they have to take some kind of medication, 20% had to undergo rehabilitation measures and 11% consulted a psychologist or psychiatrist (IMSERSO, 2005a). The INE-EDAD (2008) survey substantiates these findings and suggests that the negative impact on health is even slightly higher and increases with the age of the care recipient (Figure 13). In 2008, two thirds of caregivers of disabled people report they have some kind of health problem caused by, or related to, their caring activities. Most caregivers feel tired and an important number felt that their health has suffered because of their caring activities.

Other studies confirm that carers face many different health problems, both physical and emotional. This is particularly true with carers who look after family members with Alzheimer's or other types of dementia. These carers are prone to suffering from chronic stress syndrome (Castleman, et al, 2000; Montorio et al, 1995). Although the main health problems suffered by carers are work overload in general, anxiety and depression, other more physical problems are also common. These problems however have been studied to a far lesser extent, and in many cases are "hidden" by the carers themselves (Schulz & Williamson, 1994).

Studies carried out on the carers' state of health indicate that 84% suffer from some sort of physical problem (Badia et al., 2004). Seven out of every ten carers suffer from headaches and tiredness (Roca et al., 2000) and more than half have problems with their sleep or suffer musculoskeletal difficulties (Gómez-Ramos & González-Valvered, 2004). Carers are also at risk of being tense and stressed (Shaw et al, 1999) and have various allergies and skin, back, head and intestinal problems. (Franqueza, 2003). On the emotional level, carers are prone to suffering from depression (Clark y King, 2003), anxiety (Laserna et al., 1997) and rage (Steffen, 2000).

Figure 13: Percentage of main carers claiming to suffer from health-related problems caused by the caring activity, by age of care recipient, 2008



Source: INE-EDAD (2008) and IMSERSO (2005a).

Carers also tend to have conflicts with other members of the family (Deimling et al., 2001). These disagreements usually come about because of a lack of understanding regarding an illness or the way that the carer looks after their dependent family member. The attitude of the person being cared for is also an important factor (Flórez, 2002). Many of the carers isolate themselves socially, they live on their own and their lives revolve around people they are caring for, converting caring into a closed carer-dependent person system (Brodsky et al, 1997).

According to IMSERSO (2008b), there are significant differences between men and women concerning conflicts between caring responsibilities and family roles, in particular for carers who are also in gainful employment. While only 12% of men reported facing conflicts with between their caring and family responsibilities, 51% of women did so. Whereas only one third of men faced conflicts with family and/or work, 73% of women did so.

Despite all of these problems suffered by the carers, most carers do not perceive their caring activities as unsatisfying. If the carer is aware of the appropriate resources and is capable of adapting, caring does not need to be a frustrating experience and can even be a gratifying one (Bazo, 1998). It is not the illness that generates this positive experience, but the personal relationship that develops between the carer and the person being cared for, in their joint struggle to overcome everyday problems (Crespo & López, 2007). These findings are corroborated by the IMSERSO (2005a) study, which points out that carers reported a lower negative impact of caring on their daily lives in 2004 as compared to 1994, although the intensity and complexity of their caring had substantially increased. In fact, 79% felt caring “dignified them as a person” and 79% feel rewarded and compensated for their efforts by the gratefulness of the care recipients.

However, it should not be forgotten that for 91% of family carers, it is a moral obligation to

care. 51% admit that they have no choice and 47% point out that it is the only economically viable solution. Furthermore, a significant proportion of caregivers feel trapped and think that caring is too heavy a burden for them (21%). Both feelings are shared by the same group of caregivers, i.e., those who feel trapped, also feel overburdened. The older the carer is and the more intensive and comprehensive his care obligations are, the more likely is s/he to feel overburdened (IMSERSO, 2005a).

It is therefore important to create opportunities for carers to learn how to cope with the situation, offer them training and assistance in their daily tasks, and enable them to convert their caring experience into a valuable asset for their professional development. An empirical study carried out in Spain shows that the main action areas that can improve the health and wellbeing of carers would be to facilitate access to various educative and training resources, psychotherapy, self-help groups, health consultants etc. (Losada-Baltar & Montorio-Cerrato, 2005).

3.2 Migrant Care Assistants in Spain

3.2.1. Care assistants in domiciliary care

The findings of the INE-EDAD (2008) survey indicate that privately contracted care assistants play an important role in home care provision (see Figure 10, p. 27). However, the exact number of care assistants and their personal profiles are unknown. There is evidence that between 12% and 20% of elderly people who are in need of help are assisted by a “domestic employee” at least in some of their daily tasks.

Overall, in about 20% of cases, where there were no main carers available in the disabled older people’s households, care assistants were contracted to act as main caregivers and in over 100,000 households, care assistants were employed to live in the homes of elderly disabled people to act as the main caregivers

(INE-EDAD, 2008). A study undertaken by Jiménez-Martín (2008) indicates that people aged 80 and above who are both single and dependent, usually receive care from care assistants. On the whole, people aged 80 and above are more likely to receive a combination of help given by a carer and a care assistant, than younger dependants.

According to the IMSERSO (2006) survey of living conditions among the elderly, 18% of people aged 65 and older are assisted by privately-employed care assistants. 15.5% of older people employ domestic help on an hourly basis. 1.7% employ care assistants to live with them and 1.3% receive help from domestic helps in addition to social services. These data are in line with the findings of the White Book on Dependency, which estimates that in 14% of households in which an elderly person lives, a domestic help is employed to assist in caring for the elderly person (IMSERSO, 2004). Data collected by IMSERSO (2005a) suggests slightly lower numbers, indicating that in 92,000 Spanish households, care assistants are employed to provide support to a total of 110,000 people over the age of 64 who are not able to perform the activities of daily life without help. Thus, while sources differ in their estimations, there is evidence that, in at least around 100,000 cases, care assistants are contracted by elderly dependent people or their families.

A survey of more than 200 care assistants conducted by IMSERSO (2005a) reveals that, as in the case of family carers, the vast majority of care assistants are women; men accounted for only 3% of the sample studied. The demographic profile of the care recipient does not differ substantially from that of family care provision: 74% are women; more than 60% are over the age of 80, and 63% are widowed. Notably, in cases where care assistants are employed, the care recipients are less likely to be living with their offspring (21% of cases) and on average slightly more dependent. 41% of care recipients lived

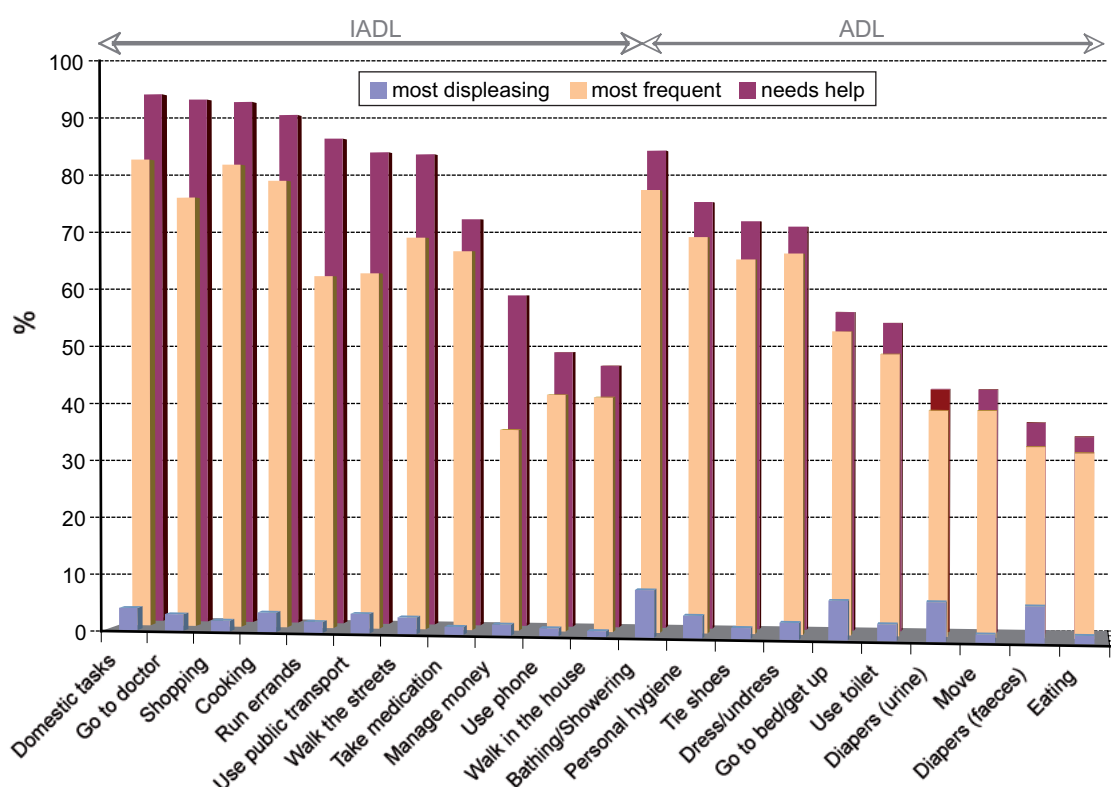
alone, 19% with their partners and 10% with the care assistants.

The average age of care assistants is 39 years; 60% of care assistants are between 30 and 50 years of age and only slightly more than 4% are over the age of 59. Roughly half of them are married (49%) or living with partners (3%); roughly half are single (27%), separated (11%) divorced (4%) or widowed (6%). The educational profile of care assistants is relatively high, nearly half of them have completed secondary education (46%) and 12% have followed university studies. Only 1.5% are illiterate. The care assistants interviewed report they are in good health, with the exception of 18% who suffer from a chronic disease.

In the sample studied, 40% of these care assistants were immigrants, in 71% of cases from Latin America. Concerning working conditions, slightly more than half of respondents worked either on an hourly basis (27%) or for half a day (27%) whereas the remaining 46% worked fulltime, half of them living in the care recipients' homes (23%). Interestingly, 85% of those living with the care recipients were of foreign nationality. Only 17% of the care assistants had a binding contract with social security benefits; in 73% of cases, there were no plans to legalise the work relationship.

Looking more in detail at the behaviour of the care recipient as perceived by the care assistants, three behaviour profiles stand out. In 55-65% of cases, care recipients demonstrate behaviour typical of dementia (losing things, forgetting routines, talking out of context), which in roughly half of these cases is accompanied by disorientation (getting lost, getting up at night). In 37-47% of cases, medical conditions, such as incontinence and accidents, drive the care demand. As a third profile, behaviour typical of depression is observed, such as complaining (69%), crying (54%) and wanting to die (39%).

Figure 14: Main care needs and most frequently performed tasks by care assistants, 2004



Source: IMSERSO (2005a), p. 165.

The tasks undertaken by the care assistants comprise domestic tasks (89% of cases) assistance in IADL (83%) and in personal care (ADL) (85%). In the vast majority of cases (70%), all three types of activities are supported by care assistants. Comparing the situation of care assistants to that of family carers (Figure 11), an overall slightly higher level of care needs emerges in the cases where care assistants are employed (Figure 14). In particular, the share of older people needing assistance in basic ADL is higher for care assistants: More than 60% of care recipients need assistance in basic activities such as bathing, personal hygiene and dressing; in only 34-42% of cases the care recipients are highly dependent, i.e. they are incontinent or need to be fed. In more than 90% of the cases in which help is needed in the area of ADL, this support is provided by care assistants.

As in the case of care provided by family members, most care recipients need assistance in

moving and coordinating. More than 90% of care recipients need assistance in going to some other place, e.g. to the doctor or to shops, and in the more complex activities in the household, such as cleaning and cooking. Only about half need assistance in other instrumental activities such as moving in the house, using the phone or taking medication. Care assistants most frequently assist in household tasks such as cleaning, shopping and cooking, they are slightly less frequently involved in running errands or managing money. The majority of care assistants do not consider their tasks as displeasing. Understandably, some tasks, such as changing diapers, bathing the care recipients or helping them to go to bed and get up are described as being less enjoyable, but even in these cases more than 90% of care assistants do not find the tasks discomforting.

On average, care assistants provide 7 hours of care per day; in 74% of cases care was delivered on a daily basis, most frequently either only in the

mornings (31%), mornings and afternoons (24%) or mornings, afternoons and night (29%). Only 29% of respondents have received some kind of preparation or training for their care tasks. On average, care assistants had been employed for one year; in 45% of cases employment exceeded one year. In 37% of cases, care provided by care assistants was the only care received; in 39% it was the main source of care and in only 24% it was a complementary form of care. Thus, in more than three quarters of the cases, the main care responsibility lay with the care assistants.

3.2.2. Immigrants in Spain

According to official statistical data for 2008 (INE-TIC-H, 2009), since 2000 the foreign population in Spain has grown more than fivefold, increasing from under one million in 2000 to a total of more than 5.2 million in 2008 and to approximately 5.7 million in 2010 (INE, 2010). In percentage terms, foreigners account for 12.2% of the total population, and 47.5% of foreigners are female (INE, 2010). By region of origin, EU foreigners represent the greatest sub-group, accounting for 41.1% of non-natives, followed by citizens from Latin America (26.6%) and from the African continent (18.4%). By country, the greatest share of foreigners comes from Romania (14.5%) and Morocco (13.1%) (INE, 2010).

Compared to the socio-demographic structure of the native population, the foreign population is extremely young, with an average age of 30 years that strongly contrasts with the average of almost 40 years that characterises the native population. 62% of foreigners are under the age of 45, compared to only 40% of Spaniards (INE, 2010). To the youth of the foreign population the relatively high educational level has to be added: 34% of foreigners have a high school diploma and a remarkable 19% of them have a university-level degree (eEspaña, 2009).

These high immigration figures – in particular as concerns females of working age with a relatively high level of education, but without

corresponding employment opportunities – together with changing lifestyles which reduce the number of female family members available for caring tasks, have triggered the recruitment of immigrants as informal care assistants.

3.2.3. Immigrants employed by as domestic care assistants

Some sources estimate that the number of migrants privately employed to assist in the care of elderly people in Spain could be as high as 200,000, or even up to 600,000.⁹ It is difficult to verify or falsify these numbers as no reliable data or research evidence accounting for all cases of informal care provision to elderly people by immigrants is available. More rigorous data collection activities provide evidence of some 40,000 (IMSERSO, 2005a) to 80,000 (INE-EDAD, 2008) foreigners employed to take care of elderly dependent or disabled people.

Geographically, the vast majority of migrant care assistants come from Latin America or Eastern Europe. While some of them have regular work contracts, not always connected with social security benefits, others have illegal residence and/or employment status. In general, care assistants are recruited by the families themselves, through word of mouth, and are not trained or qualified for their tasks (IMSERSO, 2005a).

Domiciliary care positions are often the only employment opportunities for immigrant women newly arrived in Spain in search of a better life. This is reflected in the fact that many migrant care assistants have only recently arrived in Spain and a substantial number of them are still in the process of attaining legal residence (IMSERSO 2005b). The lack of studies on immigrant caregivers is a reflection of the invisibility of this phenomenon (Galiana-Gómez et al, 2008). Little is known about working conditions, qualifications, professional

9 <http://www.madridpress.com/noticia.asp?ref=79605>

interactions with the long-term care system or responsibilities and needs.

The domestic sector in general is a sector where irregular working conditions prevail and where a relatively high share of immigrants, most of them women, are employed. According to INE-EPA (2008), in 2008, in total 280,000 people were registered as household employees; 163,000, i.e. more than half of them, foreigners. However, this number at the same time over- and underestimates the number of immigrants working as care assistants, since, on the one hand, the majority of domestic work relationships are not registered in the social security system and, on the other, in most cases domestic work is not done specifically in support of elderly people. According to IMSERSO (2005a), 17% of care assistants are registered as household employees and according to the 2002-2003 daily activity survey (INE, 2003), 9.3% of households employing a domestic help did so to cover the care needs of an adult. Hence, on the basis of these figures, if the proportion of documented versus undocumented work relationships is the same for the different kinds of domestic services and for migrant and native employees (which most probably is not the case), the total number of care assistants can be estimated at 153,000 and that of migrant care assistants at just below 90,000.

This estimate is in line with the findings of the disability survey (INE-EDAD, 2008), which concludes that for 7.0% of disabled people receiving care the main caregivers are of foreign nationality. Given that only 1.9% of disabled people are of foreign nationality, and assuming that disability and care patterns are similar for native and non-native disabled people and that cases in which family members have different nationalities are rare, it can be speculated that around 5% of disabled people in need of care are cared for by immigrant care assistants as their primary source of assistance. This would mean that for 80,000 disabled people aged 65 and older, migrant care assistants are the principle

caregivers. Given that, according to INE-EDAD (2008) data, in total, for 117,400 elderly disabled people privately employed care assistants are the main source of help, it seems that, based on this rough calculation, more than two thirds of care assistants are of migrant origin.

This finding contrasts with a survey conducted by IMSERSO (2005a) in 2004, according to which only 40% of care assistants are immigrants, in the majority of cases from Latin America (71%). Ecuadorians (13% of all care assistants) and Columbians (7%) represented the two largest nationality groups from migrant backgrounds. Other nationalities encountered in the sample include, from Latin America, Peruvians (4%), Bolivians (3%), and Dominicans (1%) and, from Eastern Europe, Rumanians (2%) and Bulgarians (2%). On the basis of this survey, the total number of migrant care assistants in Spain can be estimated at a modest, but still significant, 37,000.

