

# JRC Scientific and Technical Reports

## The Potential of ICT in supporting Domiciliary Care in Germany

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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 eInclusion<sup>1</sup> 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 (IPTS)<sup>2</sup> 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 Germany. 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>.

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<sup>1</sup> Available at [http://ec.europa.eu/information\\_society/events/ict\\_riga\\_2006/doc/declaration\\_riga.pdf](http://ec.europa.eu/information_society/events/ict_riga_2006/doc/declaration_riga.pdf)

<sup>2</sup> IPTS is one of the seven research institutes of the European Commission’s Joint Research Centre



## EXECUTIVE SUMMARY

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 in Germany. 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. ICT can help older people to stay safely in their own homes for longer, allowing them to live an independent life for as long as possible. Given current demographic developments, the use of ICT in home care is both a social necessity and an economic opportunity. This report highlights the opportunities and challenges for using ICT to assist formal and informal caregivers in domiciliary care settings, paying particular attention to the role of informal care workers.

**Opportunities for ICT in home care.** ICT not only contribute to improving the safety and well-being of people in home care, but also support formal care workers and informal carers, i.e. family members, neighbours or friends, in their tasks. Recently, a third group of caregivers has emerged, care and/or ‘household assistants’, i.e. people – often from migrant backgrounds – recruited as informal, but paid, personal care workers. Given current demographic trends in Europe, a large and possibly even growing number of immigrants and ethnic minorities (IEM), is likely to fill unmet job opportunities in home care. Since these people are often working semi-illegally, there is little evidence on the extent of the phenomenon. This new category of care workers underlines the complexity of the care situation and draws attention to the valuable contribution of informal caregivers – whether paid or unpaid – and to their particular interests and needs as untrained care personnel.

**Opportunities of ICT for caregivers.** Different ICT services and devices can assist domiciliary caregivers in a variety of ways: telecare and tele-monitoring devices and services support carers in reacting appropriately to changing health conditions and thus improve the quality of care. Assistive technologies (AT), like social alarm systems, video-monitoring, and electronic sensors of different kinds, reduce health and safety risks and help carers to react rapidly and adequately in critical situations. Furthermore, ICT offer the possibility to collect and share important information on people in need of care, facilitating interaction and knowledge exchange between the different people and institutions involved in domiciliary care. Finally, ICT can supply caregivers with valuable resources for finding and exchanging information on all aspects of home care, ranging from legal and administrative procedures, medical aspects and measures for rehabilitation, to training on the job and networks for knowledge exchange and stress relief.

**The current situation in Germany.** The importance of ICT in care – in both institutional care and home care – is growing steadily in Germany. Conventional technical devices like telephones, mobiles and computers are used by official care providers to organise and handle every day care-related tasks for professional care workers. Informal caregivers and people in need of care use phones and mobiles as well and they are also gradually beginning to use PCs to exchange information with the people in need of care, their relatives, family carers, and other people involved. Nonetheless, and despite various national, regional and local initiatives promoting or investigating different technological solutions, the deployment of ICT in the healthcare context is not very advanced in Germany. Particularly in home care, the diffusion of assistive technologies has been relatively limited so far. The same holds for ICT-based information systems suited to empowering and supporting informal caregivers.

**Barriers.** The main structural barriers for broader dissemination of ICT in home care in Germany are the segregation of competences, the differentiation between the health and care sectors, the diversity of authorities in charge of care, the reimbursement conditions, the lack

of centralised and systematic information and barriers arising from housing and technology design. Barriers related to care recipients mainly originate in older people's lack of acquaintance with ICT, which often goes hand in hand with a lack of ICT skills, financial resources and/or opportunities to purchase, learn to handle and use innovative ICT. Additionally, diffuse fears and scepticism against technology prevail. The general discussion on surveillance and intrusion, loss of control, data protection and privacy concerns has an adverse effect on the assessment of ICT in care by care recipients, their families and also professional care providers. As regards outpatient care providers and their professional care personnel, traditional structures associated with fragmented competences and responsibilities inhibit the deployment of ICT. Permanent lack of time and tight budgets further hamper the introduction of ICT, which initially incurs extra costs, including those for training. As regards informal caregivers, a lack of awareness of suitable ICT solutions together with the lack of adequate support mechanisms and systematic, centralised information constitute the main barriers to deployment. The main barriers for migrant care workers employed as household assistants consist of the uncertain legal situation regarding their living and working conditions in Germany. Their situation is further aggravated by irregular working hours, manifold tasks, limited free time and the risk of isolation. A lack of experience with innovative ICT, language problems, and short-term work contracts can further hinder their interest in using ICT.

**Drivers.** An important structural driver for mainstreaming ICT deployment in home care is the recently increased policy support, initiated with the Long-term Care Further Development Act in 2008, which promotes independent living in new forms of housing and pooling of funds. Furthermore, industry and service providers are getting more interested in the growing 'silver market'. Similarly, some housing organisations are also interested in older people and are providing technical equipment and services for their older tenants. For family carers, ICT deployment is facilitated by the necessity to stay in touch with all actors involved in the care context and organise different care tasks, along with their own private and professional lives. Family carers' concern about safety, security and efficient supervision and monitoring is a further important incentive for ICT deployment. In the near future, there will be an increasing number of older people and single households, less care personnel available and a lack of family members able and willing to perform care tasks. These demographic developments will advance the deployment of ICT as an affordable option for extending people's independent lives in their own environments. Another demographic driver is the fact that more older people will be experienced with, and open minded towards, ICT. However, the danger of a digital divide will remain as long as there are different levels of education, income and opportunities.

**Policy recommendations.** To make home care sustainable in the future, the fragmentation of responsibilities has to be overcome, synergies have to be better exploited and constructive and transparent collaboration between all actors involved in domiciliary care needs to be established. The mechanisms of healthcare insurance and long-term care insurance, the related legal regulations, the available options for support and the reimbursement possibilities and conditions should be simplified and systematised. As a first step, transparency could be significantly improved by making the information on home care, including the opportunities offered by ICT, available in an easily readable and accessible format, translated into the languages of major population groups from migrant backgrounds; disseminated via various media; and represented systematically on one official, centralised and systematic multilingual online platform. Policy action is needed to raise public awareness of old age issues, care, illness and dementia, and to reduce the reservations and information deficits related to these topics. The rights and interests of informal caregivers and migrant care assistants should be strengthened. Initiatives like the national association 'Wir pflegen' should be encouraged and empowered.



Mainstreaming ICT solutions requires that the industry increase the usability and suitability of its products, addressing particular care situations more appropriately, including possible digital and language barriers. The development of norms and standards to ease interoperability in domiciliary care is an urgent need. Justified concerns about ethical aspects, the loss of privacy, the replacement of personal care by technology and the possibility of data misuse must be taken seriously. Appropriate measures must be put in place to avoid any misuse. Education and vocational training for professional caregivers should include, from the very beginning, the use of innovative ICT to make these technologies natural tools for them, thus facilitating ICT deployment. For this purpose, adequate training material and accompanying e-learning concepts should be developed.

For professional and informal caregivers from migrant backgrounds, training and information must be made available in their mother tongues. Most importantly, the work of migrant care workers must be legalised, acknowledging their crucial role in making home care a feasible and sustainable option.



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## OVERVIEW OF THE CHARACTERISTICS OF CARE IN GERMANY AND EXEMPLARY SERVICE PROVIDERS

For readers who are not familiar with the context of social healthcare in Germany, the situation seems to be quite complicated. The following table should therefore be kind of a ‘reading aid’ to enable the reader to have uncomplicated access to the important aspects of care in Germany and/or to find specific topics and examples easily.

Specific aspects in Germany	Brief description	section / page
The German Social Care System	Based on old-age pension insurance, unemployment insurance, healthcare insurance, accident insurance, long-term care insurance and social assistance (taxes).	Section 2.2, page 12
German Social Long-term Care Insurance	Enacted in 1995 – with several modifications and additions over the years	Section 2.1.3, Box 1, page 14
Care Levels	Grade I, II or III according to the amount of time a person needs to be cared for. The minimum is 90 minutes per day.	Section 2.1.3, Box 1, page 14
Policy development	Law on structures for the support of older people, 2002 – 2008/ 2009	Section 2.1.3, Box 1, page 14
Immigrants / People from migrant backgrounds	Definition according to the Mikrozensus 2006	Section 2.1.3.2, Box 2, page 11
Caregivers in Germany	Definitions: carers (informal caregivers), care workers (formal caregivers), basic / medical nursing, household assistance	Section 2.2.3, Box 3, page 15
Non-statutory Welfare	The main actors. Characteristics, number of staff members, importance.	Section 2.2.1, page 13
Migrant care workers and carers (care and/or household assistants)	Definition, characteristics of work, legal framework	Chapter 3, page 21
Box 4: Recruitment of household assistants through ZAV (Central Placement Office)	Procedure, legal framework, working conditions	Section 3.2.2, Box 4, page 23
<b>Examples of projects and service providers</b>		
The telecare supplier Vitaphone	Description of company, services and costs	Box 5, page 32
The SOPHIA telecare service	Description of company, services and costs	Box 6, page 40
Senior Centre ‘Viertes Viertel’ (Güstrow)	Description of the institution and its specifics concerning ICT	Box 7, page 42
General recommendations for policy actions and support	Synergies, transparency, products, business models, norms and standards, ethical aspects	Box 8, page 67
Recommendations with respect to older people in need of care	Awareness, information, products, business models, ethical aspects	Box 9, page 69
Recommendations with respect to professional caregivers	Fragmentation, products, training, ethical aspects	Box 10, page 71
Recommendations with respect to family caregivers	Fragmentation, advice, awareness, products, business models, training, ethical aspects	Box 11, page 72
Recommendations with respect to migrant caregivers	Protection, transparency, information, products, training, ethical aspects	Box 12, page 73



# 1 INTRODUCTION

The use of ICT for health and social care plays an increasingly important role in the context of the demographic changes in Germany. As, on the one hand, people are getting older and the need of care is increasing, and, on the other hand, the number of informal caregivers and (young) care workers is decreasing, technical devices are seen as a possible solution of this dilemma. In the future, the use of ICT is both a social necessity and an economic opportunity. ICT can support older people so that they can stay in their own homes for longer, allowing them to live independent lives as long as possible.

The diffusion and diversification of information and communication technologies (ICT) has reached a stage where it becomes apparent that they display a huge potential for supporting caregivers and care-recipients in a number of different ways. For example, they serve as medical aids (i.e. they facilitate tele-care and tele-monitoring); as technological solutions supporting independent living; as social tools, facilitating the communication of all actors involved in the care situation; and as information resources, making relevant information, and training opportunities readily available to caregivers (and care-recipients).

Thus, ICT can support those who supervise and care for older people, whether as professionals or informal caregivers, in their tasks and contribute to improving the safety and well-being of people in home care. Furthermore, ICT offer the possibility to collect and share important information on people in need of care, facilitating the interaction and knowledge exchange of the different people and institutions involved in outpatient care. Finally, ICT can supply caregivers with valuable resources for finding and exchanging information on all aspects related to home care, ranging from legal and administrative procedures, medical aspects and measures for rehabilitation, to training on the job and networks for knowledge exchange and stress relief.

However, currently, take up of ICT in care contexts is still lagging behind. Few assistive technological solutions are implemented on a large scale and often actors are not aware of existing products and services. Questions arise concerning the actual and potential contribution of ICT to supporting domiciliary caregivers and to the role that care workers might play in enabling and mediating the use of ICT at home by elderly or disabled people.

Furthermore, in Germany as in many other European countries, the care and assistance of children, the elderly, disabled or chronically ill people in domiciliary settings, is increasingly handed over to immigrant ‘household assistants’. Given current demographic trends in Europe, a large and possibly even growing number of immigrants and ethnic minorities (IEM), is likely to be driven into home care by unmet job opportunities in this area. Since these people are often working semi-illegally, on informal contracts, there is only scarce evidence of the extent of the phenomenon, the working conditions of the immigrant care workers involved and their needs and interests. In particular, nothing is known about the extent to which immigrant caregivers use, or could benefit from using, ICT to facilitate their daily tasks and improve their personal living and working conditions.

Consequently, IPTS<sup>3</sup> decided to launch a series of country studies to approach this knowledge gap. Italy was selected in 2007 for a first exploratory study on this topic, given the very large presence and relevant role played by immigrants in domiciliary care provision in Italy. However, very little evidence on the use of ICT by caregivers emerged from this study, which

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<sup>3</sup> IPTS (Institute for Prospective Technological Studies) is one of the 7 research institutes of the European Commission’s Joint Research Centre.

is at least partly due to the low level of ICT deployment in the domiciliary care sector and the low use of ICT by older and IEM populations in Italy.

In the light of these results, three new country studies – covering Germany, Spain and the UK – were launched in 2008 on the potential of ICT in supporting domiciliary caregivers, paying particular attention to the case of immigrant care workers and informal caregivers. In these studies, emphasis was placed on the use of ICT in domiciliary care settings and by domiciliary caregivers, whether they were of migrant origin or not. The working hypothesis underlying this approach is that all findings on the potential of ICT for supporting caregivers in general will also apply to the case of migrant caregivers. Additional opportunities, challenges and barriers could then be derived by considering the particular situation and background of migrant caregivers and validating findings with the direct evidence available, e.g. by conducting key informant interviews, consulting different stakeholders and evaluating recent publications and research literature

This study assesses the situation in Germany. The content of the Report is organised in the following way: the first section of Chapter 2 contains background information and statistics about the ageing population and especially about the older people in need of care. In the second section, comprehensive information on the German healthcare system in general and on the outpatient care sector in particular, is provided. Similarly, recent statistics about the personnel in outpatient care services are supplied. Chapter 3 then outlines the situation of formal care workers from migrant backgrounds and migrant care assistants in Germany. These two chapters set the stage for an assessment of the potential of ICT to support home carers and domiciliary care workers in Chapters 4 and 5.

Chapter 4 presents some ICT initiatives to support home care. It provides an overview of the of ICT applications currently used in the homes of older people. It describes the barriers to the deployment of assistive technology and ICT and shows recent initiatives supported by the German government, including examples that are promising with respect to the potential of ICT in supporting caregivers in domiciliary settings.

Both Chapter 4 and Chapter 5 (on ICT use in home care) were completed with meaningful information received from questionnaires and in-depth telephone interviews with experts in the outpatient care field and from personal in-depth interviews with informal caregivers of German origin and those from migrant backgrounds. While the structural conditions predominate in Chapter 4, Chapter 5 focuses more on how ICT can improve both the conditions of providing home care and the situation of the caregivers. Hence, the main actors in this field – care workers, family carers and migrant care workers – get a chance to speak in Chapter 5. In addition, this chapter includes a few examples of ICT-based networks and online information portals available for informal caregivers.

We conclude with some recommendations for technological and structural improvements and policy action in Chapter 6. Migrant caregivers' needs are given special attention.



## 2 THE CONTEXT OF AGEING AND CARE IN GERMANY

### 2.1 The Ageing Population

#### 2.1.1 Overview on demographic development and the needs for care in Germany

In the coming decades, Germany will face a strong increase in the number of people aged 60 and older. In 2005, 20.5 million people aged 60 and older lived in Germany. In 2030, however, it is predicted by the Federal Statistical Offices (Statistische Ämter des Bundes und der Länder' (StBAL)) that there will be 28.4 million people of this age. This means an increase of 38% or, in other words: more than every third person living in Germany will be 60 years and older in 2030 (StBAL, 2008).

Due to greater prosperity, better nutrition, less physical strain and more progress in medical care, people live longer than ever before. Nevertheless, we face the fact that the probability of needing (health) care increases in the older age groups. In 2005, one-third (31%) of all people aged 80 and older needed care. And although people in most industrialised countries can expect to live long and mostly healthy lives (Manton, Corder & Stallard, 1993), diseases like cancer, diabetes, osteoporosis, strokes and dementia increase with advancing age (Helmchen, Baltes, Geiselmann et al., 1996; OECD, 1999; Robert Koch Institute & Federal Statistical Office, 2006), requiring treatment and care for a growing share of the population.