An exploratory study in the three regions of Valencia, the Basque Country and Madrid (IMSERSO, 2005b), surveying 54 migrant care assistants, provides some insight into their situation. According to this study, the profile of a migrant care assistant is a woman (only 7% are men) between 30 and 50 years of age who is normally single and without children. More than 60% come from Ecuador, the remainder from other Latin American countries with few exceptions coming from Eastern European countries (4 people; 7%), Morocco (1 person) and the Philippines (1 person). The vast majority of migrant care assistants have been living in Spain for longer than a year. Roughly half of them have legal residence rights in Spain. There is an equal balance between those living in care recipients' households and those being employed for a number of hours per day or per week. Salaries range from €3 to €7 for those paid per hour and from €480 to € 800 per month for those living in care recipients' households.

While there are indications that IMSERSO (2005a) have underestimated the relevance of migrants in domiciliary care, the data collected in this survey provide valuable insights into the profile and working conditions of migrant care assistants. 50% of migrant care assistants live in the same households as the care recipients - an arrangement that is far more common for migrants than for native care assistants, who only live in the same households as the care recipients in 3% of cases. When comparing the situation of care assistants from migrant origins with that of their native colleagues in the IMSERSO (2005a) survey, further differences emerge: migrant care assistants tend to be slightly younger, on average 37 years of age, compared to 41 for Spanish care assistants. They are better educated, with 56% having finished secondary education and 17% tertiary education, compared to 43% and 7% for native care assistants. Among those from Latin American countries, the share of women who are not married or living with a partner is substantially higher (57%) than for native care assistants (46%), whereas for those from Eastern European countries it is substantially lower (31%).

Immigrants tend to be more intensively involved in care tasks than natives: 90% migrants are giving care on a daily basis, as compared to 74% of native care assistants. Reflecting the different living arrangements for migrant and native care assistants, 32% of migrants compared to only 1% of native care assistants work 24 hours a day. 60% of migrant care assistants are

employed for continuous care, covering morning, afternoon and night, compared to 11% of native care assistants. Whereas 65% of Spanish care assistants work for less than 5 hours per day, only 22% of migrants do so. Furthermore, while personal care tasks (i.e. assistance in ADL) were undertaken to the same extent by migrants and natives (83%), migrants tend to be more frequently involved in performing domestic tasks (95% of migrants and 86% of natives) and in providing assistance in IADL (87% compared to 82% of natives). Migrant care assistants from Latin American countries were involved to a far higher extent (80%) in all three work areas than native care assistants (67%) or those from Eastern Europe (56%).

Moreover, migrant caregivers are employed as main caregivers more frequently than their Spanish colleagues. Whereas 31% of Spanish care assistants acknowledged that their assistance was a secondary source of assistance for the care recipient, 87% of migrant care assistants considered themselves to be the main source of care provision, in 48% of cases their assistance was the only help the care recipient received (as compared to 29% for natives). This finding, together with the higher incidence of full time employment among migrant care assistants, might account for the fact that they have legal working contracts with social security benefits (19%) slightly more often than native employees (15%). Yet, in 66% of cases (78% for natives), there are no plans to legalise the work relationship.

4. ICT and Domiciliary Care

Information on the use of ICT in domiciliary care is scarce, in particular as concerns carers and informally employed care assistants. In this chapter, the available data on ICT use by population groups represented in the home care environment –elderly and disabled people, women acting as carers and foreigners– will be presented and discussed (Sections 4.1 to 4.4) with a view to better understanding ICT access and skill levels for those involved in home care. Furthermore, the current use of the publicly funded telecare programme will be described (Section 4.5) and some assistive technology solutions that are currently available or in development will be briefly presented (4.6). The chapter closes with an assessment of the potential of ICT for home care (4.7).

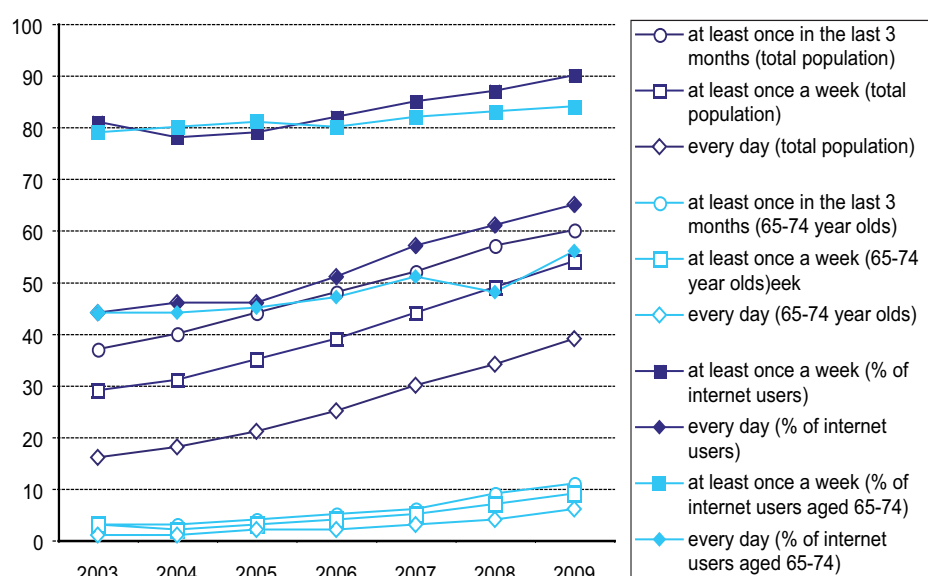
households over the last few years. However, not all population groups have participated in this rise to the same extent. According to Eurostat (2010) data for Spain, in 2009, 86% of all individuals aged 16-24 used the internet at least once a week, whereas only 19% of the 55-74 year olds (18% of those retired or otherwise inactive), were regular internet users. Whereas in Sweden, Denmark and the Netherlands over 40% of 65 to 74 year olds accessed the internet at least once a week, a figure that is 29% in the UK and 25% in Germany, in Spain only 8% of this age cohort use the internet this frequently. Thus, ICT diffusion rates among the senior population are six times lower than in leading European countries.

Furthermore, there are differences in the kind of ICT tools used: While only 19.6% of 65-74 year olds have ever used a computer, only 13.4% have ever used the internet and a mere 3.5% have ever shopped online, 64.8% of this age group uses mobile phones. The 2006 survey on

4.1 ICT Use by Elderly People

There has been a general and steady increase in the use of computer technology in Spanish

Figure 15: Internet use by 65-74 year olds as compared to the national average, in Spain, 2003-2008 (in %)



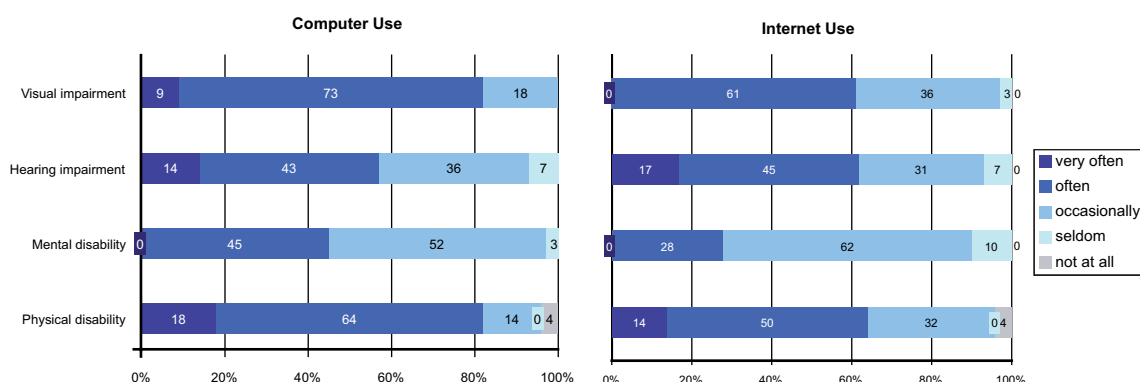
Source: Eurostat (2010) data on individuals' internet use in Spain, by frequency.

the living conditions of elderly people (Abellán et al., 2007) confirms that the internet is not used widely among elderly people in Spain. Only 10% of households in which an older person lives had internet access in 2006. Internet access is more common among those under the age of 80, who have at least primary education, are widowed or single and live in multigenerational households, in urban areas, in good health and without functional problems.

However, current trends indicate that the older generation is starting to embrace the internet (Figure 15). When looking at Eurostat data for the oldest age group for which data is collected, i.e. those aged 65-74, there has been a steady increase in internet usage. Compared to the overall population, internet usage rates among the 65-74 year olds are still very low. In 2009, only 11% of the 65-74 year olds had used the internet in the last 3 months; 9% used it at least once a week and only 6% on a daily basis, compared to a far higher share of internet use in the overall population (60%, 54% and 39% respectively). However, when looking at the frequency of internet use among those who are connected, these differences disappear: 84% of internet users aged 65-74 used the internet at least once a week and 56% on a daily basis (as compared to 90% and 65% in the overall population). Thus, once older people have become internet users, they seem to use the internet almost as frequently as other population groups.

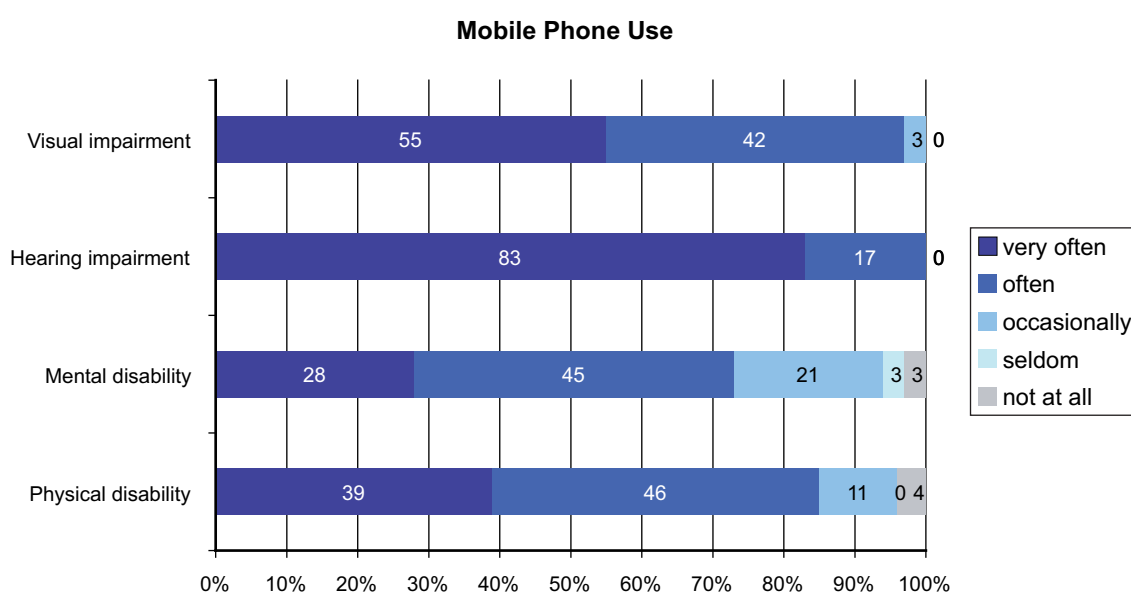
As concerns the purposes and objectives of old peoples' internet use, there are marked differences between the kind of services used and activities performed by the older generation as compared to average usage patterns, as highlighted in the eEspaña (2009) report. The first difference is that, as a general rule, the range and frequency of online activities undertaken by older people (aged 65-74) is lower than that of other age cohorts. However, as compared to the rest of the population, they make more intensive use of some internet services, such as electronic banking (47.2% of internet users aged 65-74 as compared to an average of 34.8% of the overall population) or reading newspapers (51.2% as compared to an overall 47.5%). In the case of core online activities, such as email (75% of internet users aged 65+; 82% on average) or searching for information (65+: 74%; total: 82%), and also in the case of activities that are highly demanded by the population in general, like online booking (65+: 56%; total: 62%) or eGovernment services (65+: 43%; total: 49%), usage levels are only slightly lower than the population average. However, adoption levels for peer-to-peer services (65+: 12%; total: 34%) and video sharing/downloading sites (65+: 18%; total: 42%) are significantly lower than in the rest of the population. These findings indicate that the older population conceive of the internet as a useful tool rather than a leisure environment.

Figure 16: Use of computers and internet by people with disabilities in Spain, 2003 (in %)



Source: 2007, Cuadernos Orange, Discapacidad y e Accesibilidad, Fundación Orange, (data from 2003).

Figure 17: Use of mobile phones by people with different disabilities in Spain, 2003 (in %)



Source: 2007, Cuadernos Orange, Discapacidad y e Accesibilidad, Fundación Orange, (data from 2003).

While mobile phones are used frequently by the older generation, the use of advanced mobile services is virtually nonexistent. This situation might be explained by the fact that mobile terminals are generally not adapted to the needs of users who face problems with their vision and the fine movement of their fingers. The only activity that found some acceptance by older people is to send pictures (5% of mobile users over 65). Factors accounting for the low ICT take-up rates among the older population include low-income levels (especially among those who are retired), less training in ICT, and habits and attitudes that might hinder take-up. The lack of user interface adapted to old peoples needs and the lack of online services and content addressing this population cohort constitute are important barriers to wider deployment (eEspaña, 2009).

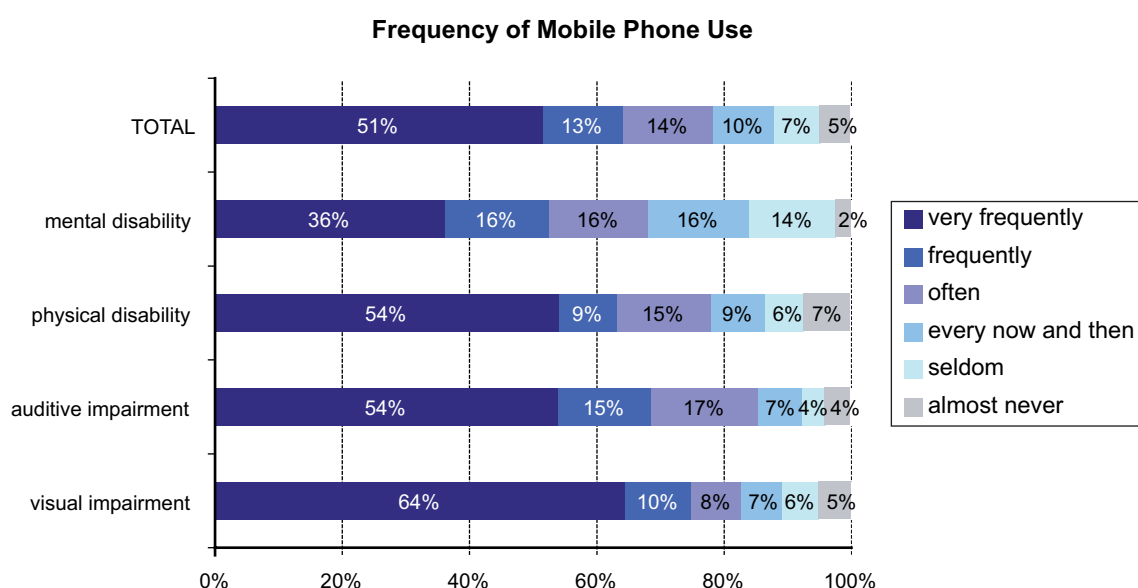
4.2 ICT Use by Disabled People

Disabled people make widespread use of ICT, though not to the same extent as people without disabilities. In 2003, Fundación Orange undertook a study on patterns of ICT

use by the disabled (Figure 16 and Figure 17). Different types of disabilities were surveyed in this study, in particular physical and mental disabilities and hearing and visual impairments. The main conclusion from this research was that all disabled people surveyed exhibited a lower level of ICT use when compared to the rest of the population. Computer and especially internet use are quite low in terms of high frequency use. Mobile phones are far more widespread and the general use of them is far greater. The increase in the number of computers in households and the increase in internet connections would lead one to suppose that these figures may have improved somewhat (Miranda de Larra, 2007, p.12).

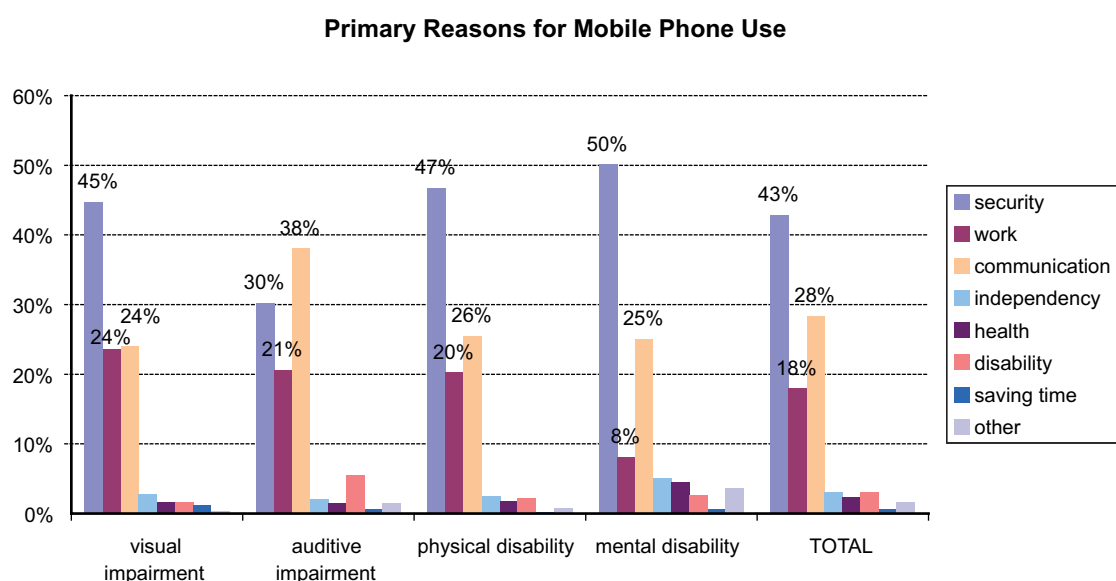
More recent data confirm the high mobile phone usage rates among people with disabilities. According to a study undertaken at the Universidad de Deusto (Aurtenetxe et al., 2007) with a total of 1,350 disabled people, mobile phones were used by 94% of those with physical disabilities, and by more than 95% of those with visual or hearing impairments. Of those with mental disability, 74% used mobile phones.

Figure 18: Use of mobile phones by people with different disabilities in Spain, 2007 (in %)



Source: Aurtenetxe et al., 2007.

Figure 19: Principal reasons for mobile phone use by disability, Spain, 2007 (in %)



Source: Aurtenetxe et al., 2007.

When asked to specify the single most important reason for using mobile phones, in all disability groups, “to feel safe and secure” was mentioned first, followed by work and communication needs and objectives. The rate of disabled people using mobile phones because of their disability, due to health reasons or to feel

more independent is relatively low. For 12.4% of the mentally disabled and 9% of those with hearing impairments one of these three factors was the main reason for mobile phone use, whereas only 6.5% of the physically disabled and 6% of those with visual impairments mentioned one of these factors as being the most important.

4.3 ICT Use by Family Carers

There is no data available on the use of ICT specifically by family carers. However, considering that the majority of family carers are women, their mean age is around 53 years old and, in the majority of cases, carers are over the age of 45; and assuming that general population patterns hold true for this population group, it can be concluded that family carers are affected by at least two digital divides, determined by gender and by age. Furthermore, given their situation, they might face additional disadvantages in ICT use and skills because of their economic situation and educational backgrounds.

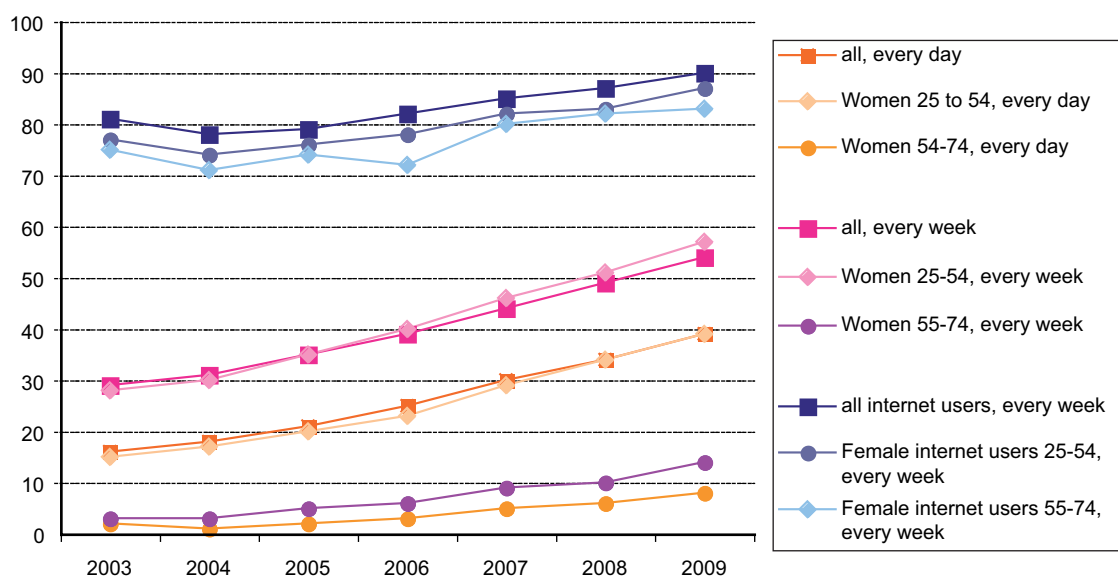
Looking at internet usage rates and patterns of women in Spain, it becomes clear that the digital literacy level of family carers will depend largely on their age and educational background. In Spain, the digital divide affecting women has been reduced over the last few years. In particular as concerns mobile phones, there are no differences between men and women and usage rate are at a very high 90%. Only among older women are rates lower, at 81% for those aged 55-64 and at 65% for those aged 65-74. Yet,

even in these age groups far more than half of women do use a mobile phone.

However, women are still lagging behind in the use of computers and the internet. In 2009, the share of computer and internet users among men and women still differed by 6.8 and 7.2 percentage points and by 8.6 percentage points for frequent internet use (INE-prensa, 2009).

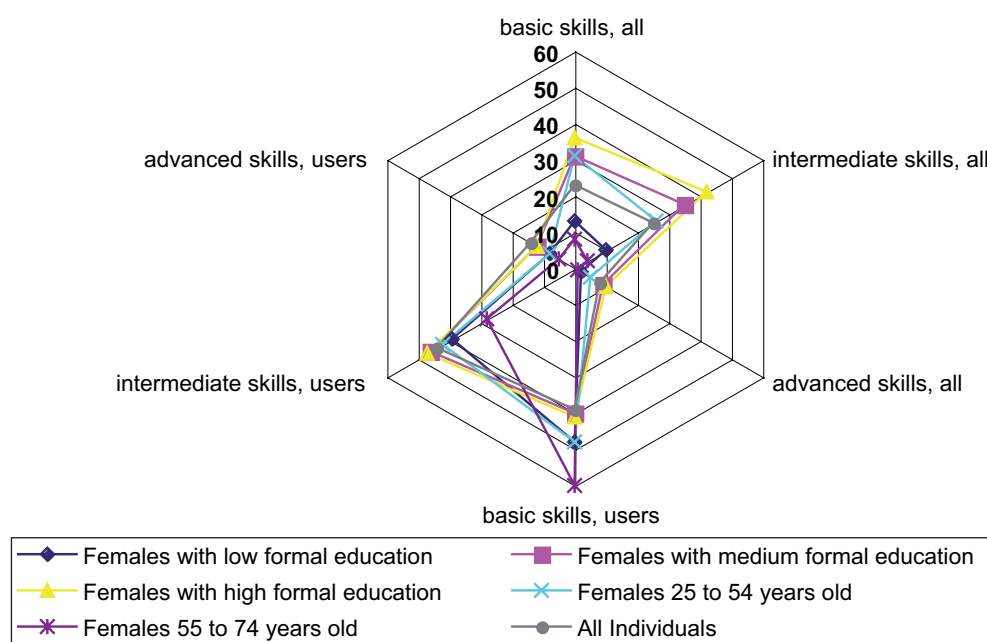
According to Eurostat data for 2009, internet usage patterns among women under the age of 55 do not differ significantly from the population average. In 2009, 39% of the whole population and 39% of women aged 25-54 used the internet every day or almost every day; 57% of women aged 25-54 used it at least a week, compared to an even a slightly lower share of 54% in the overall population. Of those women who had used the internet at least once in the last three months, 87% used it on a weekly basis (compared to 90% for all internet users). However, numbers change when we look at women aged 55-74, i.e. an age group that is overrepresented among family carers. Here, only 8% of women use the internet on a daily basis and only 14% on a weekly basis. It has to be noted, though, that those who have

Figure 20: Internet use by women aged 25-54 and 55-74 as compared to the national average, Spain, 2003-2008 (in %)



Source: Eurostat (2010) data on individuals' internet use in Spain, by frequency.

■ Figure 21: Internet use by 65-74 year olds as compared to the national average, in Spain, 2009



Source: Eurostat (2010) data on individuals' internet use in Spain, by frequency.

used the internet in the last three months in 87% of cases also use it on a weekly basis.

Internet skills differ not only with age, but also with educational background. Women who have a medium or high level of formal education have far higher internet skills than the average population, if the number of internet activities individuals have ever performed is taken as a proxy for their skills level.¹⁰ However, women with low formal education and women older than 54 have significantly lower skill levels: 75% of women with low education and 87% of women aged 55-74 (as compared to 44% of the population average and 38% of women aged 25-54) have never performed a common online activity, such as, for example, searching for information, sending an e-mail or posting a message. Most significantly, the majority of women who do use

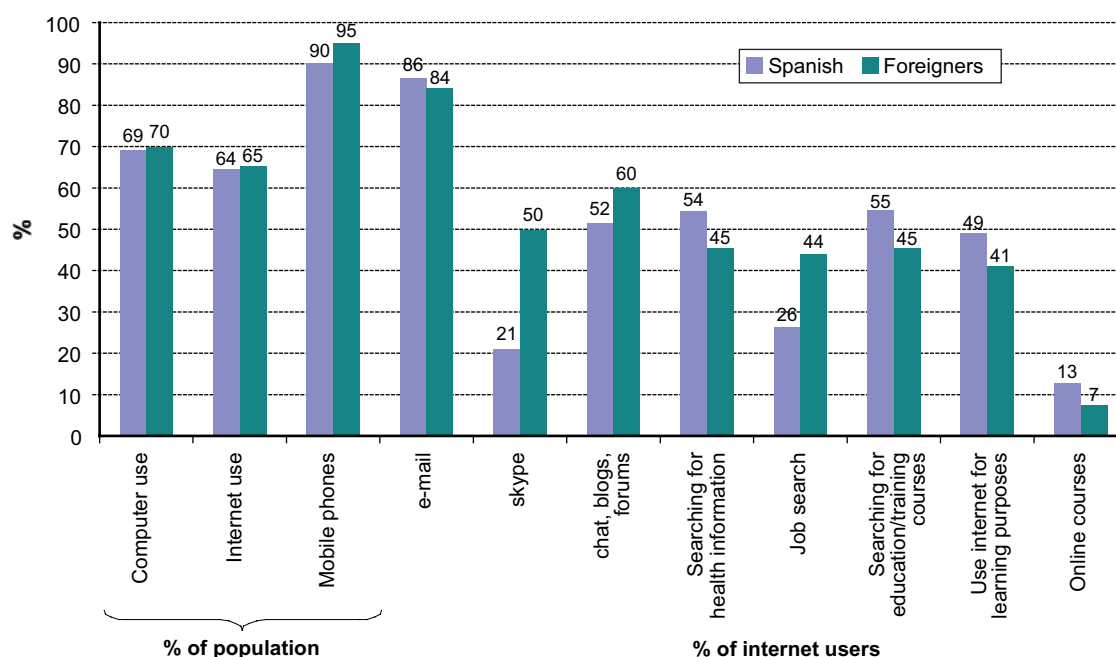
the internet, only have basic internet skills; the share of women with intermediate internet skills exceeds the population average only for female internet users with medium or high educational background. Among female internet users, age is, however, an even higher barrier to intermediate and advanced skills: Only 28% of female internet users aged 55-74 had intermediate internet skills (compared to 42% of younger females and 39% of females with low education) and only 5% had advanced skills (compared to 8% in the other two groups).

4.4 ICT Use by Immigrants and Ethnic Minorities

Current data (INE-TIC-H, 2009) suggests that foreigners living in Spain have similar levels of computer and internet use, when compared to nationals. In 2009, 95% of foreigners (90.1% of nationals) made use of mobile phones; 69.9% of foreigners (compared to 69.1% of nationals) had ever used a computer and 65.1% (compared to 64.4) the internet. 89% of Spanish nationals who accessed the internet in the last three months,

¹⁰ "Basic skills" correspond to having performed one or two tasks out of a list of most frequent internet related activities; "intermediate skills" to having performed two or three tasks; "advanced skills" to five or six. These activities include using a search engine to find information, sending an email with attached files; posting messages; skypeing; downloading; etc.).

Figure 22: Use of selected ICT services by Foreigners and Natives, 2009



Source: INE-TIC-H (2009) data on individuals' ICT use in Spain, 2009.

used it (also) from home, compared to 78% of foreigners. Foreigners are more likely to use the internet through a cybercafe or telecentres services, 32.1% compared to 6.6% of Spanish people (INE-TIC-H, 2009).

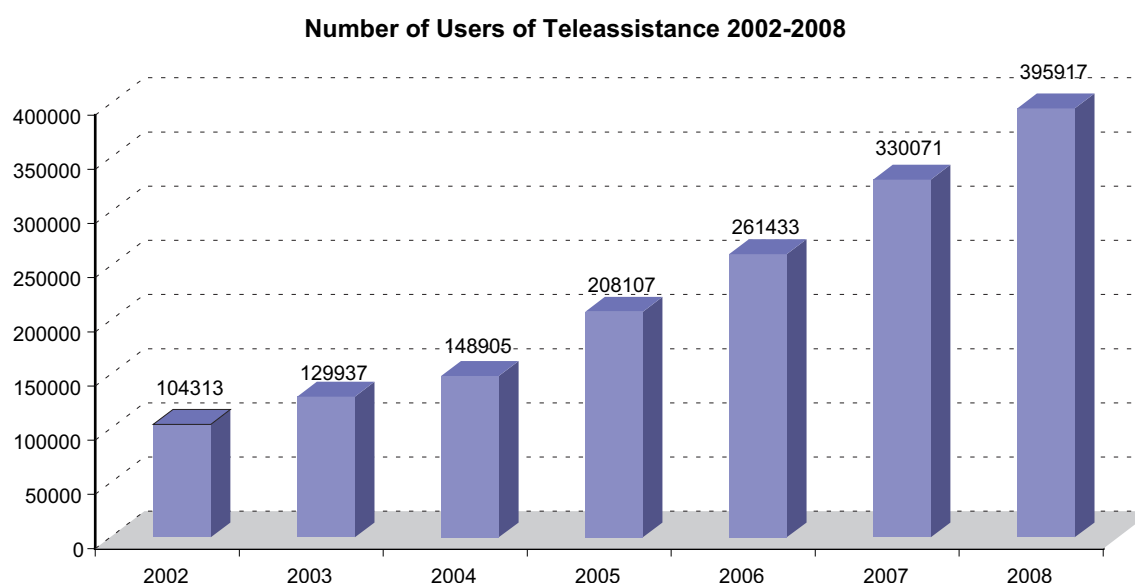
Data on the services used when online confirms that the levels of internet use are similar when comparing nationals and foreigners, while usage patterns vary slightly (INE-TIC-H, 2009). Roughly, nationals tend to use the internet slightly more frequently for information retrieval and exchange, while foreigners tend to have slightly higher usage rates concerning communication services. Of those having used the internet in the last three months, 84.1% of foreigners and 86.4% of nationals used it for sending e-mail; 63.3% of foreigners and 79.6% of nationals for searching information on goods and services; 45.3% of foreigners and 54.4% of nationals for finding information on health issues. By contrast, 37.6% of foreigners (31.2% of nationals) who used the internet in the last three months used radio and television services and 59.8% of foreigners (51.5% of nationals) for chatting and other

social online interaction. Whilst more foreigners used the internet for searching for employment (43.9% compared to 26.2% of nationals); slightly fewer used it for education purposes (45.4% of foreigners; 54.5% of nationals). Numbers differ significantly on the use of the internet for phoning, which was used by 49.8% of foreigners as compared to only 21% of nationals.

While attention needs to be paid to the fact that the category of "foreigners" includes all non-native residents in Spain, regardless of their economic, legal or labour situation, the fact that overall acquaintance with mobile phones, computer and the internet is high, indicates that also among immigrants – and, in particular those employed in domiciliary care – ICT are frequently used. This is a group of people with a great capacity to benefit from initiatives to increase their use of new technologies in their professional fields.

The differences in usage patterns between foreigners and natives do not only reflect different needs and communication habits, but are also

Figure 23: The growth of the teleassistance public service in Spain from 1999-2008



Source: IMSERSO 2009.

indicative of the existence of specific barriers that limit and hinder access to and use of ICT by foreigners. eEspaña (2009) identifies the following economic and labour barriers as the main barriers to ICT deployment by foreigners. The greatest percentage difference between native and foreign internet users can be detected in the access point to the internet. In 2009, 32.1% of foreigners access the internet from a cybercafé (compared to only 6.6% of natives); while 44.7% of Spanish natives accessed the internet from work, only 18.1% of foreigners did so (INE data, 2009). These differences might lead to a lower frequency and intensity of internet use. The lower income levels of foreigners (on average about 75% of the Spanish average income, according to eEspaña, 2009), further disfavours investment in ICT and could be a factor accounting for the differences in internet usage rates from home, which is 67.6% among foreigners compared to 82.2% among natives (INE-TIC-H, 2009). This is particularly the case for immigrant care assistants, who often live in the home of an elderly person without internet access. Considering that, in general, only 31% of people registered as being inactive and working in the household (i.e. “housewives”) use the internet, as compared to 76% of the population

who is in gainful employment, immigrant care assistants can be said to be affected by multiple digital divides, originating from different factors, including gender, nationality, labour, living and economic situation.

4.5 Public Telecare Service

In 1992, the public telecare (“teleasistencia”) programme began to be implemented to support home care for the dependant. This service allows the care recipient to contact a specialized help centre over a constantly available voice communication service. Over time, it has become a technological breakthrough that has allowed dependent users to live independent lives whilst maintaining contact with society and the family. The service decreases the risk of complications, and ensures the presence of immediate professional help if there is a crisis.