**Table 1. Population in Germany.**

**Age groups with higher risk of illness and need of care from 2005 to 2030 (numbers in 1,000)**

Population from ... to under ... years of age	2005	2010	2020	2030
Total population	82,391	81,887	80,057	77,203
Among them:				
60 – 70	10,044	9,083	10,957	12,618
70 – 80	6,815	8,131	7,601	9,446
80 – 90	3,076	3,724	5,014	4,854
90 and older	557	563	910	1,432
Changes in % in comparison to 2005				
Total population	-	- 0.6	- 2.8	- 6.3
Among them:				
60 – 70	-	- 9.6	9.1	25.6
70 – 80	-	19.3	11.5	38.6
80 – 90	-	21.1	63.0	57.8
90 and older	-	1.1	63.4	157.1

Source: Statistische Ämter des Bundes und der Länder (2008). *Demografischer Wandel in Deutschland, Heft 2.*

Table 1 provides an overview of how the age structure will develop in Germany within the next decades. What we can see is a strong increase in the older age groups. Based on what we know about the health of old and very old people, we can deduce a higher need for healthcare and support in the coming decades.

Based on the number of people in need of care today on the one hand, and on the development of the population in the next decades on the other, the StBAL (2008) predict a strong increase of people in need of care:

In 2005, Germany had to deal with 2.13 million people in need of care. In 2010, we will face 2.40 million people requiring care. Ten years later, in 2020, 2.91 million people and in 2030, 3.36 million people will be in need of care. In other words, Germany will face a 37% increase in the number of people in need of care between 2005 and 2020. Compared to 2005, the increase will be 58% by 2030.

This means that the percentage of people in need of care in relation to the total number of people living in Germany will increase from 2.6% in 2005 to 3.6% in 2020, and again to as much as 4.4% in 2030.

Beside the total increase, we must keep in mind that, at the same time, we face a dramatic change in the age structure. In 2005, 33% of the people in need of care were aged 85 and older. In 2020, however, it is estimated that 41% of people in need of care will be in this age group and in 2030, the share could be as high as 48%. The share of those aged 60 and younger who are in need of care will decrease from 14% in 2005 to 10% in 2020, and to approximately 7% in 2030.

Another scenario is based on the assumption that medical and technical progress will lead to longer lives and to a lower risk of needing care. In this scenario, the percentage of people in need of care in 2020 and 2030 will be 3.4% and 3.8% - slightly lower than if the number developed continuously from the baseline scenario. However, the percentage of people aged 85 and older will be even higher (2020: 42%; 2030: 51%).

### **2.1.2 The living situation of older people**

The growing proportion of older individuals in the population, accompanied by a reduction in the numbers of children and adolescents, marks a shift in today's social structure. The continual shrinking of the family network in particular, as well as the trend towards living alone, diminish the family's potential to care for or otherwise support the elderly individual. Furthermore, trends toward centralisation and globalisation in businesses today create a pattern of regional mobility. Consequently, parents and their adult children live further apart.

These developments are leading to the need for expanded care and support services for the vulnerable elderly. Data from the SHARE project<sup>4</sup> (based on a survey conducted among people aged 50 and older in several European countries) show that in 2004, 64.9% of people aged 80 and older in Germany who were not living in an institution were living alone. 26.7% of this age group were still living as couple and just 8.4% were living with their families (Commission of the European Communities, 2007: 69).

Whether older people live alone, with a spouse, or within an extended social network clearly affects their living situation and the social preconditions, should they need care. When domiciliary care is the preferred choice and when modern assistive technologies are to be implemented, housing conditions are of great importance as well.

Housing conditions have improved significantly in Germany since the devastating situation after World War II. At present, only 7% of dwellings are not equipped with an adequate heating system or sanitary facilities (EU-SILC, 2006; quoted from Noll & Weick, 2009).

Regarding home ownership, figures are rather low compared to other European countries, although a house or a flat of one's own is considered worth striving for in Germany as well. In 2006, 40.6% of all households owned the house or flat they were living in. 57.4% of all households in Germany were living in a rented house or flat. If we take a closer look at

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<sup>4</sup> Börsch-Supan et al., 2005; <http://www.share-project.org/>; quoted from Empirica & WRC, 2008; [www.ict-ageing.eu](http://www.ict-ageing.eu).

households in which the head of the household is older than 65, we see 47.9% owners and 51.5% tenants (StBA, 2008a: 120). Differentiated by region, the latter figures are 32.4% for East Germany and 55.7% for West Germany (Datenreport, 2008: 227)

There are, however, big differences between both living situations and regions. The probability of owning one's house or apartment increases with increasing income and with household size. Moreover, house ownership is more widespread in rural areas than in urban areas (EU-SILC, 2006; quoted from Noll & Weick, 2009; see also Mollenkopf, Kaspar, Marcellini et al., 2004).

It is common sense that older people want to stay in their houses or flats as long as possible. This wish is even stronger among house or flat owners, though tenants do not want to give up their well-known surroundings and environments with all the associated memories either. The advantages of knowing how to organise everyday life, as well as the emotional bonds, convey certainty and a feeling of safety. This leads – in combination with the changes in population structure and the demands of the labour market concerning mobility and flexibility – to care and support services having to take on what families and relatives accomplished in the past.

### 2.1.3 People in need of care

The process of ageing is associated with increasing probabilities of physical, sensory and cognitive restrictions and possibly the need for care. Findings from the German Ageing Survey (Tesch-Römer, Engstler & Wurm, 2006) show that the share of people who stated they had five or more simultaneous illnesses triples from 4% in the 40 - 54 age group to 12% in the 55 - 69 age group. Among those aged 70 to 85, about 25% stated they had five or more illnesses. The probability of suffering from a severe illness or accident increases as well. This share almost doubles from the youngest to the oldest age group (from 18% to 34%). And last but not least, the risk of dementia grows with advancing age (Gesundheitsberichterstattung des Bundes (2009), Themenheft 28).

#### 2.1.3.1 Statistics on people in need of care

Unfortunately, official statistics represent only recipients of benefits from the Social Long-term Care Insurance, that is people needing care according to care levels I, II or III. People in need of care or support of less than 90 minutes per day are not included. In terms of the Nursing Care Statistics of the Federal Statistical Office, the general qualification for registration as a *person in need of care* is the acknowledgement of the medical review board of the health insurance funds (Medizinischer Dienst der Krankenkassen – MDK) respectively of the private insurance companies about the need for care and the assignment of people in need of care to nursing care levels I to III (including cases of hardship). (For details, see Box 1: 'The German Social Long-term Care Insurance', p. 14).

**Table 2. People in need of care in Germany 2005 (number and rate)**

Age	People in need of care		
	Number of people in need of care	Quota of care	Percentage of age-groups
☞ All age-groups	2,128,550	2.6	100.0
under 75 years	700,079	0.9	32.9
75 to under 85 years	730,667	14.0	34.3
85 to under 90 years	333,741	36.3	15.7
90 years and older	364,063	60.2	17.1

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

The quota of care rises with advancing age. Up to 75, the share of people in need of care among the German population amounts to less than 1%, while in the 75 - 85 age group it is 14% and among those aged 90 and older it amounts to 60% (Table 2). The share of women amounts to 64% among people receiving outpatient care and 75% in the inpatient sector.

### **Box 1: The German Social Long-term Care Insurance**

The main purpose of the Social Long-term Care Insurance is to cover the risks associated with the need for care. The insurance emphasises the *“legal separation of medical treatment and illness, nursing and rehabilitative care, informal and formal care-giving and prevention, rehabilitation and medical care and (...) the separation of the in-patient and out-patient sectors which now belong to different areas of social security benefit.”* (Rothgang, 1997, quoted from Meyer, 2006: 21).

The guiding principles of the German Social Long-term Care Insurance are (a) a partial coverage insurance system with limited benefits and (b) benefits depending on the health status of the recipient. The level of dependency is assessed by a special institution called Medical Service of the Health Care Insurances (Medizinischer Dienst der Krankenkassen – MDK). There are three levels or grades of dependency defined (in terms of the Nursing Care Statistics of the Federal Statistical Office):

*Grade I:* People who need help at least once a day with body care, food or mobility for at least two performances in one or more fields and in addition several times per week in the household. On average this must take at least 90 minutes per day; of this, more than 45 minutes must be dedicated to basic care.

*Grade II:* People who need help at least three times per day at different times of day with body care, food or mobility and in addition help in the household several times per week. On average this must take at least three hours per day; of this, at least two hours must be dedicated to basic care.

*Grade III:* People who need help daily round the clock, also at night, on body care, food or mobility and in addition several times per week help in the household. On average this must take at least five hours per day; of this, at least four hours must be dedicated to basic care.

As home care is preferred to institutional care, the benefits are for the cared-for themselves. The Long-term Care Insurance pays – depending on the grade of the person in need of care – a monthly amount. People at Care Level 1 receive the lowest available amount, and people at Care Level 3 the highest. The amount also depends on whether it is care at home by family members, care at home by professional care services or stationary care. For example, care at home by family members is supported with 205 € per month for Care Level 1, whereas 1,688 € are paid per month for people who receive stationary care at Care Level 3 in a nursing home.

*“The benefits cover the following areas: home care / stand-in care / part-time care / short-term care / technical aids / nursing care courses for relatives and volunteer carers / social security insurance for informal care and permanent institutional care. Benefits may be paid in kind, in cash or in combination of both.”* (Seidl & Döhner, 2007: 138).

The Long-term Care Insurance also covers necessary changes in the house or flat (up to 2,557 € per measure) and auxiliary devices or assistive technologies (up to 90% per device) if they are listed in a special catalogue (Hilfsmittelverzeichnis der gesetzlichen Krankenversicherung). At the same time, there are some special measures to support the families in their caring role such as the instruction of voluntary caregivers and improved counselling (Bundesministerium für Gesundheit [BMG], 2008: for details concerning the conditions of payment and the range of benefits, see [www.bmg.bund.de](http://www.bmg.bund.de)).

## **Policy development**

### 2002 *Altenhilfestrukturgesetz (Law on structures for the support of older people)*

“Based on the world action plan for ageing, which was passed in Madrid in 2002 and as a part of the Federal government coalition agreement, a new law on structures for the support of the elderly (Altenhilfestrukturgesetz, 2002) has been under construction. One section deals with the subject of participation of the elderly and one section with support for the elderly. The second section aims to improve the quality of counselling and care. It sets out to do away with structural deficits caused by a confusing range of different services and service providers who take on various tasks and whose services are often of uncertain quality. It is intended to systematise, coordinate and ensure preventive measures, counseling and other support and care services. In addition, this law tries to target gender-specific differences among family carers in order to improve their situation accordingly. Further discussion about this law has been postponed for political reasons.” (quoted from Meyer 2007, p. 48).

### 2003 *Round Table for Long Term Care*

“Another important initiative to improve the quality of care in the home health and in-patient sectors, called the ‘Round Table on Nursing’ (Runder Tisch Pflege), was set up in August 2003 (until 2005) by the Federal Minister of Family, Senior Citizens, Women and Youth and the Federal Minister of Health. This ‘Round Table’ aims to describe examples of best practice in the in-patient and domestic care sectors as a means of orientation. Examples for possible fields of action are to:

- Improve support and promotion of low-threshold care services to strengthen the position of domestic care;
- Improve support and promotion of new residential forms; and
- Increase integration of volunteers into current service structures.

With regard to family carers, the ‘Round Table’ should answer the question of how the position of people in need of care and their family carers can be improved and it should search for ways of promoting public awareness (DZA, 2003, BMGS, 2004).” (quoted from Meyer 2007, p. 48).

### 2005 *Charter of Rights for People in need of Long-term Care and Assistance*

The Charter of Rights for People in need of Long-term Care and Assistance is a result of the work of the “Round Table for Long Term Care”. The Charter is intended to strengthen the role and the legal position of people in need of care and assistance and their relatives and to provide information and suggestions for those involved in supplying care and assistance. The Charter comprises a detailed catalogue of the basic and indisputable rights of people in need of assistance, support and care. The Charter also formulates quality criteria and objectives which should be the goals of all good long-term care and support. Furthermore, the Charter is designed as a guideline for people and institutions that have responsibility for long-term care, support and treatment. It addresses caregivers, physicians and all those who are involved, either professionally or as part of their social involvement in supporting the wellbeing of people in need of long-term care and assistance. This also includes those providing outpatient care, residential and semi-residential care facilities and those responsible in local government, health and long-term care insurance funds, private insurance companies, charitable associations and other organisations in the health and social sector. They should all be guided in their actions by the Charter (an English translation of the Charter is available at <http://www.pflege-charta.de>). A coordinating office has been established at the German Centre of Gerontology (DZA) in Berlin to monitor the implementation process.



### 2007 Office on Long-term Care

“The Co-ordinating Office Long-term Care” (Leitstelle Altenpflege) at the German Centre of Gerontology was established in January 2007 by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth to support further improvements in the quality of long-term care and assistance for the elderly. To this end, the Co-ordinating Office is active in the following areas:

- Publication and implementation of the Charter of Rights for People in need of Long-term Care and Assistance;
- Steering a campaign for long-term care as an occupational field;
- Further development of network structures for long-term care and assistance for the elderly.

The responsibilities of the Co-ordinating Office Long-term Care include targeted public relations, the conceptional preparation of transfer-oriented research and model projects and the preparation of expertise. As part of the implementation programme, the Co-ordinating Office will support several theme-oriented functions addressing the central problems of long-term care and support. Practitioners in the field, interest groups, transfer institutions and representatives of science and research will be given the opportunity to agree on new solutions. The goals of the Co-ordinating Office Long-term Care are to renew the debate on the key perspectives and strategies raised by the Round Table for Long-term Care.” (<http://www.dza.de>)

### 2008 Long-term Care Further Development Act (Pflegeweiterentwicklungsgesetz)

In 2008, the Federal Ministry for Health inaugurated a reform of Long-term Care Insurance in order to improve the situation of older people with specific needs and their families (Art. 2a G v. 15.12.2008 I 2426).<sup>5</sup> The main benefits are:

- Adjustment of the payments every two years (for example: Grade I rate for informal caregivers’ attendance allowance (‘Pflegegeld’) now is € 215 per month; in 2010 it will be € 225 and € 235 in 2012);
- Improvement of consultations by means of long-term care advisers and by setting up regional ‘Long-term Care Support Centres’ (Pflegestützpunkte);
- Improvement of quality assurance measures;
- Better support of both the caretakers and the formal and informal caregivers (for example, family caregivers are entitled to take a break after 6 months of caregiving. For up to 4 weeks per year and the costs for a substitute and the caregiver’s pension scheme are covered up to € 1,470);
- Family caregivers are entitled to a special unpaid leave of up to 10 days to organise and secure the care for a family member in need of care in an acute situation;
- People providing domiciliary care for a family member are entitled to take unpaid care-time or care-leave of up to six months. This entitlement only applies to employees of companies which employ more than 15 people;

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<sup>5</sup> For further details see: Sozialgesetzbuch (SGB), Elftes Buch (XI), Soziale Pflegeversicherung, [http://www.sozialgesetzbuch-bundessozialhilfegesetz.de/\\_buch/sgb\\_xi.htm](http://www.sozialgesetzbuch-bundessozialhilfegesetz.de/_buch/sgb_xi.htm); 2008 Care Development Act (Pflegeweiterentwicklungsgesetz); BMAS, 2008; Bundesministerium für Gesundheit (BMG): Gut zu wissen – das Wichtigste zur Pflegereform 2008

- Support for volunteer work: 30 Million Euro were announced to support volunteer companionship and support services for people in need of care (e.g. for establishing volunteer groups);
- Consideration of new forms of accommodation: ‘Pooling’ of benefits are possible to allow new forms of living for older people in need of care (for example sharing a flat and/or using jointly the support of a caregiver);
- Improvement of discharge management after stays in hospitals;
- Due to their early need for care, albeit small at the beginning, people with dementia and mentally ill people can get benefits even if they do not yet belong to Grade I (they are referred to as ‘Grade 0’), regardless of whether they are cared for in their own homes or in institutions (SGB XI § 45a).