The service uses the conventional telephone line and special communications equipment which is situated centrally in the person’s house. It can be readily used by pressing a button that gives the person rapid access to a centre

Figure 24: Public teleassistance use in Spain 2008

Region	65+ population	Nr. of users	Coverage index	Women %	80+ %	Living alone	mean age	price per user in €
Andalucía	1,196,354	65,261	5.46	84	57	77	80	116.93
Aragón	262,113	14,248	5.44	-	-	-	-	180.00
Asturias	235,428	8,960	3.81	85	75	72	83	274.08
Islas Baleares	145,675	5,504	3.78	66	67	71	82	283.73
Islas Canarias	263,027	3,148	1.20	86	51	80	76	276.24
Cantabria	107,342	6,233	5.81	-	-	-	-	306.54
Castilla y León	570,559	20,218	3.54	73	65	-	77	273.96
Castilla la Mancha	362,087	31,078	8.58	71	62	50	81	174.76
Cataluña	1,196,294	59,339	4.96	74	35	-	-	320.60
Valencia	813,214	29,537	3.63	86	61	-	82	281.00
Extremadura	207,081	9,138	4.41		62	78	79	250.76
Galicia	602,986	7,209	1.20	51	60	80	82	283.67
Madrid	895,583	106,894	11.94	80	60	61	80	256.44
Murcia	194,003	6,500	3.35	-	-	-	-	265.20
Navarra	107,020	6,303	5.89	79	63	-	82	99.06
Pais Vasco	401,688	14,333	3.57	83	71	80	80	241.24
Rioja	57,187	1,103	1.93	64	74	23	82	465.80
Ceuta	8,640	578	6.69	67	45	59	76	223.56
Melilla	7,526	333	4.42	86	39	-	-	250.44
España	7,633,807	395,917	4.72	76	58	54	80	253.90

Source: IMSERSO 2009, p. 350.

of attention, 24 hours a day. As can be seen in Figure 23, there has been a steady increase in the use of teleassistance technology since 2002. The number of users served by the public telecare service almost quadrupled between January 2002 and January 2008, registering an inter-annual increase of 48,600 users. The coverage rate increased by over three percentage points from 1.45 to 4.72 (IMSERSO, 2009, p.336).

In January 2008, the total number of users served by the public telecare service was 395,917 (IMSERSO, 2009, p. 336). The Autonomous Communities with most users are Andalusia, Castilla-La Mancha, Catalonia, Valencia and Madrid, which together represent 73.8% of the total users served by telecare. On average, there are 4.72 users per 100 elderly people; in the Communities of Madrid and Castilla-La Mancha this figure represents 11.9% and 8.6%, respectively. The regions that rate lowest are the Canaries and Galicia, with coverage of 1.2% in both cases, and the Rioja, with 1.9%.

In 76% of all cases, the telecare user is female, and a slight majority (58%) of users is 80 years old or older. Only Catalonia, Ceuta and Melilla have a higher proportion of users between 65 and 79 years, with respectively 65%, 55% and 61% of users in this lower age group. The average age of the user of telecare is around 80 years and more than half of users live alone (Figure 24).

4.6 Teleassistance, Domotics and Multimedia

There are a number of initiatives in different regions of Spain, which promote the use of advanced assistive technologies in the households of elderly and disabled people.

The Andalusian **TELEADM** (Advanced Telecare, Home Automation and Multimedia) project is part of the collaboration agreement signed between the Ministry, through the Andalusian Social Services Foundation, Telefónica

R&D and Sadiel, an institution collaborating with the Innovatec Forum. The project's objective is to develop new services based on the concepts of 'digital home' and 'ambient intelligence', which aim to enable people in a situation of dependency to remain in their normal living environment. These people benefit from services such as, for example, localisation services; Multivideoconferencia services; and multimedia services facilitating physical or psychological rehabilitation. Additionally, as part of the initiative, telecare services are offered, which had some 62,000 users over 65 years in 2007, and 165 day care centres have been equipped with computer classrooms (Forinnovatec, 2009, Website).

The **Mobile Telecare Project** (TAM) has been implemented by the Vodafone Foundation Spain and the Spanish Red Cross, with the collaboration with the Foundation TECOSOS. It allows people to be permanently connected to the Central Alarm Service of the Red Cross from any location with network coverage, to be located by GPS and Vodafone's network, through immediate support mobile telephony, mobilizing the resources of the user (family, neighbours, etc.) and the necessary resources that exist in the locality. After a 7-month pilot phase in 2004, the service is now openly available. For more information, see: <http://fundaciontecsos.es/sites/default/files/TAM.pdf>.

The technological centre **CETEMMSA** developed prototypes for the improvement of the quality of life of individuals with some degree of dependency or disability within the framework of the SmartHomeCare project, financed by the Ministry of Trade and Industry. Among these prototypes is a smart control unit allowing people with Alzheimer to continue living independently; a transmitter that makes use of contact to allow people with sensory disabilities to move around in the city safely using tactile stimuli; and mattress for people who must spend long periods sitting or lying down. The smart control unit is a device for home use that provides users with Alzheimer's disease with information reminding them of tasks

to do at a given time. In addition, a computer programme can be activated that allows the user to contact health care and assistance services automatically if required. The mattress developed uses a display to show the weight distribution of a sitting or lying person, by means of flexible textile sensors. This allows the caregiver to change the person's position and prevent sores. This approach can also be used to improve orthopaedic devices through detection of the friction points in the device.

More recently, a number of research projects have been launched, funded by the European Commission's Ambient Assisted Living (AAL) joint programme, a R&D funding programme addressing demographic ageing in Europe (<http://www.aal-europe.eu/>). The projects funded under the first call of the AAL joint programme, started in 2009 and ran between 30 and 36 months. In this first call, Spain was by far the country with the highest number of partner institutions (112) and coordinating organisations (23) submitting proposals. Also, among the projects selected for funding, Spain is leading in numbers of partner organisations (48) and coordinator posts (9).¹¹ This high involvement indicates that, in Spain, research efforts in the area of AAL are substantial. However, given the early status of these initiatives and the focus on research and development, no evidence is yet available concerning the sustainability, impact and viability of the products and services developed. Among the projects selected under the first call (2008)¹² are the following initiatives relevant for domiciliary care in which Spanish organisations are involved:

- IBERNEX is the coordinator of the European Bedmond (Behaviour pattern based assistant for Early Detection and Management of Neurodegenerative Diseases) project, which is aimed at early detection and follow up of

11 Cf. <http://www.aal-europe.eu/Published/statistics/call-aal-2009-2-statistics>

12 Cf. also: <http://www.aal-europe.eu/Published/pr-docs/flyer-aal-call-1-projects>

older people with suspected dementia and other neurodegenerative diseases, by means of implementing a sensor network in the home that allows early diagnosis. Bedmond is involves further partners Spain, Austria and Portugal and has a total budget of 2.4 million EUR.

- **eCAALYX** (Enhanced Complete Ambient Assisted Experiment) is a project led by CETEMMSA (ES) which aims to develop an efficient AAL solution for several chronic conditions that can provide a reliable long-term and maintenance-free deployment, ready for real-world deployment. The total funding is 2.7 million EUR; partner institutions are in Spain, Portugal, UK, Ireland and Germany. The underlying idea is to improve elderly people's quality of life by assessing their health risks, monitoring and controlling their health status and teaching them how to manage their chronic conditions so that they can live independently at home for longer, without adding technical complexity. Additionally, the system to be developed will allow comprehensive and coordinated global treatment from different doctors of patients suffering from comorbidity resulting in much more efficient treatment. Practical deployment aspects such as remote management and auto-configuration mechanisms will be developed so that long-term, large-scale deployment is possible with reduced maintenance costs. For more information see: <http://www.cetemmsa.com/investigacion.php?id=000000014E&id2=000000155>.
- **HELP** (Home-based Empowered Living for Parkinson's Disease Patients) is a project coordinated by Telefonica Investigacion y Desarrollo (ES), involving partners in Italy, Germany and Israel and funded with 2.5 million EUR. The project integrates a complex system that dynamically monitors and treats patients with Parkinson's Disease. The system comprises a non-invasive intra-oral drug delivery device, a pump to deliver rescue medication, a PAN (Personal Area Network) to gather user's environment information, a telecommunication and services infrastructure to transfer information between the user and an automated system and a remote point-of-care unit to supervise the patients.
- **REMOTE** (Remote Health and Social Care for Independent Living of Isolated Elderly with Chronic Conditions) is coordinated by SIEMENS S.A. (ES), funded with 2.2 million EUR and has partners in Germany, Greece, Italy, Norway and Israel. REMOTE will advance the software architecture in fields of tele-healthcare by enhancing elderly people's homes with audiovisual, sensor/motor monitoring and automation abilities to trace vital signs, activity, behaviour and health condition, and detect risks and critical situations, as well as provide effective and efficient support at home.
- **RGS** (Rehabilitation Gaming System), coordinated by Universitat Pompeu Fabra (ES) and funded with 1.8 million EUR (partners in ES, AT, DE), is an initiative that aims to develop and test a virtual reality-based system that will allow an elderly person who has suffered a stroke, to take advantage of a novel ICT-based product to manage their chronic condition. RGS deploys an individualised and specific deficit-oriented training that combines movement execution with the observation of a correlated action by virtual limbs that are displayed in a first-person perspective.
- **SOFTCARE** (Kit for Elderly Behaviour Monitoring by Localisation Recognition and Remote Sensing), coordinated by Centre de Recerca i Investigació de Catalunya S.A. (ES) with partners in UK, Austria and Finland and funding of 0.7 million EUR. This project will use behavioural pattern recognition and ZIGBEE sensing nodes to create an integral

system for home monitoring which will greatly expand existing home-based health monitoring systems, as it will take into account more than one chronic condition.

- **ALADDIN** (A Technology Platform for the Assisted Living of Dementia Elderly Individuals and their Carers), is an initiative led by Greece, with partners in Germany, Estland, Italy and UK, and with the participation of ATOS Origin (ES) and Badalona Serveis Assistencials (ES). It is funded with 1.4 million EUR. The aim of the project is to utilise state-of-the-art ICT to develop an integrated solution for self-management of dementia patients, and develop innovative tools to support this procedure. This solution can be conceived of as an integrated platform enabling distant monitoring of patient status and facilitating personalised intervention and adaptive care.
- **HAPPY AGEING - A Home-based Approach to the Years of Ageing** – is an initiative funded with 0.9 million EUR and coordinated in Italy (partners in IT, NL, UK, ES), in which CETEMNSA is involved. The initiative approaches the main limitations elderly people face due to chronic diseases, low vision or malnutrition and dehydration and manages the individual needs for dietary control, safety and wellbeing. The HAPPY AGEING system will be composed of three modules, including a lifestyle monitor for recording main activities, a navigation assistant to support user mobility in close environment and a personal assistant to support performing distinct actions. For more information see:
<http://www.cetemmsa.com/investigacion.php?id=000000014E&id2=0000000156>.
- **Health@Home** is an initiative coordinated in Italy with partners in Italy, Slovenia and, in Spain, the Hospitales Universitarios „Virgen del Rocío” (ES), funded with 1.4 million EUR. It addresses elderly citizens affected by

Chronic Heart Failure, providing them with wearable sensor devices for monitoring of cardiovascular and respiratory parameters and, at the same time, enabling the medical staff to remotely supervise their situations and take action by involving public/private healthcare organisations.

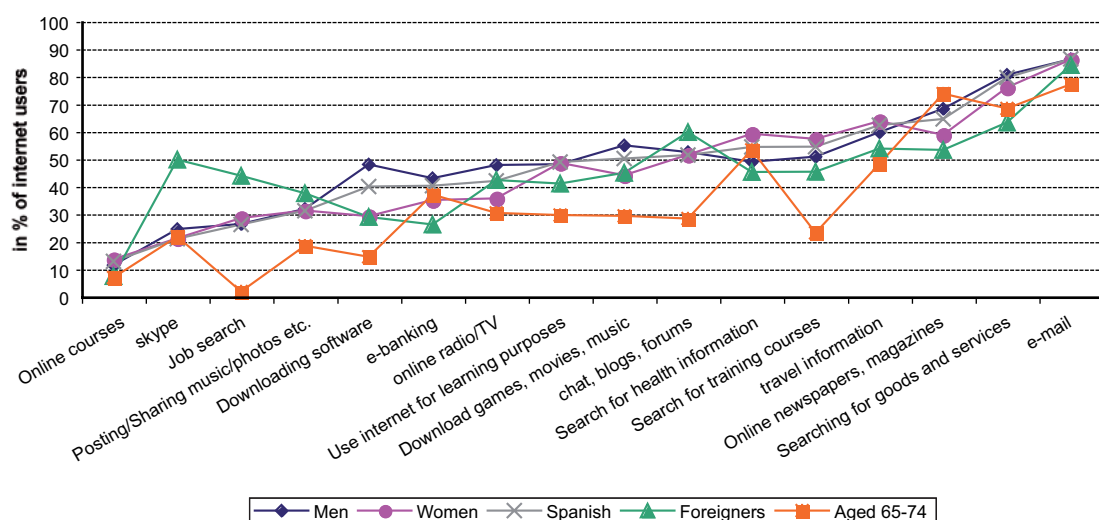
- **HOPE** (Smart Home for Elderly People) is coordinated in Greece (partners in IT, ES (Cetemmsa), GR) and funded with 1.1 million EUR. It consists of an integrated, smart platform that will enable elderly people with Alzheimer's disease to use innovative technology to live more independent lives, give them easy access to information, monitor their health, and serve as a source of inspiration for users and also for people working with assistive devices. For more information see:
<http://www.cetemmsa.com/investigacion.php?id=000000014E&id2=0000000157>.

4.7 The Potential of Internet Services for Home Care

Looking at ICT take-up and usage patterns in Spain, it becomes clear that old people in need of care and their caregivers are affected by multiple digital divides: by gender, age, nationality and possibly, as concerns caregivers, also by educational and economic divides. As a consequence, we might say that ICT tools and services – with the exception of telecare services (see section 4.5) – are currently not widely exploited to support home care.

However, when considering more in detail current ICT usage patterns in the respective user groups, a different picture emerges, at least from the perspective of the future potential of ICT. For mobile phones, digital divides are starting to disappear; already today, it can be assumed that 90% of migrant caregivers and family carers possess and use a mobile phone. This fact might seem irrelevant from a technology-

Figure 25: Use of selected ICT services by different population groups, 2009.



Source: INE-TIC-H (2009) data on individuals' ICT use in Spain, 2009.

oriented perspective, but given the care situation with its high demands on coordination and communication, the widespread availability of mobile phones can facilitate the organisation of care. Mobile phones allow caregivers to constantly keep in contact with the care recipient while they are away, to check on them, to consult them when running errands, making appointments or shopping. In the hands of the care recipients, mobile phones can contribute to their security and independence and allow them to feel safe even when their caregivers cannot personally attend them.

Furthermore, when looking at internet usage patterns among those who are already using the internet, it becomes clear that online communication services are already being used by the relevant population groups to a high degree (Figure 25). Therefore, it is to be expected that in the future, with an increase of uptake, the internet will more and more be used as an additional tool to mobile phones supporting communication, coordination and emotional support. Already today, online telephone and video communication services ("skyping") are commonly used by immigrants to keep in contact with their families abroad, overcome

their possible isolation and estrangement, and get emotional support. Interestingly, older population cohorts and women use these services already to a similar extent to other population groups (22% compared to 24% of internet users), indicating that, now, the internet is used to maintain family ties over a distance. Prospectively, with families becoming geographically separated to a greater extent, the usefulness of these already established online family networks in creating a supportive environment for home care will manifest itself and families will realize these opportunities to facilitate and improve long-term care at home.

Moreover, the internet is a very useful resource for information on health conditions and for obtaining medical advice. More than half of older internet users already use the internet to gain information on health issues. Female internet users enquire about health issues more frequently online than men (59% compared to 49%). If the reliability, usefulness and appropriateness of this information is ensured, the internet can become a powerful tool for improving the quality of home care provision. Given that 75% of older people in need of care are exclusively cared for by their families, who usually have no prior experience or training in health care, the internet could become

a key to empowering family carers and enabling them to confidently address new care tasks as they emerge with the evolving health condition of their relative.

Finally, the internet is a rich, but under-exploited resource for training. Currently, the internet is mainly used to learn about a topic by obtaining relevant information and resources online (by 48% of the general/female population, but only 41% of foreigners) or to enquire about training courses offered in a traditional, face-to-face setting (by 57% of female internet users,

but only 45% of foreigners). However, given the situation of caregivers, in particular those living with an older person, online courses and training materials could be an interesting way for them to upgrade their skills without neglecting their care responsibilities. Online training courses can contribute not only to improving the quality of care provision, but can also increase caregivers' prospects of making their care experience relevant for the labour market and thus open up (future) job opportunities for them. In this way, their care experience could even become a stepping stone for a career in the health and social care sector.

■ 5. Exemplary ICT Initiatives for Caregivers

There are various website projects in Spain, from both public and private institutions that offer support and guidance to people in need of care and their caregivers. The majority of these are directed at disabled and elderly people with a section for carers/care workers. There are a few specific website projects for family carers and care workers. In this chapter, several of these web-based initiatives focusing on supporting caregivers in their care tasks are presented, six of which are assessed and described in detail.

5.1 Identification of Initiatives

Concerning the identification of initiatives, it was necessary to provide an explanation of what kind of initiatives would become part of the study and an accompanying explanation of the inclusion criteria used to determine the most relevant initiatives.

Before describing the criteria for inclusion, it is necessary to refer to the result database that we have prepared through a systematic search on the internet using keywords on Google in Spanish: caregiver/ carer, IEM informal care assistant. The 25 sites were explored and evaluated to see whether they met the inclusion criteria described below.

It was deemed important to conduct a prospective analysis of the viewpoints of those people who are responsible for the selected ICT initiatives and, if possible, locate IEM. To increase the sources of information, requests were sent to representatives of public and private organizations for information i.e. IMSERSO, Red Cross, Public Administration, Professional Associations, etc.

Thus the generic criteria for inclusion are: project initiatives and programmes developed in Spain related to health and social care content, which contain a section for the care worker and indicate it in the main page (alternatively, this page could have a search engine to look for information). Initiatives considered relevant include websites with a section providing information for carers/care workers and platforms (web 1.0) or social networks (web 2.0) dedicated to the family carers and/or informal care assistants. We also consider Spanish initiatives that are not written in Spanish, because it is very likely that they would be used by immigrants from their country of origin.

In addition, to identify initiatives and enhance the data collection from key informants, the literature on the topic was also consulted, including lectures, conference proceedings, seminars and symposiums, etc. The underlying aim was to make the work as comprehensive as possible.

The following websites have been identified based on the main criteria. All initiatives identified have aim mainly to make information available, in some cases supplemented with additional features such as forums, chats, facts lists, and in one case (Cuidadoras en Red) using a social networking approach. All sites are mainly in Spanish.

5.2 Overview of Cases Studied In-depth

Using the list of websites addressing the needs of different caregivers, as displayed in the previous section, a number of promising initiatives were selected for in-depth study. Annex IV details the techniques that have been used to collect information on these initiatives.

Table 3: Websites supporting formal and informal caregivers

Initiatives based in Spain	
Asociación Cuidadores Familiares	http://www.cuidadoresfamiliares.org
Coidanet	http://www.coidanet.com
Consumer Eroski	http://mayores.consumer.es/documentos/cuidador/aprender/quienes.php
Cruz Roja	http://www.SerCuidador.org
Cuidadoras en Red	http://www.cuidatel.es
Cuidadoras.net	http://www.cuidadoras.net
El cuidador informal	http://www.elcuidadorinformal.es
Fisterra	http://www.fisterra.com/guias2/cuidador.asp
ForumClínic	http://www.forumclinic.org/?set_lenguaje=es&cl=es
Fundación Alzheimer España	http://fundacionalzheimeresp.org
Fundación La Caixa	http://obrasocial.lacaixa.es/personasdependientes/uncuidadorprograma_es.html
Infoelder	http://www.infoelder.com/
Portal Alzheimer online	http://alzheimer-online.org
Portal de las personas con discapacidad:	http://salud.discapnet.es/castellano/Salud/Salud%20Mayores/Psicologia%20y20Salud/Salud/Paginas/Cuidados%20del20adulto%20mayor.aspx
Portal mayores	http://www.imsersomayores.csic.es/salud/cuidadores/pyr/consecuencias.html
Sociedad Española de Geriátrica y Gerontología	http://segg.es/page/cuidadores
Todo Alzheimer	http://www.todoalzheimer.com
Todo Ancianos	http://www.todoancianos.com
Universidad de los pacientes	http://www.universidadpacientes.org
Outside Spain (resource in Spanish)	
CaregiverNJ	http://www.state.nj.us/caregivernj/index_sp.shtml
Family Caregiver Alliance	http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=545
Healthy Nj	http://www.healthynj.org/health-wellness/caregive/espanol.htm
Noah	http://www.noahhealth.org/es/bns/disorders/alzheimer/caregiver/index.html
Yale Medical Group	http://ymghealthinfo.org/content.asp?pageid=P03695

This study intends to offer different perspectives and points of view. A good example to start with is the project “Ser Cuidador” - *Cruz Roja Española*. These organizations constitute one of the most important institutions in the field of teleassistance in Spain, and are amongst the five most important providers in the teleassistance field. They are very familiar with the reality that patients, families, carers, and care workers face around Spain. They have been providing technical and human solutions for these groups now for many years. This example shows how the existing structure, training and services are adapted to accommodate IEM informal care assistants.

Another initiative is “Un cuidador, dos vidas”, an initiative of “La Fundación La Caixa”. The material provided by this financial institution is used by different organizations to train families, carers and care workers. They are working very intensively in the field of caring around Spain. From our point of view, the training of carers and care workers is one of the most important areas of work both now and in the future. In this sense, “La Fundación La Caixa” has provided a plethora of materials that have been used by carers and care workers all over Spain.

Web 2.0 tools and technologies allow us to create and share knowledge and work collaboratively in different teams. The caregiver collective is not an exception. In this sense, we present the initiative of I2BC in collaboration with the Nursing Department of the University of Malaga (UMA) called “Cuidadoras en Red”. This initiative is one example of the use of Web 2.0 applications to create a community specifically for IEM care workers.

A further initiative studied is called COIDANET, an initiative of the Galician Government. In this initiative, there are

several resources for patients and formal and informal caregivers. Coidanet is funded by the “Avanza Plan” of the Spanish Government for the development of the Information Society. In this sense, COIDANET is a good example of how government grants can encourage the emergence of projects in the field of carers/ care workers.

To offer a different perspective on care, namely that of the patients and families, the website of CEAFA, the Confederation of Alzheimer Patients Association in Spain, was selected for study. This association represents more than 200,000 patient families in Spain. They advocate for the rights of patients and they know what reality is like for carers and care workers, especially IEM informal care assistants. The patients’ perspectives are represented by more than 150 Alzheimer patient associations.

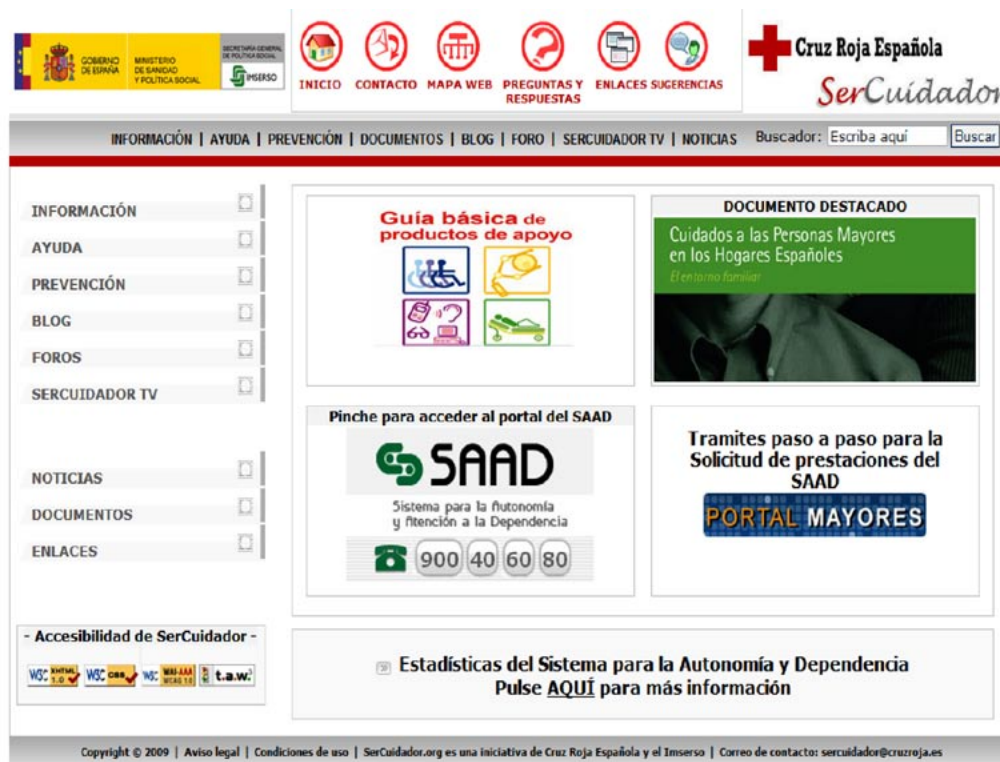
A similar initiative is “Fundación Alzheimer” another association that provides information for carers and care workers of Alzheimer patients. They provide online training for carers and care workers based on Moodle (open source platform for e-learning).

It must be noted that none of the initiatives selected are specifically designed for immigrant informal care assistants. In this sense, our aim was to enquire in how far this new reality of caring in Spain is acknowledged by the initiatives and also to raise their awareness of the fact that a larger number of immigrant people are working as care workers or carers.

To facilitate the comparison between initiatives, we have constructed a template for each. This is accompanied by a table that synthesizes all the initiatives mentioned. The structured information about each initiative is provided in the next sections.

5.3 Ser Cuidador (Cruz Roja Española)

Figure 26: Website of "Ser Cuidador"



5.3.1. Main objectives

- ✓ Information and advice for the carer/care worker: knowledge acquiring, skills and standards of care for dependent persons.
- ✓ Preventing problems associated with the carer/care workers work.
- ✓ Gaining access to various resources and services for the elderly, disabled people and their families.
- ✓ Providing information about laws that support disabled and dependent people as concerns health, social security and other services.
- ✓ To make society aware of the problems of dependency and disability and the care performed by carers.

5.3.2. Brief description

www.sercuidador.org is the new website offered by the Red Cross as tool to help carers/

care workers, and it is based on the following three lines of content:

- **Support and advice** for the carer/care worker.
- **Dependency prevention** through the promotion of healthy habits.
- **Social awareness** about disability and dependence.

The portal is a space which provides the necessary information to allow caregivers to find solutions to their problems. One example could be time management when caring for dependent people.

Link: www.sercuidador.org

Contact: Sercuidador@cruzroja.es

Where does the initiative take place? All the territory of Spain.

When did it start? November 2006.

Who promotes it?

The website www.sercuidador.org is promoted by Spanish Red Cross in collaboration with the Ministry of Education, Politics and Sport together with the IMSERSO. The portal is funded by the Ministry of Labour and Immigration.

The website states: “Our experience caring for dependent people has led us to recognise the need to increase the public awareness of dependence in Spain. We must provide support and assistance in these times of change. We want to facilitate the provision of resources to carers, informal care assistant and care workers and to improve their lives and those of the dependent people they look after”.

On the other hand, the Spanish Society of Geriatrics and Gerontology and the Kovacs Foundation, which is dedicated to medical research, have collaborated with the Red Cross to elaborate recommendations and to provide practical exercises that help to maintain the health of the carers/care workers and to care for their dependants and promote healthy aging.

5.3.3. Services provided

The portal offers these services:

- **INFORMATION:** The carer, care worker and informal care assistant can acquire knowledge, abilities, standards of care to maintain and improve the health and autonomy of a dependent person. There are distinct patterns of activity depending on the situation and the degree of dependence or reason.
- **HELP:** It provides concrete definitions and specific solutions for each case. Resources and services; aspects related to illnesses associated with addiction; guidelines to prevent situations of dependence and maximum delay of deterioration associated with aging.
- **PREVENTION:** there is advice on healthy aging, patterns of behaviour for slowing the degenerative process from certain chronic

diseases and advice for preventing home accidents.

- **CONTACT and LINKS:** where you can access the different web sites, addresses, telephone numbers of all public and private institutions that can assist carers, care workers and informal care assistant in terms of the listing of resources and services available to dependants and their families and aspects of legislation on this issue.
- The portal offers different **TOOLS** like suggestions, contacts, blogs, and forums.

5.3.4. Users

Who are the users?

- Carers/care workers for the elderly, disabled or chronically ill or long-term care.
- People who want to know the guidelines for healthy aging and prevent dependence.
- Dependent people.

Number of people who use the portal

There are 585 people registered in total (482 confirmed and 103 unconfirmed).

Number of visits 2008

Months	Number of visitors
January	15,250
February	17,422
March	18,325
April	20,223
May	29,779
Jun	25,999
July	28,323
August	26,740
September	20,808
October	19,036
November	24,360
December	23,644
TOTAL VISITS	269,909

Characteristics of the people who use the portal on a regular basis

Unfortunately, this data is not available, as the tools currently used to measure the web activity do not take into account this type of information. However, a rough idea of the visitor profile can be obtained by analyzing the emails that the portal receives. From these emails, it can be concluded that the main visitors tend to be carers, care worker and people from social services. It should be noted that this information is not reliable and that the amount of each type of visitor is unknown.

Most popular or frequent activity carried-out on the portal

Most people used the blog when connected.

Number of immigrant carers who access the portal

The exact number is unknown, but from the e-mails the portal receives, it can be concluded that immigrants are using it.

5.3.5. Observations

As part of the aim to centralize the information related to caring, the “Ser cuidador” initiative has implemented a database which contains interesting documents and links. It is hoped that this information, along with other databases under development, will become the backbone of the portal in the near future.

Although at this moment, there is no information and advice specific for IEM informal care assistants, there is high awareness on the subject. The institution responsible for the initiative has confirmed that they would like to link their web portal www.Sercuidador.org with the web portal of the Red Cross www.Migrar.es. The link of Sercuidador and Migrar would be an interesting development because Migrar has many petitions made by care workers and informal care assistant from other countries.

At the moment, these links are going to produce new tools, opportunities and news that will offer information and advice to IEMs.

5.4 Cuidadoras en red

Figure 27: Website of “Cuidadoras en Red”



5.4.1. Main objectives

To improve the quality of life of the carers, care workers and informal care assistants of old and dependent people, “Carers Network” aims to:

- ✓ Promote communication and collective action with the dual objective of supporting the working efforts and the generation of social identity;
- ✓ Create a space for exchanging knowledge, experience and resources valid for self-care and for the care offered to elderly and dependants;
- ✓ Promote and establish specific training in care to the elderly and dependants in order to facilitate the transfer from informal to formal care;
- ✓ Contribute to bridging the digital gap, enabling the reduction in the socio-economic differences that exist between communities concerning access to the internet;
- ✓ Contribute to the development of digital citizenship, which allows the implementation of human rights and of citizenship in the Information Society and opens the borders to ICT-related environments.

5.4.2. Brief description

“Cuidadoras en Red” is a social network aimed at Spanish-speaking people who provide formal or informal care to dependent adults in the household.

They could be family members or people employed in domestic services (mostly immigrant women).

“Cuidadoras en Red” offers the targeted population a framework for communication, cooperation and training in giving care to the elderly and dependent. This scheme is led by the Institute of Innovation for Public Welfare (I2BC) in collaboration with the Nursing Department of the University of Malaga (UMA).

Synergies can be created between the different groups or communities using tools such as: Photo albums, personal blogs, community blog, community forum, group files, messages, and videos.

Link: <http://cuidatel.es/>

Contact: info@i2bc.es

Where does the initiative take place?

The initiative began in Malaga (Spain) and now it works through a network.

When did it start?

November 2008.

Who promotes it?

The initiative is promoted by the I2BC (Institute of Innovation for Human Wellbeing) with the collaboration of the Nursing Department of the University of Malaga (UMA).

5.4.3. Services provided

The communities that are open at this moment are:

- Alzheimer and other dementias: Meeting point and support for the carers/care workers of Alzheimer's disease and other dementias.
- Self-care: Sharing of documents and experiences that provide knowledge and skills for caring and for improving the quality of life of carers/care workers. There is also a space to share hobbies and interests.
- Carers of Pizarra: Private community for family carers of Pizarra, -small village in the province of Malaga-; a pioneer in learning and using the internet.
- Immigrants in the family care: Meeting point and support for those immigrants who are elderly and dependent care workers.
- The Dependence: The Law 39/2006 for the Promotion and Personal Care for people in situations of dependence has revealed the reality for dependent people, and also the reality for their carers/care workers. There is a space dedicated to share experiences and information about dependence.
- Health Care: In this community, resources and expertise can be shared to improve the care that is given. The sharing of knowledge can lead to improvements in the basic needs of the elderly and dependent people i.e. food, hygiene, physical activity, leisure, social relationships, rest and sleep.
- Our News: A community where people can share news, events, projects, publications, etc. This would create greater visibility for those in social care and it would enable greater understanding of the work that is done by the carers/care workers.
- Workshop on the internet and other ICTs: Framework for teaching and learning about the management of ICT and online information processing.

5.4.4. Users

Who are the users of the service?

There are carers, care workers and social-care system professionals.

Number of people who form part of the community:

72 (20 June 2009)

Number of visitors:

644 (9 May 2009 to 20 June 2009)

Characteristics of the people who use the network on a regular basis:

Although we do not have concrete information regarding the profile of people who use the network, we can get a rough picture by analyzing the visitors' input. Through this approach, it can be said that the people who use this virtual community tend to be carers, immigrant care workers, professional health workers and other people interested in social networks and caring for elderly or dependent people.

Most popular or frequent activity carried out:

In priority order, the most popular or frequent activities carried out would be: sending messages (both individual and community), micro blogging, phrase of the day wall and archives, videos and photos places.

Number of immigrant care workers who access the network:

We still do not know exactly how many immigrants access the network, but there is a special community for "Immigrant care workers and informal care assistants" which currently has 6 members who use it on a regular basis.

5.4.5. Observations

Carers Social Network is part of the Project Cuidatel; a multi-platform for the carer, care worker, immigrant informal care assistant that promotes I2BC

The design of this social network aims to promote and generate quality input rather than mass participation. For some carers, the network is another way in which they can continue and develop relationships with other carers, previously established during the different training courses designed for them.

The strategies used to make the network more dynamic are extremely important in order to help the users take full advantage of all the resources available, making sure that they are always happy and satisfied.

5.5 Un cuidador, dos vidas (Fundación La Caixa)

Figure 28: Website “Un cuidador, dos vidas”



5.5.1. Main objectives

- ✓ Provide information and support to carers;
- ✓ Recognize the work of the carers through an innovative programme of support. It provides the tools necessary to improve their quality of life and prevent burn out associated with their work.
- ✓ Offer training to improve the quality of care.

5.5.2. Brief description

“Un Cuidador. Dos Vidas” is a programme offered by *Obra Social Fundación “la Caixa”*. This programme has the dual objective of providing information and support to family caregivers and to recognize their work, through an innovative support programme. It aims to provide initial support to caregivers in a newly arising care situation. Special attention is paid to ensuring the wellbeing of the carer to the optimum benefit for the care recipient and family. The programme includes:

- Support for daily living activities, such as guidelines for care and better care, the resources that are available in each region, dynamic images of the main techniques that are needed in their work, performance criteria, and the personal and emotional sphere.
- The family and social support to be physically active, attitudes and forms of communication, mutual aid group services and customer service.

This programme is conducted in collaboration with various regional governments and associations of various neurodegenerative diseases. It comprises three main components: A free telephone service, a guide for caregivers and a DVD with training material.