At present, 2.25 million people require care benefits from the long-term insurance in the form of material or monetary support and receive care at home or in institutions (Table 3). Some two thirds have opted for home care. Another 134,000 people received benefits from private care insurances (in 2006; Deutscher Bundestag, 2008: 15). 93,000 of them received care by ambulatory (outpatient) services and 41,000 were cared for in nursing homes. As with the Social Long-term Care Insurance, the proportion of people needing care increases with patients of the private care insurances as well. 53.2% of the people receiving outpatient care were 80 years and older. The share of women in this sector was 54%, the share in nursing homes 71% (Deutscher Bundestag, 2008: 16).

**Table 3. Recipients of Outpatient/Inpatient Care or Care Allowance in Numbers**  
(all age-groups, both sexes)

Recipients of benefits	Year
	2007
<b>Recipients of benefits total</b>	2,246,829
<b>Outpatient care</b>	504,232
<b>Inpatient care</b>	709,311
<b>Care allowance</b>	1,033,286

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

We can assume that the real number of people in need of care or at least needing substantial help in their daily life activities is much higher. For instance, about a quarter of all applications for benefits are rejected (Bundesministerium für Gesundheit [BMG], 2007), while the fact that somebody is applying for benefits can be regarded as a clear indication that they need help. Moreover, many older people abstain from applying in view of the difficulties or because they lack information. This is in line with analyses based on SHARE data showing that 30% of older people who genuinely need care because of moderate or severe disabilities do not receive help - neither formal nor informal. People living alone, women, and those who have severe physical disabilities are particularly at risk (Pommer, Woittiez & Stevens, 2007).

#### Institutional care

In 2007, of the 2.25 million recipients of benefits, 709,311 people were cared for in institutions, i.e. in nursing homes (Table 3). Most of them received permanent in-patient care (671,080). 23,196 came to institutions for day care. 15,002 people were looked after in short-term care (source: [www.gbe-bund.de](http://www.gbe-bund.de), 2008). Table 4 provides relevant information about the current kind and level of care in Germany.

**Table 4. People in need of care 2007 (number, settings and level of care)**

2.25 million people in need of care in 2007					
Care in domiciliary settings: 1.54 million people (68%)			Institutional care:		
exclusively through family members: 1.03 million people		through professional nursing care services: 504,000 people		709,000 people (32%)	
According to Grade of Dependency:					
Grade I:	61.8%	Grade I:	52.5%	Grade I:	35.7%
Grade II:	29.9%	Grade II:	35.4%	Grade II:	42.3%
Grade III:	8.3%	Grade III:	12.1%	Grade III:	20.5%
				without classification	1.5%
Accomplished through					
informal care (family, social network, legal as well as 'grey' market)		11,500 outpatient nursing care services with 236,000 employees		in 11,000 nursing homes with 574,000 employees	

Source: *Pflegestatistik 2007. Pflege im Rahmen der Pflegeversicherung. Deutschlandergebnisse. Statistisches Bundesamt Wiesbaden, 2008.*

#### Domiciliary care

Most of the people in need of care (68%) get care at home. 1.03 million of these people receive care allowances (Pflegegeld), which means that family members and/or informal caregivers provide this care, while 504,232 people are cared for by professional care services (for details about the different care sectors, see Section 2.2).

504,000 people living at home receive care from professional caregivers (Tables 4 and 5). Whereas most informal care is provided in Grade I, professional caregivers are more likely to take care of older people categorised as Grades II and III.

**Table 5. People in need of care in outpatient nursing care (by age, 2007)**

Age	Year
	2007
All age-groups	504,232
65 to under 70 years	27,161
70 to under 75 years	45,585
75 to under 80 years	76,464
80 to under 85 years	115,793
85 to under 90 years	115,387
90 to under 95 years	53,165
95 years and older	22,760

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

#### **2.1.3.2 People in need of care from migrant backgrounds**

Among the people in need of care, the number of people from migrant backgrounds is increasing. According to the German Mikrozensus of 2006 (StBA, 2008c), 19% of the population in Germany is from a migrant background. The exact number of people from migrant backgrounds in need of care and particularly the number of those who receive



outpatient care is unknown. The official care statistics do not distinguish between natives and immigrants, neither for people in need of care nor for caregivers.

### **Box 2: Immigrants / People from migrant backgrounds: Definition**

According to the definition of the Mikrozensus 2006 the “population from a migrant background” comprises:

- (a) All people who immigrated to Germany after 1949;
- (b) People born in Germany with a foreign citizenship;
- (c) People born in Germany with at least one parent who immigrated to Germany or with at least one parent with foreign citizenship (StBA, 2008c).

Different studies point to the fact that compared to the native population, in the population of immigrants the risk of long-term care dependency is significantly higher. Older immigrants seem to be dependent on long-term care at an earlier stage of their lives than native people (Korporal & Dangel, 2006; Özcan & Seifert, 2006; Dietzel-Papakyriakou & Olbermann, 2001). Older people from migrant backgrounds belong to those population groups in Germany with the highest rates of increase (Olbermann, 2007). Therefore, it is foreseeable that the number of people in need of care from migrant backgrounds will significantly increase as well. Home care is of special importance for them. Studies indicate that immigrants in need of care are receiving care more often at home and less often in institutions, i.e. in nursing homes, compared to the native population (Lotze, Mohammadzadeh & Hilbert, 2007).

The findings of a study carried out in Bremen and Bremerhaven (Lotze & Hübner, 2008) show an increasing number of people from migrant backgrounds receiving help from outpatient care services. The number of people from migrant backgrounds cared for by outpatient care services rose by 111% between 2004 and 2008. Most of them (62.2%) were immigrants from the CIS states (i.e. the former Soviet Union), 17.3% are immigrants from Turkey and 10.7% are immigrants from Poland. The distribution by sex shows a proportion of woman of 65.2%.

Overall, little is known about the situation of outpatient care in immigrant families. Studies indicate that – compared to native people – immigrants in need of care receive help more often from informal carers, mainly from female family members. Professional care services and care workers are used less by people from migrant backgrounds. This is due to language barriers and cultural distinctions, information deficits and the lack of culture-sensitive offers. In light of limited professional support, one can assume that home care in immigrant families is loaded with special risks concerning the quality of care and special stresses and strains for both the people in need of care and the carers.

In recent years, long-term care patients from migrant backgrounds have become known as a growing customer group in the field of outpatient care. This awareness has led to an increase in the efforts to develop and implement culture-sensitive offers. There is also a growing number of private nursing care services which specialise in outpatient care for immigrants, in particular for Turkish and Muslim immigrants (an example is given by Stuttgarter Zeitung, 15 April 2009) and for immigrants who came to Germany from the former states of the Soviet Union. However, currently there is no nationwide culture-sensitive care system in Germany (Friebe, 2008; Olbermann, 2008; Zeman, 2005).

#### **2.1.3.3 Characteristics of people cared for in domiciliary settings**

As for the characteristics of people cared for in domiciliary settings, we can fall back upon the *Eurofamcare* project (‘Services for Supporting Family Carers of Elderly People in Europe’;

[www.uke.uni-hamburg.de/extern/eurofamcare/](http://www.uke.uni-hamburg.de/extern/eurofamcare/)). The main purpose of this project was to “evaluate the situation of family carers of older people in Europe in relation to the existence, familiarity, availability, use and acceptability of supporting services.” (Döhner, Kofahl, Lamura & Triantafillou, 2006: 10; for more details concerning the background of the study see also Döhner, Kofahl, Lamura, & Triantafillou, 2007: 11ff).

*Eurofamcare* has “provided the basis for an in-depth analysis of the factors involved in the interdependency between the family carers’ needs and the needs of the cared-for older person, in order to better elucidate the effects of specific supporting services and informal networks on the different parameters of family care such as satisfaction and burden, self rated health status, perceived quality of life, quality of support and costs.” (Döhner et al., 2007: 12).

In the German part of *Eurofamcare*, 1,003 family carers were interviewed from December 2003 until July 2004. After one year, 45% of them were interviewed again in a follow-up study (for more details concerning the study structure and methodological approach, see Lüdecke, Döhner & Mnich, 2007: 66–83). The *Eurofamcare* sample of those receiving care included two age groups (65 to 79 years of age / more than 80 years of age) that were almost balanced (48.6% / 51.4%). Gender distribution was 31.5% men and 68.5% women (Table 6).

Most of the older people receiving care (63.5%) were widowed and nearly all older people were Germans or of German ethnic origin. 87.7% of them lived at home, in their own houses or at their children’s houses. 44.5% lived alone, 55.5% lived with others. 48.5% lived with spouse, 35.9% with children, 5.7% with grandchildren and 1.6% with paid carers.

Most of the older people in need of care mentioned ‘mobility reasons’ for their need of support (27.9%). Physical illness or disabilities (24.8%) and memory/cognitive problems or impairments (14.9%), age-related decline or old age (12.1%) were stated as further reasons.

55.8% of older people receiving care in the sample suffered from memory problems. There were three sub-groups: 20.5% of those with memory problems had undiagnosed problems. 60.5% were diagnosed by a doctor as having ‘dementia’ and 19% had another explanation or diagnosis by a doctor.

**Table 6. Mean Age of Older People Receiving Care in the *Eurofamcare* Project (by gender and age groups; in %).**

Total Mean Score (years)		Male	Female
79.67		76.53	81.11
Age of older people, grouped		Total percentage	
65-70		48.6	
80+		51.4	
Older people’ gender		percentage	
Male		31.5	
Female		68.5	
Age of older people, grouped		Male	Female
65-79		65.8	40.7
80+		34.2	59.3

Database: People in need of care in 1,003 families with family carers (Germany);  
Source: Lüdecke & Mnich, 2007: 84, Table 25.

## 2.2 The Social Care System in Germany

The German Social Security System is based on a combination of old-age pension insurance, unemployment insurance, healthcare insurance, accident insurance, long-term care insurance and social assistance. Especially important for the care of older people and family carers is the

Long-term Care Insurance that was enacted in 1995 – with several modifications and additions over the years (see Box 1, section 2.1.3).

### **2.2.1 Providers of nursing care: the main actors**

In Germany, many groups, associations, initiatives, foundations, social services or facilities look after older people in need of care – besides carrying out the many other tasks they are responsible for. They offer institutional care as well as professional outpatient care. In 2005, there were 10,424 registered nursing homes with 757,186 places available and 10,977 authorised outpatient care services looking after 471,543 people (BMG, 05/08; see also Table 7 below).

Most of the organisations in Germany are united under the ‘umbrella’ of the central associations of Non-statutory Welfare. The main characteristics of Non-statutory Welfare organisations are to be independent and non-profit oriented – which is also the biggest difference to social services offered by public authorities or commercial sellers (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege [Free Social Welfare], 2003).

*“Non-Statutory Welfare is characterised by independence and a partnership-based co-operation with the public social service providers like the State, local authorities and social insurance bodies. The objective is to effectively complement the last mentioned services’ actions in favour of those in need. Basis for this co-operation is the so-called principle of subsidiarity. In simple words this means: whatever an individual, the family or groups and organisations can achieve by their own means must not be claimed by a higher-ranking institution or the State.”* (Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege [BFW], 2003: 6).

Six organisations are particularly important for the structure and smooth running of the German Welfare State. Besides several other fields of activities and responsibilities, all of them take care of older people (leisure activities, consultation, care, institutions for older people) (for more details see BFW, 2003: 8 ff):

**Arbeiterwohlfahrt (AWO).** Workers’ Welfare Association. The AWO is both a political interest group with honorary leadership and a non-profit service organisation. It has 600,000 members and ca. 100,000 volunteers for performing tasks. Federal structure with several tiers of regional and local associations. 140,000 employees working in ca. 10,000 social services and establishments (in total; not only caring for older people).

**Deutsches Rotes Kreuz (DRK).** German Red Cross. Part of the international Red Cross and Red Crescent Movement. It employs in total (not only in caring for older people) 75,000 paid staff and has over 400,000 volunteers. It has more than 4 million members.

**Deutscher Paritätischer Wohlfahrtsverband (DER PARITÄTISCHE).** Equal Welfare Organisation of Non-affiliated Charities. Charitable association grouping independent organisations, establishments and bodies active in social work (not only for older people).

**Deutscher Caritas Verband (DCV).** German Caritas Organisation. Charitable association of the Catholic Church in Germany. The DCV has approximately 500,000 employees in all its establishments (in total; not only caring for older people).

**Diakonisches Werk der Evangelischen Kirche in Deutschland (DW der EKD).** Diaconal Charity of the Protestant Church in Germany. Welfare Services maintained by 24 United, Protestant, Reformed and Lutheran state churches, members of the Protestant Church in Germany, 9 free churches with their welfare facilities and a variety of some 90 professional associations. Altogether 27,000 independent establishments of different sizes

and legal status that offer over 1 million places for therapy, nursing or care (not only for older people).

**Zentralwohlfahrtsstelle der Juden in Deutschland (ZWST).** Central Welfare Agency of Jews in Germany. Umbrella organisation of Jewish charities and associations. 100,000 members organised in 12 Jewish regional associations, 8 independent Jewish local congregations and the Jewish Women's Association. Offers, among other services, retreats and leisure activities for older people.

Altogether, there is a wide range and dense supply of inpatient and outpatient (health-)care services, including professional and non-professional care from highly specialised professionals to non-professionals. However, as these are financed through different sources and organised by various non-profit and private institutions and local authorities, all of which may have different structures, the German system of healthcare can be characterised as lacking integration and transparency (Meyer, 2007: 40-41).

## 2.2.2 Outpatient (domiciliary) nursing care services

60% of the outpatient nursing care is provided by private organisations, i.e. facilities, maintained by private commercial institutions. 38% of services are non-profit organisations, i.e. the non-statutory welfare institutions mentioned above, including religious communities covered by public law, like Diakonische Werk or Caritas. Public organisations, i.e. services which are maintained by municipal institutions, have a share of only 2% in outpatient treatment in care in Germany (Table 7).

**Table 7. Outpatient Nursing Care Services and Customers** (numbers, Germany, 2005)

Supporting organisations of nursing homes	Nursing care services/people in need of care	
	Outpatient nursing care service	People looked after by the services
<b>Institutions</b>	10,977	471,543
<b>Private institutions</b>	6,327	203,142
<b>Non-profit institutions</b>	4,457	259,703
<b>Public institutions</b>	193	8,698

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

On average, every outpatient nursing care service is responsible for 44 people in need of care. The private organisations are a bit smaller: on average, they take care of 33 people. Non-profit organisations like Diakonisches Werk or Caritas are responsible and take care of an average of 60 people in need of care (StBA, 2008b).

In comparison to 2005, the number of people who applied for care at the outpatient nursing care services was 6.9% higher in 2007. In 2007, there were 5% more outpatient nursing care services and 10.2% more employees. This could be interpreted as a trend towards a growing importance of outpatient nursing care services within the healthcare market in Germany.

### 2.2.3 Caregivers: definitions

#### Box 3: Caregivers in Germany: Definitions

##### Carers (informal and unpaid caregivers)

= caring people in the informal social network of the person in need of care; either family members or volunteers (friends, neighbours, etc.)

##### Care workers (formal and paid caregivers)

= qualified care personnel employed by official care providers (including employees from migrant backgrounds)

##### Informal care assistants (informal, but paid caregivers)

= caregivers without (recognised) qualifications, working as care and/or “household assistants”; usually not legally employed, self-employed and/or directly paid by the care recipient; not recognised as care workers by official care providers.

*Immigrants and ethnic minorities (IEM)* can be found in all three areas: they act as carers when providing help to family members and friends, and some immigrants work as trained and qualified care workers for official care providers. Immigrants working as informal care assistants are, however, a special phenomenon. As they are often recruited from abroad, we will refer to them as:

##### Migrant care and/or household assistants

= informal caregivers from migrant backgrounds, working (and often living) in the households of care recipients. Migrant care assistants typically originate from Eastern European countries and are either recruited through the Central Placement Office “ZAV” and legally employed as “household assistants” or employed semi-legally (“grey market”).

##### Nursing

In Germany, we face a strict division between *medical nursing* (Behandlungspflege), *basic nursing* (Grundpflege) and *household assistance* (hauswirtschaftliche Versorgung). People without certified training are not entitled to do medical nursing according to SGB V or basic nursing according to SGB XI (Code of Social Law).<sup>6</sup>

##### Medical nursing (Behandlungspflege)

= carrying out tasks based on doctors’ orders (e.g. medication, surgical dressing, injections).

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<sup>6</sup> A law which came into force in August 2003 defines the vocational training for geriatric nursing all over Germany (Federal Law Gazette, Vol. 2002 part I No. 81, issued in Bonn, November 2002;

<http://www.bmfsfj.de/bmfsfj/generator/BMFSFJ/gesetze.did=3268.html>;

English translation of the Altenpflegegesetz (Geriatric Nursing Act)

<http://www.bmfsfj.de/bmfsfj/generator/RedaktionBMFSFJ/Abteilung3/Pdf-Anlagen/englische-uebersetzung-altenpflegegesetz.property=pdf.bereich=bmfsfj.sprache=de.rwb=true.pdf>).

A law which came into force in January 2004 defines the vocational training for general nursing all over Germany (Federal Law Gazette, Vol. 2003 part I No. 36, issued in Bonn, July 2003;

[http://www.bmg.bund.de/cln\\_162/nn\\_1200414/SharedDocs/Downloads/DE/GV/GT/Gesundheitsberufe/4-Gesetz-ueber-die-Berufe-in-de-.templateId=raw.property=publicationFile.pdf/4-Gesetz-ueber-die-Berufe-in-de-.pdf](http://www.bmg.bund.de/cln_162/nn_1200414/SharedDocs/Downloads/DE/GV/GT/Gesundheitsberufe/4-Gesetz-ueber-die-Berufe-in-de-.templateId=raw.property=publicationFile.pdf/4-Gesetz-ueber-die-Berufe-in-de-.pdf)).

The vocational training of nursing assistants and geriatric nursing assistants is regulated by German Federal States laws and hence, differs from state to state.

#### Basic nursing (Grundpflege)

= support for basic activities of daily living (e.g. personal hygiene, eating and drinking, getting up, getting dressed)

#### Household assistance

= support for housework (e.g. cleaning, shopping, cooking).

Care workers employed by outpatient care services have received vocational training as *general nurses* (Gesundheits- und Krankenpfleger/-in) and *geriatric nurses* (Altenpfleger/-in), or as *nursing assistants* or *geriatric nursing assistants* (Gesundheits- und Krankenpflegehelfer/-in oder Altenpflegehelfer/-in).

The vocational training for general nursing and geriatric nursing lasts three years and entitles recipients to carry out basic and medical nursing (Grund- und Behandlungspflege). The vocational training for nursing assistance lasts one year and entitles recipients to carry out basic care. Nursing assistants are not entitled to carry out medical nursing.

For household assistance, no professional training is required. Household assistants are not entitled to carry out any care treatment.

### **2.2.4 Personnel in outpatient nursing care services**

In 2007, 236,000 people were working in outpatient nursing care services. The vast majority of them were female (88%) (Table 8). 71% of them were working part time and 26% were working full time. The focus of their work is nursing. Besides that, 14% of the personnel in outpatient nursing care services do household work for those in need of care and 5% of them are responsible for management and administration.

**Table 8. Personnel in outpatient nursing care services (numbers, sex)**

<b>Personnel in outpatient nursing care services (number)</b>	<b>2007</b>
Men	29,330
Women	206,832
Total	236,162

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

Most of the 236,000 employees of the outpatient nursing care services providing nursing in domiciliary settings have special training as general nurses (Gesundheits-/ Krankenpfleger/in) or geriatric nurses (Altenpfleger/in).

Since there is no up-to-date data available for 2007 (or later) on employment contracts of employees in outpatient nursing care services, we provide here the figures for 2005 to indicate the most important employment relationships (Table 9).

**Table 9. Personnel in outpatient nursing care services and inpatient care facilities (2005)**

Terms of the work agreement	Personnel	
	outpatient nursing care services	inpatient nursing care facilities
<b>Total employment contracts</b>	214,307	546,397
Full-time	56,354	208,201
Total part-time	151,138	296,108
More than 50%	68,141	162,385
50% and less, but not insignificant	35,040	78,485
<b>Other employment contracts</b>	6,815	42,088
Trainees, pupils	3,530	31,623
People doing voluntary community service	703	4,003
People doing community service instead of military service	2,582	6,462

Source: [www.gbe-bund.de](http://www.gbe-bund.de)

In 2005, 214,307 people were working in outpatient nursing care services. As in 2007, most of these people were working part time (71%). The biggest sub-group of people were working more than 50% of their time. Nearly one-third (47,957 people) were working in an employment relationship called ‘insignificantly employed’ (geringfügig beschäftigt) or ‘Minijob’ which means they work for a maximum of 400 EUR per month ([www.gbe-bund.de](http://www.gbe-bund.de); Personal in ambulanten Pflegediensten nach Beschäftigungsverhältnis, 2005; Datenreport, 2008: 244). This fact could have consequences for the introduction, training and use of ICT in domiciliary care.

We have been unable to find any information about the age structure and ethnic membership of the employees of the outpatient nursing care services throughout Germany. However, in combination with all other information, we dare to give our assessment on these two aspects:

- In combination with information about sex (mostly females) and employment status (many women with only few hours of work per month) and the general information about who is interested in this kind of employment status, we assume: these women are probably re-entering the labour market after their family phase and/or have just a small amount of time for employment due to family and children. Therefore, most of them are probably aged between 40 and 60.
- Due to the focus of the outpatient nursing care services on nursing and the legal restrictions concerning employment in nursing, employees from migrant backgrounds are less likely to be found here. On the other hand, we know that, in institutional care, employees from migrant backgrounds are becoming more and more important for older patients who have a migrant background themselves.

We assume that employees from migrant backgrounds will become more important in the outpatient sector as well. A study in North Rhine-Westphalia (Friebe, 2005) found an employment rate of staff from migrant backgrounds of 11% (see chapter 3) and, according to information received from expert questionnaires, the share of care workers from migrant backgrounds in outpatient care services amounts to approximately 5-10%.

### 2.2.5 The informal sector

Firstly, the informal sector includes care given to people in need (registered in Grade I, II and III as described above) by caregivers such as family members, other relatives or members of the social network, friends, neighbours, volunteers, etc.

In addition, the informal sector covers those needs of care beyond the three Grades, i.e. situations in which people needing help do not get financial support from the Long-term Care Insurance. Needs like receiving visits or having company at home, accompanying help for shopping or visits to the doctors', help with cleaning, housework and gardening, help for dressing and basic hygiene tasks are not covered by insurance if a person has not been classified as needing care according to Grades I, II or III. Meeting these needs is most likely the task of the family, the social network, or volunteers –and also of the irregular care market with informal care workers, for example, from Eastern European countries (migrant care workers; see Boxes 2 and 3). The main task of these caregivers is to enable people in need of care to live at home and to support and relieve the older people's relatives. Regardless of their status as legal or illegal – without the help of paid informal caregivers many old people in need of care or in need of company to prevent danger would have to move into institutions.

#### Characteristics of family carers

With regard to characteristics of family carers, we refer again to the findings of the *Eurofamcare* project (Lüdecke & Mnich, 2007). The children of people in need of care are the strongest group among the caregivers with family relationships. 53.4% of the carers were daughters or sons. 18.4% were spouses (wife, husband) and 9% were daughters/sons-in-law (Lüdecke & Mnich, 2007: 93).

Literature and web sources concerning this topic all point to the fact that the daughters and the daughters-in-law are more likely to give care than the sons or sons-in-law. Informal care is – like professional care – female. *“It is more often women who take on the main load of family care giving, especially of people suffering from dementia. While two thirds of all male caregivers look after their spouses, it is one half of the female carers who look after a parent. With the exception of their spouses men are far more reluctant to look after people in need of care at home.”* (Meyer, 2006: 26). Meyer refers here to Gräbel (1998a) who pointed out the responsibility of the traditional role model *“which favour(s) man's orientation towards activities and acknowledgement outside of the home. This is why the son-in-law as a caregiver is practically non-existent.”*

The “strong emotional bond between the care giver and the cared-for person” (Lüdecke & Mnich, 2007: 93) is responsible for the care which is given within families. 45.1% of the family carers mentioned this reason as the principal reason for taking on this duty. 17.9% mention ‘a personal sense of obligation’ and 16.6% ‘a sense of duty’. These principal reasons for caring show a strong emotional relationship and therefore might be the background for the fact that 43.4% of family carers never consider placing the person they care for in institutional care. 40.9% are willing to increase their efforts, and another 15.8% would do so at least for a limited time.

Most family carers and care recipients live very close to each other: 36.6% live in the same household, 13.9% live in different households but in the same building. Another 17.7% live within walking distance, 14.0% live within 10 minutes drive, bus or train. Only 17.8% live more than 30 minutes drive, bus or train apart.

The average age of caregivers is 53.8 (Table 10). The share of male caregivers who are 65 years and older is higher than the share of female caregivers of the same age. This could be explained by the fact that male partners care for their wives, whereas the daughters or



daughters-in-law are more likely to care for their widowed mothers and mothers-in-law than the sons.

A future challenge will be that not only the people in need of care are getting older. The changes in the age structure of the population affect those family members responsible for giving domiciliary care and informal caregivers as well (i.e., children acting as carers of people aged 80+ are 60+ themselves). This may have an effect on the use and need for technical devices in domiciliary care.

**Table 10. Carer's Gender and Age**

<b>Total Mean Score</b>	<b>Male</b>	<b>Female</b>
53.75	53.4	53.85
<b>Age of Carer</b>	<b>Percentage</b>	
until 64	78.0	
65+	22.0	
<b>Carer's Gender</b>	<b>Percentage</b>	
Male	23.9	
Female	76.1	
<b>Age of Carer</b>	<b>Male</b>	<b>Female</b>
until 64	73.9	79.3
65+	26.1	20.7

*Database: 1,003 family carers (Germany); Source: Eurofamcare – National Survey Report for Germany 2007: 91, Table 34.*

42% of carers are in employment, 57.7% are not working. A closer look at working carers shows the effect giving care has had on their employment status: 20.6% of the employed carers had to reduce their working hours due to the care they give. 11.8% had to give up working completely, 9.6% could work only occasionally, 9.5% had not been able to take up any work at all and 8.0% say they cannot develop a career or studies due to the care they give.

The reduction of work or the negative effects on professional careers lead to negative income effects. The financial support provided by the Long-term Care Insurance is often not enough to compensate for this negative effect. Often, at some point in time, additional help has to be contracted, increasing the negative effect on their financial situations.



### 3 Immigrant Care Workers and Care Assistants

This chapter provides an overview on the different types of immigrant care workers, legally or illegally employed, to support the domiciliary care of people in need of care (for definition see again Box 3). Basically, we distinguish between *care workers from migrant backgrounds*, i.e. qualified care workers employed by formal and recognised domestic care providers who happen to have a migrant background, and *migrant care assistants*, i.e. people who temporarily immigrate to provide services in households with people in need of care outside the normal outpatient care system.

#### 3.1 Personnel from Migrant Backgrounds in Outpatient Care Services

Data about the employment of care workers from migrant backgrounds in outpatient care is barely available. As mentioned above, the official care statistics do not distinguish between natives and immigrants. Therefore, we have to fall back on findings of studies on local or regional level (Ploch, 2002; Friebe, 2005).

In North Rhine-Westphalia, 97 inpatient care facilities and 16 outpatient care facilities were interviewed about their staff's migrant backgrounds. According to this study, 30% of the employees come from migrant backgrounds. Thus, the proportion of the staff from migrant backgrounds is significantly higher in relation to the population of immigrants in North Rhine-Westphalia (23%). This is due to a high employment rate of people from migrant backgrounds in inpatient care facilities, whereas the proportion of employees from migrant backgrounds in outpatient care services is considerably lower (11%). At 92%, the proportion of female employees from migrant backgrounds in the staff of outpatient care services is higher than in the total staff of care facilities for the elderly. Above half (58%) of the staff from migrant backgrounds came as "Spätaussiedler" (late repatriates, i.e. immigrants of German origin from Eastern European states) to Germany. They have German roots and lived for a long time as non-residents mainly in Poland and in the former Soviet Union countries. Furthermore, large groups in the caring staff are immigrants from Turkey or from the former Yugoslavia (first and second-generation immigrants), followed by smaller groups of immigrants especially from different states in Southern Europe, Asia and Africa. Half of the staff from migrant backgrounds are skilled employees with vocational qualifications in general nursing or geriatric nursing. The others are mostly nursing assistants. The proportion of qualified people from migrant backgrounds was higher in outpatient care than it was in inpatient care facilities (Friebe, 2005).

A study carried out in Bremen and Bremerhaven provides further information on the situation of care workers from migrant backgrounds in outpatient care (Lotze & Hübner, 2008). 49 outpatient care services – that is 44% of all domiciliary care providers in the Federal State of Bremen – participated in the study.

According to this study, 22.1% of the total staff of outpatient care services are from migrant backgrounds. Thus, compared to the study in North Rhine Westphalia, the findings in Bremen point to a higher employment rate of people from migrant backgrounds in outpatient care services. Corresponding to the findings in North Rhine Westphalia, the vast majority of the staff from migrant backgrounds in outpatient care services in Bremen were women (89%). Differentiations by qualification level and country of origin show: 89.5% of the outpatient care services employed care workers from migrant backgrounds as nurses or geriatric nurses and 57.9% as care assistants. Three-quarters of outpatient care services had employees from the CIS-States, two-thirds from Poland, half from Turkey, 41% from other EU Member States and 29% from Asia (Lotze & Hübner, 2008).

### **3.2 Migrant Care Assistants in Domiciliary Care**

In view of the growing number of older people in need of care, and the declining younger workforce, increasingly fragile and/or remote family support networks and high costs for professional care services in both out-patient care and nursing homes, families are falling back on migrant caregivers more and more often to assist with care tasks in the older people's homes (Friebe, 2008; Kondratowitz, 2005; Weinkopf, 2005). Thus, apart from the regular personnel in outpatient care, in Germany there is an increasing number of migrant care workers who act as household and care assistants and provide care outside the normal care system.

There is practically no reliable data as yet on the volume of work performed by legally and illegally employed migrant care workers. The number of migrant care assistants employed in domiciliary care is estimated at 50,000 to 100,000 people, presumably with a high number of undetected cases. Some experts assume that the number of illegally employed migrant care assistants (mainly from Eastern European countries) alone amounts to 100,000 people (Neuhaus, Isfort & Weidner, 2009; Fussek, 2008). The fragmented and untransparent system of service provision in Germany is assumed to favour the growth of a grey market (e.g., Meyer, 2006).

The legal situation relating to the employment of migrant care workers is complex. In this report, we will focus on the main legal foundations and regulations.

#### **3.2.1 Legal framework**

For many years, migrant care workers were illegally employed in Germany because non-EU citizens only got a three-month visitor's visa that did not allow any official employment.

Since the eastward enlargements of the European Union in May 2004 and January 2007, the European basic civil rights and liberties (e.g., the right to settle, to set up in business, to move within the European member states) are in force in principle for citizens of the new Member States as well. This leads to new employment opportunities in the domiciliary care sector. However, in Germany access to the national labour market is still restricted by interim regulations for employees from the new European Member States. Until the end of the interim period (up to 30 April 2011), citizens of the new European Member States are subject to the general labour legislation for newly-immigrated foreigners. Decisive in this context is the "Regulation on the Admission of Foreigners for the Purpose of Taking up Employment" (Verordnung über die Zulassung von neu eingereisten Ausländern zur Ausübung einer Beschäftigung) which came into force in January 2005.

§ 21 of this regulation makes it possible for households with people in need of care to employ a foreign household assistant with a social security-based contract for up to three years of full-time, compulsorily-insured employment. The objective mentioned in the law is to enable people in need of care to stay in their familiar environment and to support the family caregivers. The Central Placement Office "ZAV" ("Zentrale Auslands- und Fachvermittlung") of the Federal Employment Agency acts as an agent for the employment of foreign household assistants. Currently women and men from Poland, the Czech Republic, the Slovakian Republic, Hungary, Slovenia, Romania and Bulgaria have the opportunity to make use of this legal way of taking up employment at households with a person in need of care. Household assistants are only allowed to perform household tasks. Due to the strict division between healthcare and household assistance they are not entitled to perform any nursing care (Bundesagentur für Arbeit, 2006).