There free telephone service providing information to carers; a guide “Looking out for the carer”; and a DVD pack with the all the information available.

The aim of the guide “Un cuidador. Dos vidas” is to provide information and support to family caregivers during the process of care, regardless of the nature and duration. The contents of the guide have been developed by different authors and are arranged in three topic lines:

“Caregiver”: Provides information that will cope and better manage the situation assumed by the family caregiver.

“The person in need of care”: Provides information in the form of advice or support, in response to the different situations or needs that the family caregiver may be confronted with.

“The environment”: Provides information and guidance on the changes required by the living environment and tools available to increase and optimize capacities to carry out basic activities of daily living and/or instrumental activities of daily living, as well as information on existing resources in the different Autonomous Community.

A DVD has been developed taking into account the demands expressed by family caregivers. Among others, it aims to raise awareness among other members of the family and social environment for the needs of caregivers, in particular the need for free and leisure time, to enable them to better conduct their tasks and to avoid burn-out. The techniques and exercises

can be displayed in real time, with the objective that can be implemented by caregivers correctly. The DVD comes in several customizable options: audio description and subtitles.

Link: http://obrasocial.lacaixa.es/personasdependientes/uncuidadorprograma_es.html

Contact:

Phone: 900220000. The telephone service for users is managed by the Red Cross. It is operational seven days a week from 9h00 to 21h00.

Where does the initiative take place?

In the different regions of Spain that are participating in the initiative.

When did it start?

In 2009.

Who promotes it?

Obra Social Fundación “La Caixa” in collaboration with various regional governments and various neurodegenerative disease associations. The initiative collaborates with “Fundación Alzheimer” and “CEAFA”.

Who are the users?

Family carers and other informal caregivers

5.6 COIDANET (Xunta de Galicia)

Figure 29: Website "Coidanet"



5.6.1. Main objectives

- ✓ Promote the participation and the responsibility of the socio-community.
- ✓ Ensure equal opportunities for all Galician people.
- ✓ Mitigate the causes of social disadvantage.

5.6.2. Brief description

The Galician Care and Dependency Service is a major work area of the Galician welfare system. It is led by the Vice President of Welfare and Equality of the Regional Government of Galicia. It addresses the care and empowerment of dependent individuals who are under or above 65 years of age.

The Galician Care and Dependency Service implements all activities developed by the Galician Welfare System in the field of promoting personal autonomy and care to people in situations of dependency (see disability and programmes for the elderly).

The Network for the Promotion of Galician Autonomy (COIDANET) is one of the programmes that offer people a service that embodies the development of Information Technology and Communication (ICT) and promotes personal autonomy and care for dependent people.

Link:

www.coidanet.com

Contact:

Social contact (free): 900 333 666;
Dependency Coordinating Unit: Vice-president of Equality and Wellbeing. Phone: 881 999 224; Province Delegation of the Vice-Presidency of Equality and Wellbeing.

Where does the initiative take place?

In the Region of Galicia in Spain.

When did it start?

November 2006.

Who promotes it?

The Delegation of Equality and Welfare and the Regional Government of Galicia.

Who are the users?

Coidanet is directed primarily at skilled and unskilled care workers; carers; people in dependency situations; other professionals.

Observations

Coidanet is a website in Galician. There is no indication that there is a version planned to be in Spanish.

5.6.3. Services provided

Online consultation: This service provides a point of contact with qualified professionals in the field of personal autonomy and care for dependent people (an interdisciplinary team). This service is available at any time of day and anywhere. This service will be provided initially by the professionals of the Coordination Unit, Department of the General Secretariat for Welfare.

Forum: The registered user can participate on the forum of Coidanet.

Self-care: The COIDANET portal provides all the measures needed to facilitate the work of the carer/care worker. They are available through the following programmes: Psychological help; physical care service; respite service; guides (in development); carers' rights (in development)

Accessibility: Adaptation in the house: provides guidance and advice on possible adjustments to the environment of the person with reduced mobility. It promotes and provides optimal conditions for accessibility in their immediate environment; their home. Galician Service of Mobility to Support Staff; to access this and the relevant content the user must be registered with COIDANET.

Assistive Technologies: The Network Support COIDANET has put into operation a service that loans technical aids. The objective is to temporarily provide a catalogue of technical aids (Rail articulated bed, cranes,) for people who have a limitation or restriction on their daily activities. This will allow a greater level of personal autonomy for dependants. The length of the loan would be a minimum of 1 month up to a maximum of 3 months, with an extension of another 3 months depending on the circumstances of each user. The costs of collection and delivery of technical aids would not exceed more than 20€.

To access this service, users must register with Coidanet as someone interested in Teleassistance.

Teleassistance: The programme of resident teleassistance is one of continuous monitoring. The beneficiaries use ICT, which provides a contact with personnel who can instigate an immediate response to situations of emergency, and support in cases of loneliness and isolation. This programme includes the following services:

- **Alarms and programme management:** The Rapid Response Service provides communication between the user and the centre of attention, which will be attended by qualified personnel to act appropriately in cases of emergencies, insecurity, loneliness and isolation. This is complementary to a calendar reminder service for certain tasks: the control of chronic and medical treatments and medical and social consultations.
- **Localization service:** GPS tracking system designed for people with minor or moderate dementia, intellectual disability and / or minor mental illness.

Teletraining: This service consists of a training platform for carers and care workers, offering a range of different workshops, for example on bioethics and dependence; the Law of Dependency and other legal regulations; burn-out syndrome.

Employment: In order to access this service it is necessary to register on Coidanet. Its target audience is:

a) Families with people in a situation of dependency requiring professional care: access to contact local service professionals with expertise in caring for people in situations of dependency, and trained in various programmes.

b) Professional care workers of people in a situation of dependency: ability to insert resumes into the jobs section of Coidanet, to offer services and respond to demands that may be of interest.

5.6.4. Observations

COIDANET is an initiative that appeals both to carers/care workers and the cared for. They offer a tele-training course that consists of a training platform and centre for workshops. It has equal access for care workers and carers and the people in situations of dependency. There are online consultations, documentation and forums. We do not know the extent of the network and its efficacy; this would require further investigation. Accessibility is restricted to those people who are carers, care workers and dependants. The website is not available in other languages except “Gallego”. This restricts the access of IEM informal care assistants who struggle with Spanish.

5.7 Fundación Alzheimer

Figure 30: Website "Fundación Alzheimer"



5.7.1. Main objectives

The statutory objectives of the Foundation are:

- ✓ Facilitate the provision of information and guidance to people suffering from Alzheimer symptoms or as a form of preventive care.
- ✓ Provide technical assistance and healthcare to people who are affected by Alzheimer's disease or dementia. This is done either in the foundation's centres or establishments or through institutional arrangements in hospitals or private centres.
- ✓ Promote and encourage research and the study of Alzheimer's disease. In particular, the pathology of the brain related to the deterioration of neurons or cells of the nervous system.
- ✓ Undertake activities whose purpose is the development of therapies for the degenerative pathological processes of the brain.

5.7.2. Brief description

Spain's Alzheimer Foundation (AE) is a non-profit organisation that was created in July 1991 with the purpose of assisting and improving the quality of life of the affected people as well as the care workers and the carers.

Link: http://www.fundacionalzheimeresp.org/index.php?option=com_content&task=view&id=63&Itemid=80

Where does the initiative take place?

In the different regions of Spain.

When did it start?

July 1991.

Who promotes it?

Alzheimer's Disease Foundation. The Spanish Alzheimer Foundation could not achieve its goals without the support and assistance of institutions, public entities and private

organizations, NGOs or other organizations created by civil society. They have a great number of sponsors.

Contact

Address: C/Pedro Muguruza, 1, 6C. CP. 28036 MADRID. (Spain)
Telf: 913-431-165 y 913-431-175. Fax: 913-595-450.
Fax: 91 359 54 50.
Email: administracion@fundacionalzheimeresp.org

5.7.3. Services provided

Most of the carers who have come to Spain's Alzheimer Foundation have gained experience of how the family can cope when one of its loved ones has Alzheimer's. There is a lack of sufficient information on socio-medical, psychological, legal and other aid associated with Alzheimer's disease. The Alzheimer Foundation offers a virtual platform for e-learning in open source, using Moodle, a Course Management System. There are free web applicators that educators can use to create online learning sites.

The priority objective of SAF is to provide services dedicated to care workers; services dedicated to patients and their carers/ care workers; services for family carers; reception, orientation and counselling of carers and family members.

5.7.4. Observations

The Spanish Alzheimer Foundation could not achieve its goals without the support and assistance of institutions, public entities and private organizations, NGOs or other

organizations created by civil society. They have a great number of sponsors.

Legal Framework: Rated by the Ministry of Social Affairs "as a particular charitable organization" according to OM dated 15 December 1994 and registered under nº 28/0953"; Registered in the Register of Entities, Services and Centre for Social Action and Social Services of the Autonomous Community of Madrid under No E-2100.E-1183/Cod. 0796-07, by Resolution No. 1703-95 of 6 February 1995 of the Technical Secretariat of the Ministry of Social Integration; Authorization for the Service of Information and Guidance on Alzheimer's disease in Spain, with attention to social sectors of the Elderly, Disabled, Seniors and the entire population with no registration E1183.

Association: Spain's Alzheimer Foundation is a member of:

- The Spanish Association of Foundations,
- The Foundations of the Health Sector,
- Alzheimer Bureau of the Ministry of Social Affairs of the Autonomous Community, Madrid.

In Europe: Since the beginning, the FAE was aware of the importance of relationships with other Alzheimer organizations in Europe. In 1991, the FAE participated as a founding member in creating ALZHEIMER EUROPE together with family organizations from Ireland, Belgium and Holland. They have constantly worked within the framework of this European organization. They have participated in projects financed by the European Commission and they have integrated their representatives within government structures.

5.8 CEAFA (Confederación Española de Familiares de Enfermos de Alzheimer y otras demencias)

Figure 31: Website of CEAFA



5.8.1. Main objectives

- ✓ Represent all Federations and Associations of the Autonomous Communities
- ✓ Coordinate the activities of the member federations and Autonomous Associations
- ✓ Serve as a link between the various members of the Confederation
- ✓ The defence of rights and enforcement of duties of the various federations and Autonomous Associations
- ✓ Promote awareness of Alzheimer's disease and other dementias
- ✓ Manage and get relevant resources at the state level and internationally
- ✓ Offer resources to different members

5.8.2. Brief description

CEAFA is a NGO, whose goal is to improve the quality of life for Alzheimer patients and their families. Its principal activity is to be the

spokesman and the defender of the Associations of Relatives of the Patients with Alzheimer's disease and other dementias in Spain. CEAFA represent about 200,000 families around Spain. Link: <http://www.ceafa.es/>

Where does the initiative take place?

In the different regions of Spain.

When did it start?

In 1990, there existed the Associations from Barcelona and Madrid when patients suffering from Alzheimer's disease had unprotected status. Since then, people with Alzheimer's disease and their families have come together to work on improving the quality of life and rights of those affected.

Who promotes it?

A board of trustees made up of individuals and associations of families of Alzheimer patients nationwide.

5.8.3. Services provided

- Specific information on Alzheimer's disease.
- Specific information on the law of dependence.
- Specific Information on how to volunteer for CEAFA.
- Information on the various associations that exist all over the country.
- Communicate various news, awards, activities and conferences.
- Different to Deriva health portal, foundations, NGOs, Associations CEAFA, Alzheimer's, Laboratories and Institutions.

Who are the users?

The initiative involved some 200,000 carers of Alzheimer patients.











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5.9 Summary of ICT initiatives for caregivers

Type - name - date - users - web	Goals	Services	Developed by
Social Network - Cuidadoras en Red November 2008 – carers, informal care assistant and care workers. www.cuidatel.es	<ul style="list-style-type: none"> Promote communication and collective action. Be a space for exchanging knowledge, experiences and resources. Promote and establish specific training in giving care to the elderly and dependent. Contribute to bridging the digital gap. Contribute to the development of digital citizenship. 	<ul style="list-style-type: none"> The communities that are available at the moment are: Alzheimer and other dementias, Self-care, Carers of Pizarra, Immigrants in the family care, The Dependence, Health Care, Our news, Workshop on internet and other ICTs. Tools: Blog of the community, personal blog, forum of the community, messaging, videos, pictures. 	  
Web 1.0 - Coidanet (in Galician) November 2006 - People in a situation of dependency, carers and care workers. www.coidanet.com	<ul style="list-style-type: none"> Promote the participation and the responsibility of socio-community. Ensure equal opportunities for all people and Galicians. Mitigating the causes of social disadvantage 	<ul style="list-style-type: none"> Online consultation Accessibility Forum 	 
Web 1.0 – Ser Cuidador November 2006 - carers and care workers. www.sercuidador.es	<ul style="list-style-type: none"> Information and advice for the carer/ care worker: knowledge acquiring, skills and standards of care for dependent persons. Preventing problems associated with the caring work. Gaining access to various resources and services for the elderly, disabled persons and their families. Providing information on the law of the disabled and independent people in health, social security and services. To make society aware of the problem of dependency and disability and the care performed by carers. 	<p>The portal offers these services:</p> <ul style="list-style-type: none"> Information Help Aspects related to illnesses associated with addiction. Guidelines to prevent situations of dependence and the maximum delay of deterioration associated with aging. Prevention Contact and links 	 
Web 1.0 - Fundación Alzheimer España July 1991 - People who suffer from Alzheimer's disease and their families and friends, carers, care worker, and volunteers. www.fundacionalzheimeresp.org	<ul style="list-style-type: none"> Facilitate information and guidance to persons with Alzheimer's disease. Provide technical assistance and healthcare. Promote and encourage research and study of the Alzheimer's disease. Carry out activities with the purpose to develop therapies for degenerative pathological processes of the brain. 	<ul style="list-style-type: none"> Services dedicated to care workers Services dedicated to patients and their carers Services for carers and care workers Reception, orientation and counselling of carers and the family 	 Fundación Alzheimer España
Web 1.0 - Programa Un cuidador, dos vidas 2006 - carers and care workers. http://obrasocial.lacaixa.es/personasdependientes/uncuidadorprograma_es.html	<ul style="list-style-type: none"> Provide information and support to family carers. Recognize the work of the family carer through an innovative programme of support; providing the necessary tools to improve their quality of life and prevent burnout associated with their work 	<ul style="list-style-type: none"> Telephone service to help carers <p>This web site contains among other programmes one aimed at the integration of immigrants</p>	
Web 1.0 – Ceafa People who suffer from Alzheimer's disease and their carers. www.ceafa.es	<ul style="list-style-type: none"> Promote awareness of Alzheimer's disease and other dementias. Manage and get relevant resources at the state level and internationally. 	<ul style="list-style-type: none"> Specific information on Alzheimer's disease, the law of dependence, volunteer in CEAFa. Communicate various news, awards, activities and conferences. Different to Derive health portal, foundations, NGOs, Associations CEAFa, Laboratories and Institutions. 	

■ 6. The Use of ICT by Migrant Care Assistants

6.1 Interviews with Migrant Care Assistants

To gain a better understanding of the current and potential use of ICT by migrant caregivers, I2BC conducted interviews with a group of 13 randomly chosen migrant care assistants in the city of Malaga. Additionally, a person who, on behalf of a religious charity, acts as a mediator in the placement of care assistants, was interviewed.

According to the expert interviewed, “migrant care assistants are a transient workforce”. The main reason for this labour mobility, apart from the death of the cared person, is the low salary. Many subscribed to the credo “For a few Euros more in salary, I will work for another family”, which is, according to the expert consulted, also a consequence of the lack of quality of life experienced in the caring situation: “After the isolation they have suffered, they are only interested in money because it is what they value the most”.

The salary care assistants receive varies, depending on the family employing them and the number of hours worked. It ranges from €600 to €800 per month. This salary is very low, not only in absolute terms, but, in particular, when considering the activities that care assistants are expected to perform. They accept these terms for lack of alternatives and are welcomed by families, irrespective of their level of competences and training.

In addition to the domestic work, they have to realize complex caring procedures. These procedures may include the following: preparing and administering medication, giving basic hygienic care, feeding, avoiding dangers, providing remedies, preserving the integrity of the person cared for.

Migrant care assistants carry out these tasks in a different culture from their own and within a health system that they are not familiar with. Additionally, at least those who do not come from Latin America, they face problems in understanding and speaking the Spanish language. Although there is no real evidence about the extent of the work that care assistants perform, it is probable that they suffer injustice in terms of conditions of employment.

Migrant care assistants are most commonly introduced to their tasks by the family and by the social service personnel, which visit the dependent people in their homes. Most migrant care assistants possess no formal training in long-term care. However, some of the Latin-American care assistants bring with them natural and home-made remedies that they incorporate into their caring procedures, i.e. natural plant oils used to give massages.

The interviews conducted with migrants in Malaga shed some more light on the concrete situation of migrant caregivers and, in particular, their use of ICT. Table 4 summarizes the profile, background and current situation of the 13 interviewees.