According to § 30 of the Regulation on the admittance of newly entered foreigners, the employment of migrant nurses as nursing care workers is possible if they possess

qualifications equivalent to the German professional requirements and German language skills. As in the case of domestic help, the precondition for admittance is a respective agreement with the Employment Agency of the country of origin. Until now, such agreements only exist with Croatia (Bundesagentur für Arbeit, 2005a). Therefore, there are no legal possibilities for foreign employees to take up employment as nursing care workers apart from this exception.

According to the freedom to provide services, enterprises and freelancers are entitled to offer and perform services across borders. This also applies to domiciliary care services. Thus, nursing care agencies from the new European Member States are entitled to dispatch their employees to Germany for one year at most to perform tasks in domiciliary care (Bundesagentur für Arbeit, 2005b). The employee must have been employed for at least one year at the sending agency and has to establish proof of his or her professional qualification for the task to be carried out in Germany. Also self-employed people of the new European Member States are entitled to perform services for private households in Germany. Self-employed service providers have to fulfil some preconditions, too. In their home country, they have to declare to the authorities that they are trading, pay taxes and social insurance. Further, they have to perform services for several customers and they may not live in the household of customers they work for.

All in all, the legal situation of migrant care workers is often unclear and consequently the employment relationships and working conditions of migrant care workers vary a lot. For a more detailed description of the current situation of migrant care workers, we differentiate between (a) household assistants recruited through the German Federal Employment Agency's Central Placement Office (ZAV), as the "100 per cent"- legal employment of migrant care workers, and (b) migrant care assistants (household and care assistants) in the "grey" market, which includes more or less legal or illegal ways of service provision in domiciliary care.

### **3.2.2 Migrant household assistants recruited through the ZAV**

Since 2005, the Central Placement Office "ZAV" of the Federal Employment Agency (<http://www.arbeitsagentur.de/>) has acted as agent for household assistants from Poland, the Czech Republic, the Slovakian Republic, Hungary, Slovenia, Romania and Bulgaria for German families with family members in need of care. This procedure underlies strict regulations to protect German employees from cheaper competitors. The person requiring care must belong to Grade I, II or III in accordance with the Long-term Care Insurance Law (since 2008, "Grade 0" is also accepted). The household assistant is employed by the person in need of care or his/her family.

#### **Box 4: Recruitment of household assistants through the ZAV**

The procedure to employ an Eastern European "household assistant" is as follows: family carers or people in need of care who would like to employ an Eastern European household assistant go to their local labour office. There, they file an employment application and the proof of care level. The labour office checks the local labour market. If there is nobody suitable available, the local office sends the documents to the ZAV. In the case of a demand for a named "household assistant", the ZAV sends the documents directly to the employment administration of the Eastern European partner country. In other cases, the ZAV selects appropriate candidates out of the applicant pool or asks the labour administrations in the partner countries to suggest an appropriate candidate. Before the start of employment, the household has to obtain the "work permit-EU" from the local labour office (Bundesagentur für Arbeit 2008).

The employer has to provide appropriate accommodation and has to pay the current tariff for “household assistants in households of people in need of care”. This means a salary of € 1,065 to € 1,307 (depending on the current tariffs in the German Federal states) plus social security contributions. Household assistants are entitled to holidays of 26 – 30 days, depending on their age. Officially, weekly working hours are 38.5 hours ([www.bundesagentur.de](http://www.bundesagentur.de)).

The ZAV works closely with the labour administrations of the Eastern European countries. Generally, the ZAV is not in contact with private service agencies who act as agents for Eastern European household assistants and home carers.

The ZAV provides support for family carers and people in need of care looking for a foreign household assistant by phone and Email. Further information and the contract formulas in different languages are available online on the website of the Federal Employment Agency.

In 2008, the ZAV placed 3,051 people from Eastern European countries in household assistant jobs (in 2007: 3,032 people, in 2006: 2,241 people, 2005: 1,102 people). More than two thirds of them came from Poland (2,254), the others mainly came from Hungary (286) and Romania (273) and only few came from other Eastern European countries.

Statistics about age, German language skills, place of living and job tenure of these legally employed foreign “household assistants” are not available (according to information from the *German Federal Employment Agency in April 2009*).

Household assistants are entitled to perform household work only. Due to the strict division between healthcare and household assistance, they are not allowed to perform any nursing care. However, the reality may be different (e.g., Sattler, 2007). The restricted regular tasks and working hours of household assistants recruited by the ZAV often do not meet the demands of the domiciliary care settings. For this and other reasons (e.g. bureaucracy, waiting periods, costs), this official variant to employing a migrant care worker is not appropriate for many people in need of care and their families. Nevertheless, an increasing number of people seem to use this employment variant to legalise an existing unofficial employment relationship with a migrant care worker. An indicator for this is the high proportion of named applicants (Neuhaus, Isfort & Weidner, 2009). However, up until now the vast majority of people in need of care have fallen back on other ways of employing migrant care workers, most of them in the “grey market”.

### **3.2.3 Migrant care assistants recruited from the “grey market”**

As mentioned above, care providers (companies with employed care personnel or self-employed people) from the new Eastern European Member States are, in principle, entitled to offer services for domiciliary care in Germany. According to the complex legal situation, however, it is difficult for people in need of care and their families to recognise which of these home care service offers are legal and which are illegal. Overall, it can be assumed that, in many cases, the employment of migrant care workers does not fulfil the diverse legal conditions and that there is a big grey market with different kinds of more or less irregular employment relationships.

In many cases, Eastern European service providers cooperate with care service agencies set up in Germany. They establish contact with the clients and organise contracts between the Eastern European service provider and the German clients. An examination conducted in May 2009 by a consumer safety organisation revealed that many service agencies treat regulations laxly, for example, they do not check the Eastern European carers’ social insurance or qualifications (Stiftung Warentest, Ausgabe Mai 2009).

Recently, a new model has emerged which has not yet been disseminated widely but which might become more important in the future: service delivery by migrant care workers with quality control by a German service provider. Usually, the provider holds local branches run by qualified care personnel who supervise the clients and the migrant care workers in their region. In cases where medical treatment is needed, local care services are used (for further information see Richter, 2008; Oberschür, 2008). This procedure ensures a certain quality management. Moreover, the providers guarantee legal employment by accepting only foreign partners whose employees have health-, accident- and social security insurances and possess an E 101 certificate. This certificate is accepted by the 'German Finanzkontrolle Schwarzarbeit der Zollverwaltung' (German Customs Administration; [www.zoll.de/d0\\_zoll\\_im\\_einsatz/b0\\_finanzkontrolle/index.html](http://www.zoll.de/d0_zoll_im_einsatz/b0_finanzkontrolle/index.html)) as certification that the employer pays taxes and insurances for the employees in their native country (Richter, 2008). These providers do not intend to compete with existing qualified outpatient care services. Instead, their approach is meant as a supplement suited to closing gaps in the care system.

Another way to employ migrant care workers is by recruitment through informal contacts (e.g., neighbours, friends, doctors) or non-eligible agents. Because in Germany private people are not permitted to act as employers for foreign employees – apart from the recruitment by the ZAV – this way of employment of migrant care workers is illegal. Nonetheless, experts assume that it happens frequently (Richter, 2005). This is explained by the untransparent care system, the complex care market and the lack of adequate and affordable options. Frequently, people in need of care or their families fall back on this possibility because all their attempts to find a legal, payable and practicable solution were in vain (Fussek, 2008).

These illegal working conditions are associated with high uncertainties and risks for the people in need of care, their families and also the migrant care workers (Grieshaber, 2004; Hamm, 2006). Employment contracts are often unclear or not drawn up; additional costs are not anticipated or well defined; and the quality of care is not ensured (Richter, 2008). At the same time, the illegality reduces the possibility of integration that is already limited for migrant care workers.

### Background and motives

The vast majority of migrant care workers come to Germany from Eastern European countries, mainly from Poland and, to a lesser degree, Hungary, Rumania, the Czech Republic, Slovakia, Ukraine and Belarus. Some experts assume that partly due to the implementation of the Euro in the new Member States, the costs of migrant care workers from these countries will increase, so that the border for recruiting will shift more and more towards the East (Richter, 2005).

The reasons for looking for employment in domiciliary care of older people in Germany are manifold. Firstly, the pay differential between the East European neighbour countries and Germany plays a role. The second reason is the lack of adequate employment and career options in immigrants' countries of origin. Therefore, people with low and also high qualifications are prepared to make the effort to live apart from their families for several months (Richter, 2005).

In consideration of the motives, the following main groups of migrant care workers can be distinguished (Lutz, 2007):

- Young women who are unable to find jobs in their country of origin. By migrating, they try to either broaden their professional competencies through acquiring language proficiency or pursuing studies in Germany, or earn money for financing studies in their home country;

- Divorced women and single mothers who want to earn their living and support their children's education;
- Women with financial problems or women whose families are in difficulties and who want to help solve the problems by taking a job abroad;
- Further motives are to earn money to build a house, to set up a business or similar objectives.

According to the agencies we interviewed, occasionally male migrant care workers are placed in German households, especially if a lot of physical effort is needed in the domiciliary care setting. Apparently, men are increasingly interested in employment in German households with people needing care; for instance, teachers from Poland who are paid poorly or find no employment.

Most migrants do not strive for definitive emigration. Instead, they migrate for a limited time in order to solve pressing (financial) problems. Many of them leave their homes and work abroad in order to finance living permanently at home in the future (Friebe, 2008; Weinkopf, 2005; Morokvasic, 1994).

### Qualification and skills

Migrant care workers' qualifications are quite diverse. According to literature and the interviews we have conducted for this report, some migrant care workers are well-educated nurses. However, the vast majority of them are not particularly well educated in health or social care. Some have long histories as domiciliary care workers, while others have no experience in support for people in need of care. According to our interviews, particularly young migrant women, who take up illegal employment in private households with a person in need of care, are often completely unprepared. Usually they get the job offer at very short notice through informal contacts, and have hardly any information on the situation in the household or on the tasks they are expected to perform. Accordingly, the migrant care workers' expectations often differ substantially from reality. In our interviews, the migrant care workers stated that they felt very stressed and burdened because of their lack of knowledge, especially about dementia. Agency experiences also indicate a high need for training and education, in particular on dementia.

In addition, our interviews confirm the experience reported in the literature that migrant care workers, especially from Poland, often take on a lot of responsibility for the care recipient. This can result in excessive demands on the informal care worker and is not always beneficial for the person cared for. Hence, the interviewed agencies refer to the need for training for migrant care workers, to enable them to protect themselves from excessive demands and also to recognise the particular problems and needs of the person cared for with a view to developing their potential and promoting their independence and wellbeing.

Sufficient knowledge of the German language for communication between the migrant care worker and the person in need of care is an important precondition for a satisfactory shaping of the care situation and the quality of care. Experiences show that this is not always ensured and that problems arise due to communication difficulties (Richter, 2005). However, language barriers do not seem to be seen as a problem by most people or families employing a migrant care worker. In a recent study (Neuhaus, Isfort & Weidner, 2009: 63), almost four out of five households (78%) reported that their migrant care workers had sufficient German language skills. An explanation might be that the level of formal education is often high among both private employers and migrant employees (Lutz, 2009: 64).

Furthermore, the interviews of our study indicate that there are also families from migrant backgrounds who employ migrant care workers from their country of origin. Especially in the



case where the family member in need of care does not have good German language skills, the possibility to communicate with the migrant care worker in the common mother tongue is advantageous.

#### *Working and living conditions*

In general, migrant care workers are employed in order to ensure domiciliary care for 24 hours. Usually they live in the household of the person in need of care and hence, are available day and night (which can be particularly necessary in the case of dementia). Though they are often employed to do household tasks, in fact they nearly always take on some caring duties. Service agencies for the placement of migrant care workers rarely offer further training, provide guidance, supervise their staff or conduct quality control checks.

The relationship between the person in need of care or family carers and the migrant care worker varies a lot and is described as a mixture of friendly and working relationships (Neuhaus, Isfort & Weidner, 2009). The migrant care workers' social situations are often difficult because of their separation from family and friends in their home countries and the lack of social contacts and activities at their place of work. In this situation, new media and communication technology play an important role. Especially mobile phones and sometimes internet (Email, Skype etc.), if available in the household, were used by migrant care workers to keep in touch with family and friends at home, as well as with the employer or agent or with other migrant carers from the same country of origin.

According to the statements of the interviewed agencies, migrant care workers are often connected and in some places, there are special meeting points for migrant care workers who spend their leisure time together. Use of mobile phones seems to be very popular among migrant care workers. Because saving is a high priority, they try to keep costs low. Hence, some migrant care workers have several mobile phones with different rates. For private communication, SMS is used a lot.

Most of the migrant care workers stay in the households for two to three months. In order to ensure continuity, some agencies try to organise teams of two or three people who rotate (Richter, 2008; Oberschür, 2008). Furthermore, our interviews with migrant care workers point to the fact that some of them stay longer than originally intended and different employments over several years seem to be not uncommon. Some of the migrant care workers, mainly young women, participating in our study, were able to profit from their care work insofar as they started training as geriatric nurses or nursing assistants as soon as they were able to legalise their stay in Germany.

#### *Payment and compensation*

Costs for 24 hour assistance by migrant care workers recruited through official agencies amount to 1,200 to 2,500 Euro per month, depending on the extent of the tasks. Moreover, the employee receives accommodation and food for free and, in some cases, reimbursement of travel costs (Friebe, 2008). Costs for illegally employed migrant care workers (without social security insurance, etc.) are substantially lower. They amount to 500 to 1,000 Euro plus accommodation and meals (Friebe, 2008, Richter, 2004, 2006; Weinkopf, 2005). The costs of regular German outpatient care services for assistance around the clock range from 2,700 to 3,200 Euros. However, currently most of outpatient care services do not provide 24-hour-care arrangements (Stiftung Warentest, May 2009).

### **3.2.4 Implications for migrant care workers and the people in need of care**

With regard to the employment of migrant care workers in domiciliary care, we notice opportunities and risks. Migrant care workers enable people in need of care to live in their

familiar environment and reduce the stress and burden of family members who feel responsible for their needy relative. For the migrant care worker, the employment is an opportunity to improve their personal living conditions and those of their families in their home countries. The main risks stem from illegal employment relationships where migrant care workers have no, or reduced, social rights and hard working conditions, e.g. availability around the clock, excessive demands because of lack of qualifications and training, and social isolation. There are associated risks for the person in need of care that result from the migrant worker's lack of qualifications, possible communication problems, isolation, work overload etc. ICT could contribute to making better use of opportunity to employ migrant workers as support in domiciliary care and also reduce the risks.

## 4 ICT INITIATIVES SUPPORTING INFORMAL CAREGIVERS

It is a nearly insoluble task to give a complete overview of *all* initiatives addressing the use of Information and Communication Technologies (ICT) in support of informal caregivers. As the focus of our study is on informal domiciliary care, we searched for discussion contributions, solutions and projects in this area. Many existing initiatives are primarily situated in the context of professional care and/or institutional care. We included them in this chapter whenever we were convinced they had a (certain) relevance for the informal context as well. The chapter is subdivided into four sections. These will:

- give an overview of ICT in domiciliary care and show the equipment with and use of a selection of ICT appliances and applications in the homes of older people;
- describe the German background (reimbursement situation etc.) with focus on barriers to the deployment of assistive technologies and ICT;
- show recent developments supported by the German government, and in this context describe relevant projects, including the German Ambient Assisted Living Congresses, held in Berlin in 2008 and 2009; and
- summarise the implications for caregivers in domiciliary settings.

### 4.1 ICT in Domiciliary Care and the Use of ICT by Older People

The use of ICT for health and social care plays an important role in the general discussion concerning the development of society and age structure in Germany. As on the one hand people are getting older and the need for care is increasing, and on the other hand the group of (young) caregivers is decreasing, technical devices are seen as a possible solution to this dilemma. For the future, the use of ICT is both a social necessity and an economic opportunity. ICT can support older people so that they can stay in their own homes for longer. It can also support those who supervise and care for them, whether as professionals or informal caregivers.