On the whole, the profile of the care assistants interviewed in this small sample coincides with similar studies (IMSERSO, 2005b) and the general characteristics of migrant care assistants as described in the first part of this study (see Section 3.2). Compared to other studies, there are slight deviations concerning the demographic profiles and the countries of origin. Notably, in the Malaga sample, there are no care assistants from Eastern European countries and migrant care assistants from Morocco (4 interviewees) and Paraguay (five interviewees) are

Table 4: Migrant care assistants' background and situation*

	Age	Sex	Country	Family	Education	Legal status	Languages	Motive	Arrival	Living situation
1	29	F	Chile	married, 1 child	uni degree (tourism)	undocumented	spanish, english	gain money to buy house	06/2007	with partner, daughter and other couple in rented flat
2	32	F	Morocco	single, 1 child	primary	Legal residence	spanish, arab	work	2000	with daughter in rented flat
3	52	F	Paraguay	married, 4 children	second-ary	in process	spanish; english	to support children's studies	12/2005	with daughter and granddaughter in rented flat (EUR 600 rent)
4	24	F	Morocco	married, no children	primary	other	spanish, arab, french	work	10/2008	with husband and sister in rented flat
5	21	F	Paraguay	single, no children	second-ary; 2 years uni	undocumented	spanish	work	03/2006	NR
6	21	F	Paraguay	single, 1 child	second-ary	undocumented	spanish; portuguese	work	09/2008	NR
7	44	F	Paraguay	married, 3 children	primary	in process	spanish	work	05/2007	NR
8	21	M	Ecuador	single; NR	second-ary	undocumented	spanish	support family and finalize study	11/2008	NR
9	35	F	NR	married; 2 children	second-ary	undocumented	spanish	work	01/2006	with family and friends
10	27	F	Bolivia	single, NR	university study	undocumented	spanish	economic reasons	04/2005	alone
11	58	F	Paraguay	single, 4 children	primary	in process	spanish	support family	01/2005	alone
12	22	F	Morocco	single, 1 child	primary	in process	spanish, arab, french	work	2006	with friends
13	32	F	Morocco	single; no children	primary	in process	spanish, arab	work	NR	with boy friend

*NR = No response

overrepresented. In the case of Morocco and care givers from Morocco, this is most probably due to geographical proximity. Furthermore, the age profile, while concurring with general findings for the age range – 21 to 58 years of age – classifies the sample as rather young with an average age of just 32 years, when compared to IMSERSO (2005a & 2005b) where the average age was 37 and 42 years respectively.

The vast majority of the migrant care assistants who took part in the study are women aged between 21 and 58 years of age with an average age of 32 years old. Only one man was found in the survey of 13. Eight respondents (62%) are not married; four of these have at least one child. In total, eight of the twelve women interviewed had children; six (50%) were single mothers (i.e. living

with their children, but without their partners), five of these (42% of the total) have children who are still minors, which, as they testified, can lead to a conflict of commitments between dedicating time to the dependant and time to their own children.

Six (46%) interviewees were residing illegally (undocumented) in Spain and five (39%) were in the process of attaining Spanish residence. Other studies, such as those conducted by IMSERSO (2005b), find similarly high shares of migrant caregivers illegally residing in Spain. When looking at the literature, this finding is often explained by the fact that domestic services, including home care, are sectors where recently arrived migrants find employment and from which they move on to more stable work relationships

within the first three years of residence in Spain. However, in this sample, at the time of the interview (April 2009), the majority of immigrants had been living in the country for more than three years; only three had been in the country for less than a year. Yet only one respondent, who had arrived in 2000, had obtained legal residence at the time of the interview. Thus, eleven out of thirteen migrant care assistants (85%) are socially invisible and without civil rights, which leads to precarious living and working conditions with a lack of job security, low wages, a lack of social protection, no legal constraints on working hours, no social support, difficulty in gaining access to the necessary training, etc. Respondants reported

that, because of their precarious legal situation, they take up jobs where they can remain hidden and one of these jobs is in the homes of dependants.

The level of education is quite heterogeneous, depending on the country of origin, age and gender. It ranges from primary education, which was the highest level of education of six respondents (46%) to a university degree. In two cases, the care assistants had interrupted their university studies and were struggling to complete their degrees in Spain. For all the respondents, economic aspects were the main motive for immigrating to Spain. In eight cases,

Table 5: Migrant care assistants' professional profile and working conditions*

	Profession in country of origin	Previous work experience	monthly income	Start	Residential care	Nr of care jobs	Total duration (months)	Cohabitation	Salary	Qualification	Training preferences
1	Cashier in casino	call centre, waitress, care assistant	1000	12/2007	<input type="checkbox"/>	1	12	<input type="checkbox"/>	600	<input type="checkbox"/>	nursing
2	none	cleaning homes/hotel; kitchen help; construction	600	three years ago	<input type="checkbox"/>	1	5	<input type="checkbox"/>	500	<input type="checkbox"/>	personal relations, nursing
3	hairstresser	caregiver; domestic aid	600	NR	<input type="checkbox"/>	1	36	<input checked="" type="checkbox"/>	600	<input checked="" type="checkbox"/> degree	NR
4	waitress; nanny	Caregiver of 97 year old lady	NR	10/2008	<input type="checkbox"/>	1	5	<input checked="" type="checkbox"/>	700	<input type="checkbox"/>	Personal care (old people, children)
5	domestic aid	domestic work, waitressing, nannying, home care	600	03/2006	<input type="checkbox"/>	2	8	<input checked="" type="checkbox"/>	800	<input type="checkbox"/>	medical conditions and care
6	domestic aid	nannying	650	09/2008	<input type="checkbox"/>	1	6	<input checked="" type="checkbox"/>	650	<input type="checkbox"/>	some training
7	care assistant	nannying; home care; cleaning	NR	2 years ago	<input type="checkbox"/>	3	16	<input checked="" type="checkbox"/> twice	700	<input type="checkbox"/>	qualify as nursing assistant
8	student in vocational training	care assistant; cleaning; painter; deliver newspapers	NR	01/2009	<input checked="" type="checkbox"/>	0	2	<input type="checkbox"/>	400	<input checked="" type="checkbox"/>	what is necessary to care for old people
9	hairstresser; tailor	hairstressing; dressmaking; care assistant	900	NR	<input type="checkbox"/>	1	8	<input type="checkbox"/>	800	<input type="checkbox"/>	some
10	student at professional college	care assistant	700	05/2005	<input type="checkbox"/>	1	NR	<input checked="" type="checkbox"/>	700	some know-ledge	NR
11	care assistant	care assistant	NR	01/2006	<input type="checkbox"/>	0	NR	<input type="checkbox"/>	1050	NR	NR
12	cleaning; home care	cleaning; home care	NR	2 years ago	<input type="checkbox"/>	1	26	<input type="checkbox"/>	300	<input type="checkbox"/>	nursing
13	home care; cleaning restaurant	home care; cleaning restaurant	NR	NR	NR	NR	NR	NR	NR	NR	NR

* NR = No response; ☒ = yes; ☐ = no

“working”, i.e. finding employment and earning money, was the main reason for moving to Spain. In four cases, working and earning money in Spain was described as a means to achieve some other objectives, such as supporting the family; supporting the children’s study; supporting ones own study or buying a house.

The differences in the educational background of respondents are not reflected in differences in professional profiles and work experience, which mostly relate to the service sector (Table 5). In their countries of origin, respondents’ professional profiles include a waitress, hairdresser, cashier, tailor, nanny, student and work in the domestic service. Furthermore, many respondents have, additionally to their engagement as home care assistants, collected professional experiences in other occupations in the service sector, mostly in domestic tasks, such as cleaning, cooking and nannying.

Of those surveyed, only three had previously received training in care of the elderly and dependent people; one of them being a qualified nursing assistant (in Paraguay). In fact, when questioned on the kind of training they would like to receive, all the migrant care assistants interviewed said that they would like to receive more training in nursing, some to improve their skills, others to gain some kind of recognition and certification of the work there are doing, in view of future professional opportunities.

Salary and working conditions vary across the sample. Roughly half the respondents had been employed to live in the house of the elderly person they are caring for, providing a 24h/day supervision with little leisure time. In these cases, a salary between €600 and €800 was paid. Those not living in the household of the care recipient were contracted to provide care on different time schedules, but usually on a daily basis. One respondent was employed for 10 hours a day, from 10 a.m. to 8 p.m., another for a half-day service. Correspondingly, salaries range from €300 to €1,050, and also depend on the

demands of the care situation on the caregiver. In this sample, work relationships of under one year prevail; there is no apparent relationship between the duration of the care agreement and the salary paid. Rather, those who present a more diverse professional profile with a variety of different jobs that are undertaken in parallel or in sequence, tend to have worked as care assistants for shorter periods of time. Also, the three oldest respondents have longer care relationships and seem to have developed a more consolidated profile as care assistants, while younger respondents seem to have been more inclined to take up different jobs, for shorter periods, moving on when a better employment opportunity arose.

With respect to the use of ICT (Table 6), all interviewees, without exception, report they use mobile phones extensively, also to look for work. As regards the use of computers and the internet, however, a more diverse picture emerges. A majority of nine interviewees possesses at least some computer and internet skills. Only a third of them has ever undergone a computer course; the majority acquired their skills through ICT use. A minority of four respondents have a computer with internet access in their home; the remaining nine respondents (69%) have neither a computer nor internet access in their homes. In total, seven respondents (54%) use an internet café or a public access point to go online. Interestingly, three of the four respondents who have internet access at home also make use of public access to the internet. Four respondents do not use the internet from home or from a public access point - these are the four who claim not to have any computer or internet skills.

Thus, there seem to be three different kinds of user group, each comprising roughly one third of the respondents: (1) the digitally included, i.e. those who have ICT skills, who frequently use computers, who access the internet from their homes and possibly other places (four respondents); (2) those restricted in access, i.e. those who possess ICT skills, but no computer or internet access from their home and thus

Table 6: Migrant care assistants' use of ICT*

	Mobile phone	Use phone for work	Computer access at home	Computer skills	Internet access at home	Internet skills	Internetcafe	Computer course	Search for Health information	Webpages for caregivers	Member of social network	Usefulness of ICT for work	Internet access at care recipient's home	Caregiver allowed access	Problems in ICT use	Main ICT use
1	■	■	■	■	■	■	■	■	■	□	■	■	□	□	none	communicate with family abroad
2	■	■	□	□	□	□	□	□	□	□	□	■	□	□	lack of time	NR
3	■	■	■	■	■	■	□	□	□	□	□	□	■	□	NR	speak to family abroad
4	■	■	□	■	□	■	■	□	□	□	□	■	■	■	lack of time and opportunities	speak to relatives abroad
5	■	■	□	■	□	■	■	■	■	■	■	■	■	■	none	communication
6	■	■	□	■	□	■	■	□	□	□	■	■	□	□	none	communicate with family abroad
7	■	■	□	■	□	■	NR	□	□	□	□	■	■	■	lack of time, but interested	none
8	■	■	■	■	■	■	■	□	□	□	■	■	NR	NR	none	job search
9	■	■	□	■	□	■	■	□	□	□	■	■	□	□	lack of access and practice	job search; communication with children
10	■	■	□	□	□	□	□	□	□	□	□	■	■	□	no skills; no course available	NR
11	■	■	□	□	□	□	□	□	□	□	□	■	□	□	NR	no use
12	■	■	■	■	■	■	■	■	□	□	□	■	■	□	none	job search
13	■	■	□	□	□	□	□	□	□	□	NR	NR	NR	NR	none	NR

* NR = No response; ■ = yes; □ = no

use the internet more sporadically from public access points (five respondents); and (3) the digitally excluded, i.e. those who do not have any computer or internet skills. They have no computer equipment where they live and do not use public access points (four respondents).

There is no straightforward pattern discernable differentiating the digitally included from those without computer facilities at home. Educational background and/or aspirations might play a role. Of the four respondents with internet access from home, one has a university degree, another (the only male respondent) is still studying or at least aspiring to finish university studies and a third is living with her daughter and granddaughter, whose education she is supporting with her care activities. However,

educational background or aspirations are not a guarantee of ICT literacy. Quite the contrary: one of the digitally excluded respondents is a student at tertiary level at a vocational college.

Those who use the internet, use it primarily to communicate and keep in contact with their families abroad. In the interviews, some respondents mentioned online video telephone services such as skype as their main communication means, others mentioned messaging and four respondents are members of an online social network, such as facebook, which was explicitly mentioned by one of them. In second place, the internet is used as a means to find work. Compared to these uses, other online activities are far less frequently performed. In particular, only three respondents ever consulted

the internet for information on health-related issues. Only one interviewee ever accessed a webpage directly addressed at caregivers and their needs. Therefore, it seems that respondents conceive of ICT as a tool for their private lives, which supports their personal communication needs and the improvement of their economic conditions. They do not seem to use ICT to develop their professional profile, to improve their caring skills or as a means of facilitating their work as caregivers.

Surprisingly, given the current lack of ICT use for professional purposes, almost all respondents consider that the use of ICT in their work environment could facilitate the work. Thus, there is a general awareness of the potential usefulness of ICT and also an interest in using ICT, even from those who are digitally excluded at the moment. However, respondents do not seem to be aware of existing tools or services to support home care.

Main barriers to the use of ICT, as perceived by migrant care assistants, are lack of time, access opportunities and skills or training. An additional barrier emerges in cases where the caregiver resides in the household of the elderly person cared-for and has no internet access there. In one of these seven cases of co-habitation, there was no internet available in the home of the elderly person. In half of the six remaining cases, the family did not permit the use of their computers and internet facilities by the care worker. Thus, families employing care assistants do not seem to consider the internet as a tool for care assistants to improve the quality of care provision. On the contrary, as reported in one case, the family was afraid that the care assistant might neglect their caring obligations if they were granted internet access.

6.2. Key Informant Interviews

With a view to gaining a deeper understanding on the work and needs of family carers in general and migrant care assistants in particular, a series

of four interviews were carried out with experts in this area. The conclusions gained from these interviews are outlined below.

Communication and information needs of immigrant caregivers

The interviewees could not really comment on the communication and information needs of migrant caregivers due to lack of information. However, they considered that these needs depend greatly on the amount of time the migrant caregiver has spent in Spain, their knowledge of Spanish, their acquaintance with Spanish culture, and their knowledge of the long-term care system.

As an example of cultural misunderstandings that impact on the quality of care provided, the case of a caregiver from the Maghreb was quoted. This caregiver did not understand the need to carry out some hygienic procedures for her terminally ill patient. In accordance with her culture, she treated her patient's skin with henna and refused to wash it off. Although the importance of hygiene was explained to her, according to the caregiver, this was not seen as a priority.

Carers' knowledge of ICT

In general, the experts consider that family carers and other informal caregivers do not have an extensive knowledge of the use of ICT products and services in caring. This is mainly due to the socio-demographic profile of family carers, which reflects prevailing digital divides. As a consequence, carers tend to be people who are not accustomed to using new communication technologies and lack skills in this area.

Nevertheless, according to the experts, there are a number of pioneering projects such as the initiative in Río Nacimiento, in Almería, and in Pizarra and Torremolinos, in Málaga. Also, thanks to the development of specific courses and the use of free access computer rooms, such as in the Guadalinfo centres, more and more carers

are training themselves to use information and communication technologies. The benefits of ICT training for caring can be seen in the various specific courses that have been available since 2006 in these centres, with a total of 112 female carers (normally of elderly or dependent people) having received training (information from the towns studied).

More recently, networks for carers have been developed, although these are still scarce and in an experimental stage. “Carers’ Network”, www.cuidatel.es, is such an initiative, launched by the Institute of Innovation for Human Wellbeing in collaboration with the Nursing Department of the University of Malaga, and the website www.cuidadoras.net launched by the district of Río Nacimiento in Almeria (cf. Chapter 5).

Access to different forms of communication (phone, internet, interactive TV)

All of the professionals interviewed agreed that carers used both land-line and mobile telephones, although few had access to the internet or interactive television.

Problems preventing the use of ICT products and services

According to the interviewees, the main problems that prevent carers from using information communication technologies are the following: “a lack of time to dedicate to training in using the new technologies”, “a lack of information and training”, “a lack of confidence in using the new technologies”, “a lack of technological resources (computers, internet connection)”.

The potential of ICT

A general theme identified by all the professionals interviewed was that information communication technologies have great potential to influence some aspects of the lives of both the carers and those being cared for. During

the interviews, the following statements were highlighted: “ICT improves the quality of caring”, “ICT can halt the process which leads to complete dependency by increasing the level of autonomy of the person being cared for”, “ICT improve the quality of life for both the carer and the person being cared for”, “ICT encourage participation in different leisure activities, enhancing the social participation of the carers and strengthening links with the social support network”, and “ICT encourage learning of skills and techniques of self-caring, converting the users into agents of their own social wellbeing”.

Through the creation of a technological system of contact centres connecting caregivers and patients, informal care assistants could have at their disposal resources which would enhance their knowledge about the care they give and the care that they should take of themselves so as to prevent injury, share the burden of caring, etc.

Traditionally, the main ICT training carers receive is through the different courses organized by social care institutions and other organizations such as town councils and town halls, etc.

In some cases, younger carers use the internet to find out about the illness that their family member or person being cared for suffers from. They tend to look for information about how they can improve the care that they give and the different associations that exist that could help them. They also use the information communication technologies to look for work.

Networking and social networks

The development and maintenance of a platform dedicated to carers and connecting them with professionals who can resolve queries and problems regarding caring is extremely necessary. A platform of this kind would be of benefit because it would:

- Give carers a chance to share knowledge and experiences with other carers;

- Provide support and assessment from specialized care professionals;
- Improve the quality of caring in general, both at an emotional level (allowing people to express their feelings and emotions) and at an educational level (information regarding all areas related to caring and self-caring);
- Create a forum whereby different people such as carers, family members, public administration etc. can interact;
- Help make online information resources more accessible. For example, those that could be missed due to inadequate search criteria or lack of ICT skills (common amongst informal care assistants);
- Help integrate carers (the majority of whom are women) in the information society, contributing to their social empowerment.

■ 7. Key Findings and Recommendations

Synthesizing the evidence collected in this report, the following main findings and recommendations emerge.