In science, literature, the media and the internet there are many sources dealing with ICT in the context of ageing and care. Unfortunately, in many cases no distinction is made between formal / institutional / inpatient care and informal / in-home / outpatient care. Nevertheless, the data give a general overview of the use of ICT among older people, and with further information, we can deduce the role ICT could play in informal domiciliary care.

Firstly, one has to note that considering the implementation of technological solutions in older people's households is not straightforward. *Eurostat* data on internet access and e-skills in the EU27 show that more than 40% of households had broadband internet access in 2007 (*Eurostat* news release, 166/2007). Household internet access ranged from 19% in Bulgaria to 83% in the Netherlands. The Member States most often reporting high proportions of individuals performing different internet activities were Denmark, Estonia, Luxembourg and the Netherlands, while Germany took a medium position (Table 11).

**Table 11. Individuals who use the Internet at least once a week  
(selected countries; in %)**

Age/Country	Men			Women		
	16 - 24	25 - 54	55 - 74	16 - 24	25 - 54	55 - 74
<b>EU 27</b>	79	61	31	77	55	19
<b>NL</b>	95	92	64	98	87	46
<b>UK</b>	83	76	50	83	68	33
<b>FI</b>	98	86	48	98	87	40
<b>DE</b>	90	78	44	87	69	26
<b>FR</b>	84	67	34	84	63	23
<b>IT</b>	61	45	17	57	34	6
<b>RO</b>	50	23	4	48	21	2

Source: Eurostat news release 166/2007: Internet access and e-skills in the EU27 in 2007.

These are promising figures. However, *Eurostat* data include only individuals and households of people aged 16 to 74, thus excluding the oldest users who – as studies repeatedly show – are the least equipped. The use of ICT decreases with age in all EU member states. Many older people still do not use computers or mobile phones. Older women, in particular, risk being excluded from participation in the information society.

The fact that older people are excluded from ICT participation is backed up by data of the Federal Statistical Office (Statistisches Bundesamt, Fachserie 15, Reihe 4, 2009<sup>7</sup>): while 82% of all interviewees used a mobile phone in 2008, only 25% of the respondents aged 65 and older used one. 82% of all interviewees used a computer, 76% of them did this within the three months (January to March 2008) before the research. In the age group 65+, only 39% ever used a computer, 28% of them used a computer within the same three months. Concerning the internet, we get similar results: 75% of all interviewees used the internet at least once in their lives, 71% from January to March 2008. The age group 65+ used the internet much less often: just 25% had had access, 22% of them used it from January to March 2008.

Closer inspection of those aged 65+ who use the internet shows that looking for information about health seems to be more important for them than to all the other interviewees (all: 50% / 65+: 54%). In comparison to overall figures, older people are more interested in sending and receiving e-mail, whereas the younger people show a stronger use of internet telephony, chat rooms and forums. Furthermore, older people seem to be less interested in e-learning (all: 49% / 65+: 29%).

The *Seniorwatch 2* Report (empirica & wrs, 2008b; for further details see also [www.seniorwatch.de](http://www.seniorwatch.de)) provides overall data on ICT use in households with at least one member aged 50+ in European countries. Within this sample, family carers show similar usage patterns of computers (40%) and internet (34%) to the total population 50+ (43% /

<sup>7</sup> Total sample: 23.582 people (10-15years: 2,606 people; 16-24 years: 2,766 people; 25-44 years: 6,884 people; 45-64 years: 7,430 people; 65+: 3,896 people).

35%, respectively).<sup>8</sup> 25% of family carers declare they use the computer every day; 20% say they use the internet every day.

This means, however, that half of the family carers do not have access to digital information – hence, the digital divide we can observe in society in general is carried forward to care. The situation is even harsher for people in need of care and care recipients. They show a very low usage of computers (27% and 21%, respectively) and internet (20% and 15%, respectively; empirica & wrc, 2008b: exhibit 4-18: 111). Hence, the individual preconditions for more extensive implementation of ICT have not been favourable until now.

#### Use of the internet for health information

Individuals who use the internet in general, use it for health information as well. Information about a healthy lifestyle, about diseases, medication or diagnosis or treatments by a doctor are of great interest to those who used the internet within the last three months before being interviewed (empirica & wrc, 2008b: exhibit 4-18: 109).

Even if the database for Germany is small (only 8.3% of the family carers or care recipients who use computers in Germany use them regularly or occasionally), it seems to be correct to assume that e-mail contact with a doctor is more likely to be made by the ‘young’ old (EU sample 50+: 3.4%).

#### Use of social alarms and interest in enhanced products and services

In the European Union, 5% of the households who took part in the *Seniorwatch* research in 2007 had access to a social alarm system. As a social alarm system is accepted and used in case of illness or in order to protect the person in case of an emergency, the share of older people using this system is higher than the share of younger people.

In Germany, 30% of those who use a social alarm have a non-homebound system that works inside and outside the home. The interest in additional features is quite high, both among those who use social alarms and those who are caregivers to a person using such a device. 66% stated that additional security features (e.g., automatic detection of fire or gas leaks) would be beneficial to them and 77% agreed that additional health-related features (e.g., fall detector, detector for emergencies) would be beneficial (empirica & wrc, 2008b: exhibit 4-23: 113).

Another way of getting in touch with one’s care service provider is by e-mail. The *Seniorwatch* data show, however, that this option is practically never used – as is the case with contacting a doctor (see above). Just 4.2% of the family carers and care recipients in the German sample who are also computer users make regularly use of this electronic way of getting in touch and another 4.2% use it occasionally (empirica & wrc, 2008b: 113).

We can broaden the picture of ICT use in home care by including another useful source of information: the *ICT & Ageing* report (empirica & wrc, 2008a; available at [www.ict-ageing.eu](http://www.ict-ageing.eu)) on the role that ICT is playing in the everyday life of older people in need of care. In the following, we summarise the most important aspects.

#### Technical Devices and examples of projects

##### *a) Social Alarms*

Social alarm systems for personal safety and security and for cases of emergency have been available in Germany for more than 25 years. Supplementary services, for instance for more

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<sup>8</sup> Sample size: 500 interviews per country (Germany, France, Great Britain, Poland). 2,500 interviews in total; households with at least one member 50+. For more details see *Seniorwatch 2* (empirica & wrc, 2008b, Final Report Annex A: Methodological notes, pp 149 ff).

convenience, have not been common up until now. Nearly 90% of these alarms are provided by the six large non-statutory welfare associations (see Chapter 1, Section 1.2.1). Commercial providers are Recontrol, Tunstall Group, Bosch Security Systems, HausNotrufServiceGmbH and Vitaphone (empirica & wrc, 2008a).

**Box 5: The telecare supplier Vitaphone ([www.vitaphone-telecare.de](http://www.vitaphone-telecare.de))**

Vitaphone is a leading company in the field of transmitting biological signals and biochemistry parameters by means of mobile ICT. Founded in 1999, Vitaphone TeleCare is a support-, care- and emergency case service via phone. It was founded by four experts from different fields. The main purpose is to develop special technologies for the transmission of biological signals and biochemistry parameters by innovative ICT and at the same time to offer innovative service concepts. The technologies used offer the opportunity to collect, transmit and evaluate data concerning the health status or care status of a person at any time. Special phones for example with three keys only are optional. Existing phones and mobile phones can be used as well.

Staff with medical training at a call centre are available 24 hours a day, 365 days a year. Doctors support the staff. All relevant information about the member person (state of health, allergies, medical treatment, name and number of doctors, available pharmacies, name and numbers of neighbours, relatives and friends) is available to the call centre staff. In the case of an emergency, the call centre is authorised to give this information to the emergency doctor, the hospital or other medical staff. The call centre can be contacted in case of everyday life emergencies like lost keys or a closed door.

Vitaphone can be used by private people and also by institutions like private domiciliary care providers, sheltered housing, etc. The Vitaphone TeleCare service is available to all existing mobile and fixed line networks, with a user-friendly 3-key-mobile phone with one direct connection-key to the service centre, with different scales of charges and with other phones offered by Vitaphone.

The Vitaphone TeleCare *basic package* covers 24-hour / 365 day a year personal assistance in everyday life and in case of emergencies, used with the existing phone in the household. It is also available with a fixed line network phone called Amplicom PowerTel 50 alarm. It has big keys, programmable keys for emergency numbers, and a hand alarm (mobile emergency button) and it is compatible with hearing aids.

Vitaphone TeleCare *Active* covers the same services and comes with an easy-to-use mobile phone (Vitaphone 1100, 1300, Amplicom PowerTel M5000 (details see below) under a 24-month mobile phone contract. Vitaphone TeleCare *Assist* offers the same services and devices as TeleCare *Active* – but with a prepaid sim-card.

The costs differ according to device and services. For example, with a prepaid card the cost of a special phone with three keys and a sim-card is € 49.95. The installation fee is € 19.95. In addition, € 90 per year are charged for the Vitaphone service, plus the cost of loading the prepaid card. If the special three key phone (Vitaphone 1100) is bought with a Vodaphone contract for 24 months, the price is € 29.95. Other phones are available; again prices differ according to the chosen mobile phone contract (prepaid card or 24 month contract). That is, a Vitaphone 1300, an easy to use mobile phone with emergency key, costs € 280,- / € 299. For the Amplicom PowerTel M5000, with big display and big keys, compatible to hearing aids, the price amounts to € 99 - /€119.90. The service fee (€ 90 a year) and installation fee (€19.95) remain the same. Additionally, costs for the Vodaphone contract apply. (empirica & wrc, 2008a; own internet research, May 2009)

As there are different commercial providers and two public organisations (Bundesverband Hausnotruf and Bundesarbeitsgemeinschaft Hausnotruf) in Germany, and as many people pay their social alarm out of their own pockets, systematic data about dissemination is not available. An estimation of the total number of users aged 65 and older is possible, based on information given by the different providers. The researchers of *ICT & Ageing* (empirica & wrs, 2008a) for example estimate that 2.6% of the people aged 65 and older in Germany use a social alarm system. The rate in other European countries is much higher. In years to come, an increase due to the (new) possibility of reimbursement can be expected in Germany as well.

Moreover, more and more housing organisations, in Wuppertal and Gelsenkirchen for example, are offering social alarm services included in various ‘packages’ (ranging from a call button in case of emergency to a security package or comfort package with picture phone and extra services; see also the paragraph on ‘Telecare’ below).

#### *b) Telecare*

After some years of pilot projects, telecare services are slowly getting a hold in Germany. An additional positive effect on the implementation of telecare services might come from the new ‘advice centres’, established in connection with the last reform of the Long-term Care Insurance. These centres offer help and advice on how to adapt the home for in-home care. New technologies will be important for the possible solutions they offer. If certain criteria are fulfilled, up to € 2.557 per installation or reconstruction can be reimbursed for technical solutions.

An exemplary system, available in several regions and cities, and used, for example, by a major housing organisation in North-Rhine Westphalia, is SOPHIA. This system is a

*“commercial picture-based care and communication service for older people, operated as a franchise company which aims to work nationwide. The service model is for new standards for safety and security, communication, comfort, telemedicine, multimedia and facility management. It is currently the only picture communication service and several other efforts to establish comparable services on the German senior market failed.”*  
([www.ict-ageing.eu/countryprofiles/germany](http://www.ict-ageing.eu/countryprofiles/germany). See also [www.sophia-nrw.de](http://www.sophia-nrw.de) and Box 6).

#### *c) Home telehealth*

This area seems to be developing as well – but, for the time being, home telehealth plays a minor role in the German in-home care. The *ICT & Ageing* study (empirica & wrs, 2008a) lists a few examples, which are integrated in the healthcare programmes of several healthcare insurance companies (for further details see [www.ict-ageing.eu/countryprofiles/germany](http://www.ict-ageing.eu/countryprofiles/germany)):

- BKK Company insurance Taunus (Betriebskrankenkasse BKK Taunus) in cooperation with PHTS (Personal HealthCare Telemedicine Services GmbH) Telemedicine provides home monitoring for patients with chronic heart conditions and diabetes. The services were tested in several Federal States and are now offered nation-wide to all members of the Taunus BKK. The BKK Taunus is however a rather small health insurance.
- PHTS, which is one of the main service providers, also co-operates with the IKK (Guild insurance) health insurance and several other health care insurances. Cooperation with the IKK health insurance, for example, was already taking place from 2004.
- The programme Corbene aims to improve care for people suffering from heart failure. People who are insured within the BKK North Rhine (company insurance BKK North



Rhine) can participate in the Corbene programme which, amongst others, includes telemonitoring of patients and also provides a mobile alarm with location functionality.

- Techniker health insurance, together with a health service company (Dr. Hein) offering several solutions (e.g., telemedicine), provides video-based therapy for Parkinson patients in several regions.

As patients leave hospitals earlier than previously – due to corresponding financial incentives for hospitals – many care tasks requiring technical support have to be performed at the patients' homes. More and more technical devices must be understood and operated – a task informal caregivers often cannot manage at this early stage of care. In such cases, hospitals, hospital associations, and commercial providers offer home care services. A list of ongoing projects and trials which focus either on fundamental research or on application research can be found at: [www.ict.eu/countryprofiles/germany/hometelehealth](http://www.ict.eu/countryprofiles/germany/hometelehealth).

Another important aspect of the implementation of ICT in domiciliary care is the fact that due to the segregation of health insurance and Long-Term Care Insurance, the combination of telecare and home telehealth is hindered. *ICT & Ageing* lists only two trials for Germany (see [www.ict.eu/countryprofiles/germany/hometelehealth](http://www.ict.eu/countryprofiles/germany/hometelehealth)):

- TeleMom. *'Homecare platform for secure and interoperable exchange of patient data with the objective of enabling effective telecare services at home. The project makes use of wireless connections for a number of monitoring systems.'*
- Assisted Living. *'Systems using assisted-living components at four locations in Rhineland-Palatinate. Within the project new age-friendly buildings are designed from scratch or existing buildings are refitted with devices which provide observation of vitality data and personally-tailored alarm features.'*

#### d) Smart homes

In Germany, we have not found wide use of 'smart homes' so far. Most settings and demonstration sites are experimental. Interestingly, there has been a switch in this domain from 'everything that is technically possible' to more emphasis on the integration of the needs and necessities of older people. Out of the whole range of examples, we would like to mention just two which are already working with this focus on the needs of older people as the target group:

- *OFFIS apartment* for older people (ideAAL; for further details see [www.ideAAL.de](http://www.ideAAL.de)) is a 2-room-apartment of 48 square metres with kitchen and bathroom, where every day life can be simulated. The integrated technology is based on the experience of interdisciplinary scientific research with a focus on the user. The apartment is open for specialists.
- Another example working in this area is *inHaus* – Innovative Centre for Intelligent Room and Building System (for details see [www.inhaus-zentrum.de](http://www.inhaus-zentrum.de)). Operated by the Fraunhofer Gesellschaft, it integrates interdisciplinary science experiences as well.

For further information, we refer to the *ICT & Ageing* report, which contains an overview of the existing research labs and demonstration homes (see [www.ict.eu/countryprofiles/germany/hometelehealth](http://www.ict.eu/countryprofiles/germany/hometelehealth) or – for more details – the internet pages available for each lab or demonstration home).

As we found the claim for integration in many sources of the desk research, we pursued this approach further in the course of the second phase of this study and carried out in-depth



interviews with appropriate people involved in two initiatives – the *SOPHIA Franken Care Service* and the Senior Centre '*Viertes Viertel*' Güstrow (see Boxes 6 and 7 in Section 4.4).

## **4.2 Barriers to the Deployment of Assistive Technology (AT) and ICT<sup>9</sup>**

For a better understanding of the situation of AT and ICT in domiciliary care of older people, we would like to give a brief overview of the main barriers and the reimbursement situation in Germany. Even when the following explanations refer to *all* those people in Germany who are ill or in need of care, regardless of age, it is far more likely that old people and their caregivers are concerned and have to deal with these guidelines.

The main objective of Germany's care policy is to maintain the independence of old people as long as possible. With the establishment of the Social Long-term Care Insurance, home care has been further encouraged. Surprisingly, technology does not play a major role yet. Moreover, there are several barriers to the deployment of AT and ICT.

### **4.2.1 Barriers for professional caregivers**

The most important barriers for *professional caregivers* (care services and care workers) are:

- The rather traditional structure of home care services in Germany;
- Lack of necessary infrastructure, lack of clear responsibilities, lack of budget to build this infrastructure.
- Uncertainty concerning the right use of technology, particularly by those care services which cannot take part in building their own infrastructure (e.g., due to restricted financial resources) and hence rely on the technologies available on the market;
- The incompatibility between the different systems due to the lack of collaboration between the different device manufacturers and, as a result, the incompatibility between care providers with different solutions.

### **4.2.2 Barriers for care recipients and carers**

The most important barriers for people in need of care and informal caregivers are:

- Lack of interest and demand due to lack of information (Who can get reimbursement? Under what circumstances are technical devices reimbursable? Which devices are suited for my specific case?).
- Reluctance to pay for medical support. In previous years, people in Germany did not need to pay for medical care and a range of assistive devices, and are therefore not used to investing their own money. This is changing, as people are now obliged to pay a share for many medications and services.
- Fear of being responsible for costs in case of false alarm.
- Fear of admitting the need of care or help. Associated with this is the fear of having to move to institutional care or to hospital soon.

The statements of the experts interviewed (depicted in Chapter 4) confirmed the barriers listed above for caregivers and care recipients.

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<sup>9</sup> The following sections combine information from specific journals for professionals in care like 'Pflege Aktuell', 'Altenheim', 'Sozialstation' as well as information drawn from the study 'ICT & Ageing. European Study on Users, Markets and Technologies' (empirica & wrs, 2008a).

When we try to figure out how the use and meaning of ICT in older age will develop in the future, we have to include the experiences people have already had with new technologies and ICT in general. With birth cohorts getting more and more used to computers and internet in their jobs as well as at home, it is very likely that ICT will also get more and more common in care within the next decades. Based on the desk research, we assume that people in need of care will then use at least mainstream ICT to ease the burden of their situation and to organise care for themselves or for their older relatives.

#### **4.2.3 Legal, structural and economic barriers: reimbursement procedures**

In Germany, *health insurance* pays in cases of illness and if home-care is needed only for a short period. If a person is in need of care for more than six months, the *Long-term Care Insurance* is responsible. The payment is not income-related, and is based on the three levels of need of care (for details, see again Chapter 2, Box 1).

Within the Long-term Care Insurance, every device to be used in care (regardless of the status of the caregiver) which is reimbursable is listed in a catalogue (Hilfsmittelverzeichnis). Typically, people have to pay 10% (max. € 25) for each device.

The costs for technical devices (i.e. a social alarm) will be reimbursed:

- If the person in need of this device is in need of care corresponding to one of the three levels. If the person in need of care is receiving a cash payment and the reimbursement (e.g., for a social alarm service) is rejected, the cash payment can be used for this service;
- if, in an emergency, the person would otherwise not be able to call for help (e.g. via telephone) – regardless of whether the person who needs the device is ‘in need of care’ corresponding to one of the three levels or not.

For telecare devices and services people in need have to pay privately. As already mentioned, the cash payment can be used for telecare – but telecare has not developed much in Germany up until now and this money would not then be available for paying the respective nursing staff.

#### **4.2.4 Tendencies supporting the deployment of ICT**

Beside the barriers to more use of ICT in domiciliary care, there are also some possible drivers. Considering the demographic development and the restricted funds for the Long-term Care Insurance, the possibility of using technical devices to support older people in need of care is becoming more and more important. This is underlined by new large-scale research projects launched by the government (for details, see Section 4.3).

Developments in the care market (increasing numbers of people in need of care and of families in need of support, decreasing numbers of employees in care) will influence the demand for technical devices further. The possibility of reimbursement by the Long-term Care Insurance – for small devices like social alarms and also for comprehensive home adaptations – will support the demand as well.

Another important aspect that might raise the interest in and encourage the use of technical devices is the widespread (emotional) barrier against accepting support and help from family members or strangers with routine tasks (e.g., measurement of blood pressure and announcement to a doctor, reminders to take medicine at a certain time each day). Older people seem to have problems admitting that they have difficulties with such minor tasks. Technical devices could help them to remain independent and give them the feeling they can still manage every day life on their own (see, for example, Garms-Homolová, 2007: 24-25).

The use of telecare or telemonitoring receives further back-up from programmes addressed to general practitioners or – launched by health insurances – for people in need of care:

- General practitioners get payments for telephone or mail contact after initial examination in their office or within certain telehealth programmes;
- Certain health insurances have implemented integrated health care/telemonitoring devices free of charge for policy holders who are suffering, for example, from heart failure, or diabetes, regardless of their age. Presumably, older people can be found more often in these programmes than younger ones.

Further endeavours to promote ICT-based solutions in home care have been taken by the Federal Ministries and governmental bodies at Federal State level. The next section deals with these programmes.

### **4.3 Initiatives and Programmes supported by the German Government**

In Germany, care policies pursue the strategy “outpatient care before inpatient care”, i.e. the intention is to enable people in need of care to live at home as long as possible. The improvement of outpatient care and the promotion and support of home carers are central German policy aims. In this context, the potential of ICT is attracting increasing attention. Recently a number of initiatives and programmes have been started which include the development, evaluation and dissemination of Assistive Technologies in order to support domestic care and healthcare at home.

#### *The Intelligent Home (Das intelligente Heim)*

As part of the programme ‘Das intelligente Heim’, launched by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ, 2008) in 2006, initiatives and projects are supported that help older people stay in their homes with innovative technologies and/or that promote the re-modelling of nursing homes. Industry, welfare organisations and commercial care providers are seen as important partners in the programme for coping with future demands in both inpatient and outpatient care. All projects should aim to maintain the independence of older people and/or people who live with (age-related) handicaps. They should support the training and re-learning of possibly lost capabilities and they should support participation of old (and handicapped) people in everyday life. Technology should support old people in need of care as well as caregivers – but it should never replace social contact.

#### *Economic Impact of Older People (Initiative “Wirtschaftsfaktor Alter”)*

Against the background of demographic change, the consumption power of the “silver economy” is of growing importance. In view of this, the Federal Ministry for Family Affairs, Senior Citizens, Woman and Youth (BMFSFJ) and the Federal Ministry of Economics and Technology (BMWi) have just launched the initiative “Economic Impact of Older People”. With this initiative, the government aims to improve the quality of life of elderly people, to identify market potential, initiate the development of new products and services, and to strengthen the consumer protection of older people (BMFSFJ & BMWi, 2008).

#### *Assistive Systems for Healthy and Independent Living in Old Age (Altersgerechte Assistenzsysteme für ein gesundes und unabhängiges Leben)*

In April 2008, the German Federal Ministry of Education and Research (BMBF) launched a research programme called ‘Altersgerechte Assistenzsysteme für ein gesundes und unabhängiges Leben’. The total funding budget of € 30 million goes to projects which

develop technologies suited to supporting older people living at home (<http://www.bmbf.de/foerderungen/12394.php>).

#### Ambient Assisted Living (AAL)

An even more ambitious programme is the national AAL research programme funded by the German Federal Ministry of Education and Research (BMBF). Germany has played an active role in planning the European “Ambient Assisted Living Joint Programme” (2008-2013) ([www.aal-europe.eu](http://www.aal-europe.eu)) and was co-founder of the AAL Association. It was also one of the first partner states, which assured binding cooperation with this programme. The BMBF is in charge of this initiative ([www.aal-deutschland.de](http://www.aal-deutschland.de)). The Federal Ministry is actively supported by VDI/VDE Innovation + Technik GmbH. The Ministry will provide 125 million Euro over three years to develop new assistive solutions to the demographic challenge (BMBF press release, 015/2009).

*“The overall objective of the programme is to enhance the quality of life of older people and strengthen the industrial base in Europe through the use of Information and Communication Technologies (ICT). The motivation of the new funding activity is in the demographic change and ageing in Europe, which implies not only challenges but also opportunities for the citizens, the social and healthcare systems as well as industry and the European market. The understanding of “Ambient Assisted Living” (AAL) is that it aims:*

- *to extend the time people can live in their preferred environment by increasing their autonomy, self-confidence and mobility;*
- *to support maintaining health and functional capability of the elderly individuals;*
- *to promote a better and healthier lifestyle for individuals at risk;*
- *to enhance the security, to prevent social isolation and to support maintaining the multifunctional network around the individual;*
- *to support carers, families and care organisations;*
- *to increase the efficiency and productivity of used resources in the ageing societies.”* ([www.aal-europe.eu](http://www.aal-europe.eu))

## **4.4 Exemplary ICT Initiatives with Relevance for Domiciliary Care**

Beside the national programmes, there are a range of initiatives and programmes supported by the Federal States. Below, we present a selection of projects that are exemplary for specific aspects in the field of domiciliary care from the many funded by the various ministries.

### **4.4.1 Environments for maintaining independent living at home**

#### GAL – Gestaltung altersgerechter Lebenswelten (Design of Environments for Ageing)

The aim of GAL, the Lower Saxony Research Network Design of Environments for Ageing – ICT for Promoting and Sustaining Quality of Life, Health and Self-sufficiency in the Second Half of Life – is:

- *“to identify, to enhance and to evaluate new techniques of information and communication technology for the design of environments for ageing (scientific aim); as well as*
- *to enable the Lower Saxony Research Institutions to participate as a leading actor in national and international research projects within this topic (research strategy).”* (<http://www.altersgerechte-lebenswelten.de>).

As the partners (OFFIS Institute for Information Technology, Brunswick Technical University, Hannover Medical School, University of Oldenburg) stress:

*“A successful introduction of “intelligent” IT based assistance systems to environments for ageing requires not only solutions for a multitude of technical challenges, but also a consistent consideration of the issues of user requirements, user acceptance, the embedding into medical and nursing care structures as well as the consideration of economic questions.”* (Eichelberg, Appell, Boll et al., 2009).

In order to realise appropriate assistance for older people, the researchers implement scenarios for new forms of living and care:

- Personal activity and household assistant;
- Monitoring of vital functions when engaging in preventive and rehabilitation sports;
- Sensor-based activity determination;
- Sensor-based fall prevention and recognition.

(For further information see <http://www.altersgerechte-lebenswelten.de>, also available in English.)

#### Centre for Living and Competence (Sarstedt).

This project involves informal caregivers. It also aims to strengthen the social environment as well as the integration of intelligent technologies to enable independent living as long as possible. The focus is on the development and differentiation of a structure including all living possibilities (from living at home and receiving care to living communities, meeting places, senior dwellings, up to institutional care) in a small provincial town. A coordinated offer of consulting and support for prevention and rehabilitation so older people can avoid needing care is implemented as well as intelligent technical devices (safety alarms etc.). The initiative promotes the engagement and initiative of all community members and the participation of relatives and neighbours ([www.daheim-sarstedt.de](http://www.daheim-sarstedt.de)).

#### **4.4.2 Environments for domiciliary health and care provision**

##### Project Association „E-Health@Home”

Concerning ICT and domestic care a new interdisciplinary research project [E-Health@Home](http://www.e-health-at-home.de) is of particular interest. In this project, the association of seven scientific and commercial partner organisations is supported and funded by the Federal Ministry of Education and Research (BMBF) over three years (9/2008 – 6/2011) with more than € 2 million.

The aim of this interdisciplinary project association is to investigate how the use of ICT applications can enable elderly people with physical or mental disabilities to live a self-determined life at home as long as possible. The basic research question is: how can the current and future technological potential be used to better and more efficiently support and care for the elderly in domestic environments?

[E-Health@home](http://www.e-health-at-home.de) identifies, develops, evaluates and if necessary supports the implementation of innovative business models with the aim to improve the self-determined life of the elderly in a private environment through innovative, technology-supported services. Technical, medical, social and economic aspects are taken into account and integrated equally. The starting points of the project are, on one hand, older people's support needs and support wishes and, on the other, the current and future potentials in the areas of telemedicine (telemonitoring, teleconsultation, telehealing) and Ambient Assisted Living (AAL). These technologies are to support life models, new approaches and services, which at the same time

raise the perceived quality of life and reduce the associated costs (macro economically as well as specifically for each individual person or family). A premise of the project is that ICT has to be embedded in the wider environment of the “regular” health and care services, and the medical and caring staff especially has to be convinced of the application of ICT. This is also the case with regard to the family carers, friends and neighbours.

Based on the evaluation of former, current and new telemedical activities and models in Germany, the project will formulate strategies for improving the acceptance and the consumer satisfaction of ICT support, and for the development of optimised and integrated application concepts and user-oriented qualification and training measures ([www.e-health-at-home.de/](http://www.e-health-at-home.de/)).

#### *The Care Service SOPHIA: Living at home safely*

SOPHIA GmbH & Co. KG ([www.sophia-tv.de](http://www.sophia-tv.de)) is a care service working as a franchise system, selling services and products directly to older people or through housing organisations. Before it became a company (in 2004), SOPHIA was supported by national and regional governments. Using ICT systems, SOPHIA works in Franconia, South Bavaria, North Rhine-Westphalia, Berlin and Hessen. SOPHIA’s experiences show that the integration of the target group of older people (in need of care) and safe, innovative technology that is affordable and easy to handle are essential for a successful development and implementation of technical devices for older people (Nunner, 2009; Zahneisen, 2009).

#### **Box 6: The SOPHIA telecare service ([www.sophia-tv.de](http://www.sophia-tv.de))**

SOPHIA is an innovative service for older people who want to stay in their houses or apartments, even if handicapped or in need of support or (health) care. SOPHIA addresses both individuals and housing organisations, which are trying to offer customer-tailored services to their older tenants.

SOPHIA offers safety and services 24 hours a day, 7 days a week. A wide range of needs are covered: emergency calls; organisation of outpatient care and assistance in finding and contracting repair services for the household, personnel for daily household tasks, escorts for visits to the doctor, or social companions, etc. Every participant has a ‘godfather’, a personal contact person who calls at least once a week to chat and to check whether something has to be done in the household or for the older people themselves. ‘Godfathers’ are volunteers. Recruitment and training of volunteers is organised by the non-profit SOPHIA foundation.

The SOPHIA telecare service uses an age-friendly phone set as well as modern technology like an emergency wristband (bracelet/watch), or screen-/TV-communication. The emergency wristband can be used as an alarm call system to be actively triggered by the participant or passively by sending a signal, for example, if the wearer is not moving, and enables the service centre’s staff to initiate adequate intervention. The screen-/TV-communication can be used to communicate with the service centre, the ‘godfather’, other users of SOPHIA or with the older users and their families (if the technical requirements are available). In addition, smoke/fire/gas detectors are available.

SOPHIA is available in six different ‘packages’ ([www.sophia-tv.de](http://www.sophia-tv.de) from 2.5.2009 / costs and conditions 2008):

- BASIS guarantees 24 hours reachability of the service centre by phone. In addition, the service centre gets in touch with the participant regularly. Household assistance or services around the house/household are mediated. The cost of this package is € 20.90 per month. Ordered services are charged extra. Technical condition: phone.
- SAFETY contains the BASIS package plus an emergency call system with an intelligent wristband. The cost of this package is € 32.80 per month. Technical condition: phone; fixed line network (analogue or ISDN).

- CONTACT contains the BASIS package and offers video communication via TV. The cost of this package is € 39.80 per month. Technical condition: broadband connection (DSL or cable) with min. 1024 bit download / 128 Kbit upload.
- COMFORT combines the packages BASIS, CONTACT and SAFETY. The cost of this package is € 49.80 per month. Technical condition: see SAFETY and CONTACT.
- FAMILY is possible, when the SOPHIA software is installed on the PCs of family members or friends. In this case, the SOPHIA user can use the videophone technology with his or her social partners. The cost of this package is € 49.80 for the first installation of the software and the first 12 months of use. After 12 months, the cost is € 19.80 per year. Technical condition: the SOPHIA user has booked SOPHIA CONTACT and the communication partner has the technical conditions described under CONTACT available.
- HOME SECURITY covers the installation of smoke-/fire detectors, water detectors, alarm systems. Users must pay extra for these services.

If the user is eligible for support under the Long-term Care Insurance scheme, the fees can be reimbursed up to € 18.36 per month.