7.1 Technological Solutions for Domiciliary Care

The teleassistance home service has made an impressive impact on the homes of the elderly and disabled in the last ten years. It now serves almost 400,000 homes in Spain. Its recent rapid take up in the different regions of Spain has given rise to optimism as regards its future mainstream deployment.

TELEADM – Teleassistance, Domotics and Multimedia – is a recent phenomenon that is providing new technology for ambient assistance. There is no evidence of its success yet, and there is little awareness of it in the general public.

Future research should be carried out in order to determine the opportunities these services offer, the barriers that need to be overcome, and the impacts on the lifestyles of the people using them. Other technological options for relieving informal caregivers should also be investigated and promoted.

Recommendations:

- Increase awareness of the technologies available to the elderly and disabled;
- Mainstream existing technologies;
- Ensure the financial accessibility to technologies that improve independent home living;
- Supply training for both informal caregivers and care recipients in the use of the technology.

7.2 Access and Use of Internet Services

One of the main obstacles to the adoption of ICT-based services is the lack of internet access in care recipients' households, by the care recipients themselves, by their family carers and, in particular, by care assistants employed to assist them in their daily activities. Often, families are not aware that granting care assistants internet access may improve the care provision of their relatives. On the contrary, they tend to be afraid that attention will be withdrawn from the core care tasks, that the service will be abused and that the electronic equipment might be damaged.

Today many older people in need of care, especially if they are living on their own (with the help of a (migrant) care assistant), do not have internet access in their home. However, in the future, this will change. Given current trends, the internet will be accessible in almost all Spanish homes. This tendency, when combined with the growth in computer literacy and use by immigrants and ethnic minorities in Spain, could prove to be of great value for overcoming the isolation dependent people and their caregivers currently suffer. Access to the internet could enable them to both take part in society and better understand and influence the medical situation they are faced with.

The current economic downturn in Spain may affect the ability of organisations to offer ICT technology at affordable prices to low income customers. COIDANET provides such a service of loaning and reduced prices for technical aids. However, it is uncertain whether this initiative will be sustainable over a longer period. Secondly, considering that the current economic crisis has prevented the UK government from passing a bill on ICT and care, the question arises as to whether, if the Spanish government were to decide to take

action to mainstream ICT in the caring sector, the current economic climate would impede the effectiveness of the measures taken.

Recommendations:

- Promote internet access and skills for people in need of care;
- Raise awareness for the usefulness of ICT for improving the quality of life of both care recipients and caregivers;
- Campaign for care assistants to have access to ICT within the household as an aid to caring;
- Make technology available at affordable prices for both caregivers and the care recipients.

7.3 Social and Emotional Support Online

As the examples studied in Chapter 5 show, ICT in general, and the internet in particular, can contribute to providing support to carers and other informal caregivers, by supplying information and allowing for knowledge exchange. While online social networks among carers and care assistants are not yet a common phenomenon in Spain, experiences in other countries, such as the UK (cf. Yeandle & Fry, 2010), suggest that social networks can play an important role in easing the care burden by providing emotional and psychological support and by transcending the isolation often experienced by domiciliary caregivers.

Recommendations:

- Set up and advertise a central online social network where caregivers can meet anonymously and gather in groups of common interest, with links to initiatives offering training, information and support;
- Provide incentives for online services and platforms that already deal with migrants to

build and maintain a community for migrant care assistants;

- Carry out further research and take legal action if necessary to ensure that information revealed on social networking sites is protected. Users need guidelines to help them communicate protected, delicate or personal information online safely; migrant care assistants must be sure that their real identity is not, and cannot be, revealed (e.g. to the immigration office).

7.4 ICT for Training and Skilling

As illustrated by the example 'Ser cuidador', ICT can be effectively used to supply training. Connecting information and training on domiciliary care to other websites, which are frequented by carers and/or care assistants, can improve the accessibility to these training opportunities. In the case of 'Ser cuidador' an online TV training service and training documents and collaboration with the migrant platform 'www.migrar.es', were used to make training available to migrant care assistants using ICT. Building on these efforts, this network could be extended and integrated to provide training from other relevant organisations and associations. It would thus evolve into a broad support network for care.

Recommendations:

- Improve access to training programmes for all caregivers including migrant care assistants;
- Develop targeted and structured online training courses and materials that are easily understandable and accessible;
- Make training courses and materials available in different languages;
- Integrate qualification and certification schemes into training, which will enable caregivers to develop a caring career and create a care sector with a more holistic approach to caring.

7.5 Improving Informal Care Provision

Work load, work intensity and low status negatively affect informal caregivers' lives and wellbeing and, consequently, the quality of care provision. For (migrant) care assistants, the lack of other professional opportunities drives them into caring, but, in general, they are not interested in pursuing a career as a care worker or investing in training to develop their skills. These findings are corroborated by our field research, which indicates furthermore that job mobility is extremely high, mainly due to the low pay and the low status of the occupation. Immigrant caregivers in older peoples' homes are often socially invisible. They are often illegally residing in the country, without legally binding work contracts or occupational rights, and they may not be covered by the social care system. Thus, their precarious situation poses a threat to their own health and wellbeing, and indirectly impacts the quality of care provided to elderly people.

Recommendations:

- Decriminalise and regulate the provision of domiciliary care to families;
- Improve the status, work conditions and salary of domiciliary care assistants;
- Recognise the professional experiences of care assistants and implement training schemes that aid care assistants (and also family carers) in developing careers in the social care service.

7.6 Addressing the Challenges of Multiculturalism

It is no coincidence that immigrants from Latin America make up the majority of migrant care workers in Spain. The fact that Spanish is

their mother tongue facilitates substantially the communication intensive work of a caregiver. However, even when there are no language barriers, cultural barriers still pertain. Families and care assistants both need to be aware of each other's cultures so that there is no confusion over customs and practices in such a sensitive area as domiciliary care.

Many of the initiatives examined in Chapter 5 fail to recognise and confront the multicultural changes that have occurred in Spain over the last few decades. These platforms do not address immigrants and ethnic minorities and the information is not provided in such a way that its content is easily understandable for non-native speakers. Different cultural perspectives on long-term care are not discussed.

Recommendations:

- Encourage a reflection on the multicultural society and on the vital socio-economic role of immigrants in many sectors, including the long-term care sector, to raise awareness of different cultural perspectives and create an understanding of the problems and needs of migrants;
- Provide crucial information on the Spanish health system, the organisation of long-term care, first aid and basic medical and hygiene principles in different languages, online and in the form of brochures;
- Create incentives for online services and platforms addressing issues relevant for long-term care to provide content in different languages;
- Provide online courses in the Spanish language, targeted at migrant care assistants. This would enable them to train their language competences in situations relevant for their daily lives.

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■ Annex I: Glossary

Carer	A "carer" or "family carer" is a relative (i.e. parent, spouse, partner, daughter, son, grandchild etc.) or acquaintance (friend, neighbour, volunteer) who provides regular and substantial unpaid care to someone.
Care assistant	A person contracted and paid by the care recipients or their family to provide care on a daily basis or for some hours every week. The care assistant may or may not live in the same household; s/he might be legally or illegally employed; might be eligible to social security benefits or not.
Care worker	A professional employed person who is contracted from outside of the family in order to administer basic care to a family member and who receives payment for their services. This person could be an IEM or native and could be a skilled and qualified worker.
Dependant	A person who relies on another person for help and support. The person's quality of life is contingent on the person caring for them.
Deficiency	The problems in the corporal functions or the structures of the body. There are 35 types of deficiencies that have been classified in 8 groups: mental, visual, auditory, language, speaking and voice, osteoarticulation, nervous system, visceral and other deficiencies.
Disability	Any type of limitation that prevents realization of the activities of daily life that has lasted or is anticipated to last more than a year and has its origin in a deficiency. There are 44 types of disabilities classified in 8 groups: Vision, Hearing, Communication, Learning and application of knowledge and development of tasks, Mobility, Self medication, domestic Life and personal Interactions and Relations.
E-Inclusion	Activities related to the achievement of an inclusive information society.
E-Equality	Activities related to the achievement of a greater access for the population to the information society
Formal care	Is defined as professional or free of charge attention provided by public or private institutions and non profit-making organizations.
ICT	Information and Communication Technology
Institute for the elderly and Social Services (IMSERSO)	Is the branch of the social security whose role is to assess the need of families who look after dependants. It uses the criteria defined in the law to contribute to the pensions or allowances of the dependant. This confers more responsibility to the family to seek some form of private domiciliary care as opposed to rely on the socio-sanitary service (Social Security Website, 2009).
Instrumental Activities of Daily Living Scale (IADL)	The activities often performed by a person who is living independently in a community setting during the course of a normal day, such as managing money, shopping, telephone use, travel in community, housekeeping, preparing meals, and taking medications correctly. (Farflex Medical Dictionary, 2009, Website).
Job Mobility	The ability or willingness of workers to move to different geographic locations in order to work.
System for the Autonomy and Attention to Dependents (SAAD)	Is a constitutionally created organization that tries to guarantee the equality of treatment of the services; to make sure that the dependence law is being fairly administered. This requires a communication between the public administrations and the autonomous regions (SAAD Website, 2009).
Telecare (Teleassistance)	A combination of equipment, monitoring and response that can help individuals to remain independent at home.

■ Annex II: Activities of Daily Living: Definitions

KATZ BASIC ACTIVITIES OF DAILY LIVING (ADL) SCALE		
	Independent	
	YES	NO
1. Bathing (sponge bath, tub bath, or shower) - Receives either no assistance or assistance in bathing only one part of body.		
2. Dressing and undressing – Puts on and off clothes without any assistance except for tying shoes.		
3. Personal Hygiene – Goes to toilet room, uses toilet, arranges clothes, and returns without any assistance (may use cane or walker for support and may use bedpan/urinal at night).		
4. Transferring – Moves in and out bed or chair and from bed to chair without assistance (may use walker or other mechanical aids).		
5. Continence – Exercises complete self control over urination and defecation (without occasional “accidents”).		
6. Eating – feeds him/herself without assistance (except for help with cutting meat or buttering bread); food preparation might be done by another person		
7. Moving around (as opposed to being bedridden)		

LAWTON - BRODY INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)			
A. Ability to Use Telephone		E. Laundry	
1. Operates telephone on own initiative-looks up and dials numbers, etc.	1	1. Does personal laundry completely	1
2. Dials a few well-known numbers	1	2. Launders small items-rinses stockings, etc.	1
3. Answers telephone but does not dial	1	3. All laundry must be done by others	0
4. Does not use telephone at all	0		
B. Shopping		F. Mode of Transportation	
1. Takes care of all shopping needs independently	1	1. Travels independently on public transportation or drives own car	1
2. Shops independently for small purchases	0	2. Arranges own travel via taxi, but does not otherwise use public	1
3. Needs to be accompanied on any shopping	0	transportation	1
4. Completely unable to shop	0	3. Travels on public transportation when accompanied by another	0
		4. Travel limited to taxi or automobile with assistance of another	0
		5. Does not travel at all	

LAWTON - BRODY**INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)****C. Food Preparation**

1. Plans, prepares and serves adequate meals independently	1
2. Prepares adequate meals if supplied with ingredients	0
3. Heats, serves and prepares meals, or prepares meals but does not maintain adequate diet.	0
4. Needs to have meals prepared and served	0

G. Responsibility for Own Medications

1. Is responsible for taking medication in correct dosages at correct time	1
2. Takes responsibility if medication is prepared in advance in separate dosage	0
3. Is not capable of dispensing own medication	0

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")	1
2. Performs light daily tasks such as dish washing, bed making	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness	1
4. Needs help with all home maintenance tasks	1
5. Does not participate in any housekeeping tasks	0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income	1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	0
3. Incapable of handling money	0

Sources: 2009, Katz *Basic Activities of Daily living (adl) Scale* & the Lawton – Brody *Instrumental Activities of Daily Living Scale (I.A.D.L.)*, [online] The Center on Aging, The University of Texas School of Nursing at Houston pp. 1-2; http://son.uth.tmc.edu/coa/FDGN_1/RESOURCES/ADLandIADL.pdf; http://en.wikipedia.org/wiki/Activities_of_daily_living; <http://www.annalsoflongtermcare.com/article/6412>.

■ Annex III: Interview Methodology

Each method of data collection has advantages and disadvantages and therefore is more or less appropriate depending on the information to be obtained. Hence the need for an appropriate combination of them, so that there is complementarity.

As a preliminary step, a two level of analysis was employed, focusing on:

- The identification of initiatives and the deepness of them.
- It will enable us to qualify the results obtained in the first level and provide information that may be useful in making decisions.

Thus, once located, and after making contacts with the various initiatives, will be undertake a series of interviews, surveys and focus group described below.

Methods of collection information which we used:

- *Survey*: surveys that we use in the study are a closed type, where responses are limited to some specific values of the type either divided or multiple-choice type.
- *The Interview*: The semi-structured interviews are using standard questions in which the respondent seeks to express freely his opinions, attitudes, interests or preferences on the subject of study, trying not to lose the object of study. Therefore, it is necessary to create a favourable climate in which the respondents can express what they really feel about the subject for which are consulted (to be held for the IEM care workers and professionals).

The first thing to do is to design different types of surveys, interview scripts and the Focus Groups, which are needed to cover in depth and in the most efficient way possible.

All the techniques or combinations of techniques mentioned above are used to gather information from key informants among which are:

- Responsible for various initiatives
- IEM care workers participating in the initiatives: We will attempt to contact care workers, either directly or through the initiatives, to conduct in-depth about their perceptions of the use of ICTs for their work in caring for themselves.
- Responsible for business and third sector organizations: It is important to take them as key informants because they are service providers in the area of care workers: as far as possible in the case of IEM care workers because they are core stakeholders related to the subject, as many care workers are working under this type of business, so these can provide very important information.

Interview with immigrant informal care assistants: Survey Template

1. - Personal data:

- 1.1. Age:
- 1.2. Sex: Woman ☐ Man ☐
- 1.3. Country of origin:
- 1.4. Marital status: Single ☐ Married ☐ Separate/Divorced ☐ Other:
- 1.5. Number of children:
- 1.6. Level of studies:
- 1.7. Residence: Without papers ☐ Process: ☐ Residence permit ☐ Other:
- 1.8. Do you belong to any association or church? No ☐ Yes ☐ Name:
- 1.9. Usual occupation:
- 1.10. Languages spoken:
- 1.11. Hobbies:

2. - Living in Spain:

- 2.1. What is the main reason for you stay in Spain?
- 2.2. When did you leave your country of origin?
- 2.3. When did you arrive in Spain?
- 2.4. What is your current family situation?
- 2.5. What work has been done?

3. - Caring labour:

If you've ever worked as a caregiver for the elderly and/or dependants, please tell us:

- 3.1. When did you start?
- 3.2. Has worked in No ☐ Yes ☐ Name:
- 3.3. Has worked in private homes? No ☐ Yes ☐ Numbers:
- 3.4. How long have you stayed in each one?
- 3.5. Work regime: External ☐ Internal ☐
- 3.6. What's the average salary you have received?
- 3.7. Do you have training in caring for the elderly and / or dependants?
- 3.8. What training would you like?

4. - Use of ICT:

- 4.1. Do you use a mobile phone? Yes ☐ No ☐
 - 4.2. Using their mobile phones for work? Yes ☐ No ☐
 - 4.3. Do you have a computer at home? Yes ☐ No ☐
 - 4.4. Do you know how to use the computer? Yes ☐ No ☐
 - 4.5. Do you have internet at home? Yes ☐ No ☐
 - 4.6. Do you know how to use internet? Yes ☐ No ☐
 - 4.7. Do you access the Internet in public (Guadalinfo, internet cafes...)? Yes ☐ No ☐
 - 4.8. Have you done any computer courses? Yes ☐ No ☐
 - 4.9. What are the main problems when using ICT?
 - 4.1. Why use the Internet mainly?
 - 4.11. Have you ever visited websites with health information? Yes ☐ No ☐
 - 4.12. Have you ever visited websites for caregivers? Yes ☐ No ☐
 - 4.13. Belongs to a virtual social network? Yes ☐ No ☐
 - 4.14. Do you think the use of ICT will facilitate the work? Yes ☐ No ☐
- If you have worked for family caregivers in private homes:
- 4.15. Does the family have the Internet? Yes ☐ No ☐
 - 4.16. Could you have internet access at your work place? Yes ☐ No ☐

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Abstract

This report documents the findings of the study on the potential of ICT in supporting the provision of domiciliary care in Spain, with particular attention to the case of immigrant care workers and informal caregivers. This country study was launched by JRC-IPTS in 2008 in parallel with two complementary country studies, assessing the situation in Germany and the UK, with the same focus and objectives. All three studies were prompted by the findings of a previous exploratory study on the use of ICT by immigrant care workers in Italy.

In Spain, the use of Information Communication Technologies (ICT) for health and social care is playing an increasingly important role in the context of the demographic changes. As, on the one hand, people are getting older and the need for care is increasing, and, on the other hand, the number of formal and informal caregivers is decreasing, technical devices are seen as a possible solution to this dilemma. At the same time, people in need of care and their relatives have a tendency to informally employ private care assistants, often from migrant backgrounds, to assist those in need of care in their homes with daily tasks, in order to avoid and postpone their transferral into institutional care.

This report gives an overview on the situation of domiciliary care in Spain, outlining the current use of ICT in home care and gathering evidence on ICT initiatives for domiciliary caregivers. It investigates the opportunities for ICT in home care and identifies drivers and barriers for the deployment of ICT by caregivers with a particular focus on migrant care assistants. The research undertaken in this and the other national reports is exploratory in nature. The study employs a triangulation of methods, comprising desk-based analysis of existing data and scientific publications; analysis of information and service web sites; and fieldwork involving direct questioning of experts, service providers, and a sample of carers and care assistants, including immigrants.

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