Overall, people's experience with SOPHIA is very positive (statements made at expert interviews). Older people and their relatives feel comfortable and safe, as SOPHIA makes an independent way of life for the older person possible, even if the person has to cope with restrictions due to age or health problems. The biggest benefit is the possibility to stay in one's own home. More than 800 older people in the Franken region and about 2,000 older people across the country were served in spring 2009.

In most cases, SOPHIA first draws the attention of sons or daughters looking for help for their older relatives in need of support. The older people also welcome the basic idea of SOPHIA. Using the phone and having a 'godfather' to talk to individually is very attractive and well used. SOPHIA stands for **SO**ziale **P**ersonenbetreuung – **H**ilfen **I**m **A**lltag ('Social care for individuals – help for everyday living').

The older the participants are, the more they dissociate themselves from innovative technologies like video communication or even the emergency wristband. However, with training and support they can be convinced of the emergency call system at least. Video communication often seems to be too complicated. The management of SOPHIA Franken, one of the interview partners in this research, assumes that the packages using video communication will become more and more interesting in the (near) future, as people who have experience with this kind of technology in everyday and business life get older. He suggests that at present, these offers are on the market too early.

The SOPHIA Telecare Service was selected as a "good practice case" by the ICT & Ageing study team (empirica, wrc & forttec, 2009) because of three key points:

*"A differentiated set of service components addresses a continuum of user needs that had been identified in a demand-driven manner throughout the piloting phase; a flexible financing model enables tailoring of a "business case" towards local circumstances and the particular requirements of the actors involved; and systematically managed cooperation of professional staff and voluntary supporters at the local level enables provision of personalised support spanning across a spectrum of user needs (e.g. management of personal risks, support in daily living, social interaction)."*

(Analysis of information brochures; [www.sophia-tv.de](http://www.sophia-tv.de); empirica, wrc & forttec, 2009; expert interviews April 2009; see also Annex 3)



#### **4.4.3 Solutions related to architecture and technology**

Because of the high investment needs, it is easier to implement architectural and technological innovations in institutional care units than in private homes. The following examples focus on linking living at home and institutional care. We present them here because we think that the technologies involved in these projects would suit domiciliary care and the linking of professional and informal care.

##### *Integrated technology for more quality of life. Fürstlich Fürstenbergisches Altenpflegeheim (Nursing home Hüfingen).*

Focus: in a newly-built care unit of a nursing home situated in an old castle, automatic doors (admission check), fall detectors, 'intelligent' (adaptive) light, computers for organisation of care, networking of all departments (care, kitchen, laundry, administration) and other technical devices were installed ([www.altenpflegeheim-huefingen.de](http://www.altenpflegeheim-huefingen.de); see also Heeg & Volpp, 2008; Volpp, Mollenkopf & Heeg, 2009).

##### *Living in care. Senior Centre 'Viertes Viertel' (Güstrow).*

Focus: in the historic centre of an old town, a nursing home was supplemented with sheltered housing and a meeting place. The project aims to integrate living, care and support and also integrates individual areas and common spaces (kitchen with technical standards suitable for old people, bathroom with light and sound). A further objective is to reduce bureaucracy due to technical documentation process of all data concerning support and care and facility management, by backing up this process with technology ([www.baumodelle-bmfsfj.de/Baumodelle/33\\_Guestrow/33\\_Guestrow\\_F.html](http://www.baumodelle-bmfsfj.de/Baumodelle/33_Guestrow/33_Guestrow_F.html)).

The following description of the specific aspects of the Güstrow Senior Centre (see Box 7 below) should convey the similarity of every day life in this institution to the life people used to have before they moved to Güstrow. This similarity was one reason why we considered this project as an interesting example of using ICT for integrating several forms of living and caring. Another reason was the plan to deduce aspects for future developments in domiciliary care from the experiences in this project.

#### **Box 7: Senior Centre 'Viertes Viertel' (Güstrow)**

Güstrow is a town with 32,000 inhabitants in Mecklenburg-Vorpommern. The number of people 60+ is steadily increasing. The senior centre 'Viertes Viertel' in the historic centre of the old town, including a nursing home, sheltered housing with four units of accommodation and a community meeting place, is one of the architectural-technological solutions and an example for new, innovative ways in institutional and domiciliary care.

'Viertes Viertel' Güstrow is managed by the German Red Cross (DRK). It is supported by the Federal Ministry for Family Affairs, Senior Citizens, Woman and Youth (BMFSFJ; [www.baumodelle-bmfsfj.de/Baumodelle/33\\_Guestrow/](http://www.baumodelle-bmfsfj.de/Baumodelle/33_Guestrow/)) and is part of the Federal Ministry's programme 'Baumodelle. Altenhilfe, Behindertenhilfe' ([www.baumodelle-bmfsfj.de/Modellreihen\\_IntelligentesHeim.html](http://www.baumodelle-bmfsfj.de/Modellreihen_IntelligentesHeim.html)) with the aim of advancing:

- the planning and documentation of care;
- technology for people with dementia;
- technology-supported 'ordinary' living in old age;
- integrated architectural-technological solutions.

At the moment, 30 apartments for sheltered housing (Betreutes Wohnen) in three houses are being built. They will be ready at the end of 2009. In addition, a community building for



approx. 50 visitors will be constructed. The DRK will establish 15 places for daily care (Tagespflege) as well. The community building and the gardens and parks around all the buildings are open to the public. The goal is to create a lively multi-generational living centre in the city centre of Güstrow.

So far, Güstrow 'Viertes Viertel' has 44 inhabitants who live in four households with four 'care assistants' (Pflegepräsenzkkräfte). These employees have undergone household training, completed with special training offered in the institution itself.

The leading idea of Güstrow 'Viertes Viertel' is living together, like at home. The focus is on the human being, not on the fact that the person is in need of care. Therefore, every inhabitant can maintain the highest degree of independence and codetermination possible. The following facilities have been put in place:

- Single rooms, equipped with a special bed and a built-in wardrobe. The room offers several possibilities for technical connections to guarantee high flexibility, i.e. at least four possibilities to place the bed to ensure conditions similar and close to home. With the concept of just basic equipment (bed + wardrobe), people can bring furniture from home to create a feeling of being at home;
- The single rooms are connected to a living room and kitchen, and a dining room for all eleven inhabitants and care assistants, so that different types of contact or interaction can be satisfied, the need for contact and conversation can be fulfilled as well as the need for retreat;
- In every house unit, eleven inhabitants are supported by four care assistants present to cope with every day household activities: the inhabitants are involved in shopping, cooking, laundry – as far as they are able;
- For elderly people in need of healthcare, the institution employs 13 care workers who work like an outpatient care service and visit the people in need of care in their house units, in their respective rooms.

Touch screens are installed in every room. The employees use these touch screens for documentation as well as for communicating with each other and the management (intranet) and for communication with suppliers. This optimises procedures.

For the residents, the rooms are equipped with an intercom with different call- / question-and-answer-possibilities, with access control and smoke/fire detectors.

To make household tasks easier and safer for the older people, innovative household technology is used. For example in the kitchen, there are induction cookers and steam ovens. Even if residents were not used to using these technologies before, they get used to them with the support, training and guidance of the care assistants present.

The experience of the DRK, the management the care assistants and the professional care workers are generally positive. Due to the similarity to living at home, the satisfaction of the residents and their relatives is very high.

*(Expert interview, April 2009; see also Annex 3)*

#### **4.4.4 Designing new neighbourhoods for independent living**

For some years now, several major housing associations have made efforts to adapt their buildings – frequently extended housing units and neighbourhoods – to their older tenants. Projects dealing with architecture, technological equipment and new concepts of housing, community life and mutual support and care are associated with the idea of 'living at

home/staying independent'. A few interesting examples of up-to date projects and initiatives are presented here:

*More than living. Co-operative Living Spaces (Hoyerswerda).*

Focus: Social and architectural enhancement of an urban neighbourhood, shaping a community-orientated infrastructure, supporting independent living for people in need of care through request-oriented technology; integration of the social and living environments; consultation; service offers and inter-generational services ([www.lebensraeume-hy.de](http://www.lebensraeume-hy.de)).

*HousingProgress (WohnFortschritt) – District development through smart technologies and social services.*

This initiative shows how a local housing association tries to meet the future demands of older people living independently in their rented or owned homes. All flats are barrier-free and equipped with displays that show whether windows or doors are open or not, automatic cooker-switch off in case of smoke, fire detector networks and two-way video communication. Possible services range from support with cleaning and shopping, meals on wheels, up to therapeutic measures and qualified medical outpatient care (<http://www.dogewo21.de/>; see also Wortmeyer, 2009).

*PAUL (Personal Assistant Unit for Living): Assisted Living in Kaiserslautern*

The project entitled 'Assisted Living', established at the Technical University of Kaiserslautern, is funded jointly by the Ministry of Finances and Construction (MFB) Rhineland-Palatinate and the housing associations involved. Basic technology is PAUL, an easy-to-handle touch screen computer, with offers concerning health, safety and comfort. The aim is to maintain independent living for 'normal ageing people' in the environment of their choice. The research – conducted by urban sociologists and engineers from the Technical University of Kaiserslautern – shows different usage patterns and different degrees of integration of the technology into every day life. The longer people used the technology, the more tasks they carried out and the more offers they used (Spellerberg & Schelisch, 2009).

Not all of these initiatives take care workers and care givers from migrant backgrounds into account. However, the results could also be relevant for care givers and care-recipients from migrant backgrounds. Additionally, the initiatives should be re-focused to consider the special living conditions and needs of immigrants, as these will affect the access and utilisation of ICT to support domiciliary care and caregivers.

An example of a project that focuses on the interests and needs of people from migrant backgrounds is:

*"Active Ageing of Migrant Elders Across Europe" (AAMEE)*

The AAMEE project ([www.aamee.de](http://www.aamee.de)) is funded by the Ministry of Intergenerational Affairs, Family, Women and Integration of the State of North Rhine-Westphalia and the European Commission. The project focuses on the promotion of active ageing and social, cultural and economic integration of immigrant and ethnic minority older people, emphasising volunteer activities and the emergence of new culturally-sensitive products and services in the fields of, for instance, housing, care, education, leisure, culture and marketing. In this project, a mixture of practical and scientific activities and a variety of approaches such as conferences and exchange programmes are used. As part of this initiative, the First European Conference on Active Ageing of Migrant Elders in Europe was organised in October 2008, which led to the formulation of some recommendations concerning ICT, which are also relevant for the field of home care: *"Information and Communication technologies (ICT) must better meet the*

*needs of migrant elders. The European Commission is asked to support a special programme to consider the needs of migrant elders in terms of information and communication services. New media enable migrant elders to stay in touch with their families throughout Europe. ICT services can also support independent living at home and must be accessible and understandable.”* (MGFFI 2008).

#### **4.4.5 The German ‘Ambient Assisted Living’ Congresses 2008 and 2009**

In the context of the AAL research programme, the German Federal Ministry of Education and Research (BMBF) and VDE (Verband der Elektrotechnik, Elektronik, Informationstechnik e.V.) organised two congresses which displayed current developments and topics under discussion with respect to ambient assistive technologies.<sup>10</sup> All people involved in projects, services, new concepts, developments and business ideas concerning technical solutions for the support of older people were invited to contribute. The idea was to generate synergies by giving researchers, politicians, service providers and producers a chance to discuss the pros and cons of technology within the context of domiciliary care from different perspectives and with different experiences.

The first congress on ‘Ambient Assisted Living’ held in Berlin in 2008 presented an overview of possible and also existing technical solutions for the changing demands that will arise in the care of old people due to the changes German society will face in the coming decades. This conference – as well as the second conference held in 2009 – gave a qualified overview of the state-of-the-art in AAL in Germany.

In 2008, more than 100 presentations on the development, application and use of electronic, microelectronic and information technology in the domains of ‘health and homecare’, ‘safety and the private sphere’, ‘supply and housework’ and ‘social environment’ were given.

Many of the presented technologies or applications still were in an experimental stage. As described in *Mollenkopf* (2008), several tendencies became clear:

- *Specification* of already known and used technologies and their application in new environments. Example: surveillance and recognition of falls via sensor mats, wearable computers etc.;
- *Growing complexity* of electronics, microsystem- and information technology. Example: infrastructure like WiMac@home, projects like SOPRANO or PERSONA, which combine different information sources to take care of a person in need of care and to trigger security and intervention measures if needed.
- *Focus on home care*: Shift of (health-)care from hospital or institutional care to the home of the person needing care. Example: biosensoric, telemonitoring, tele-medicine, e-Health, u-(ubiquitous) health to support chronically ill people at home, enabling them to maintain their independent lifestyle as long as possible.
- *Growing interest from housing agencies*. Example: SmarterWohnenNRW, ‘Smart Living Manager’ for integrated living in the neighbourhood in Cohn’sches Viertel Henningsdorf – again to maintain an independent life in one’s well-known residential area and social environment (for this topic see again section 4.4.4).

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<sup>10</sup> 1. Deutscher Kongress mit Ausstellung. Technologien – Anwendungen – Management. 31.1. – 1.2.2008, Berlin. Tagungsband ‘Ambient Assisted Living’, VDE Verlag GmbH, Berlin, Offenbach, 2008. / 2. Deutscher Kongress mit Ausstellung. Technologien – Anwendungen. 27.1. – 28.1.2009, Berlin. Tagungsband ‘Ambient Assisted Living’, VDE Verlag GmbH, Berlin, Offenbach, 2009.

At the same time, it became obvious at the congress that there are still several difficulties which have to be solved:

- *Lack of standards*: Most of the technologies presented were heterogeneous single solutions. The lack of norms and standards makes it difficult to combine several interesting ideas to create individual settings for people in need of care and to support them in their own living environments.
- *Unclear responsibilities*: who is responsible for what action to support or help or even save in case of an emergency? Who is responsible if there is a false alarm or if the system breaks down?
- *No experience of everyday suitability*: Most of the technologies are tested in labs or as prototypes; 'real life experience' is rare.
- *Unclear reimbursement situation* through the Long-term Care Insurance. Lack of willingness and/or capability of people in need of care to pay privately for expensive technology.

Despite these, as yet unsolved, difficulties, the AAL-systems show the potential to maintain an independent life in old age in residential settings and social environments people are used to.

In 2009, the congress took place for the second time. Again, the goal was to achieve an overview of the state-of-the-art of AAL. The topics, ideas and perspectives were even wider than in 2008. Interesting from our point of view is the greater focus on:

- *an independent life style in one's own home* because the strengthening of the own home has direct (positive) impact on domiciliary care.
- *the perception of (old) users and the integration of their needs for development and design of technical devices* because taking into consideration the needs and wishes of potential users will increase their interest and demand.
- *access to information (i.e. internet) for (old) people* because all people involved in informal care could be provided with necessary and important health information.

#### **4.5 Main Barriers and Drivers – and the Implications for the Caregivers**

Before taking a closer look at the use and impact of ICT in domiciliary care in Chapter 5, we would like to draw some conclusions on what we have ascertained so far:

- A considerable number of actions – initiatives, programmes, projects etc. – have been undertaken in Germany, all trying to foster the development and dissemination of ICT applications from single devices to comprehensive (AAL-) systems.
- Besides other aims (as, for instance, to promote German industry), and despite the differences between the various initiatives, the main objective is always to enable older people to maintain independent lives in their own homes and familiar environments when their competences decrease and/or they need care. This includes, first of all, help for people in conducting everyday tasks, access to medical treatment and the facilitation of all kinds of communication.
- Furthermore, technical developments aim to support care workers in their professional outpatient care work (better organisation, reduction of bureaucracy, more transparency and higher quality).
- Compared to this, family carers, (migrant) household assistants and other informal care givers play – if at all – only a minor role. This is all the more surprising as the main focus in German Long-term Care Insurance is on domiciliary care and the 2008

Care Development Act aims explicitly to support informal care givers. Institutional care should be the 'last choice', the last resort when informal care givers and outpatient care workers can no longer ensure adequate support (see Section 2.1.3, Box 1).

We found barriers to more extensive and efficient deployment of AT and ICT at several levels:

- Segregation of competences among Federal Ministries;
- Segregation of responsibilities between Healthcare and Long-term Care;
- Segregated view of projects and programmes: older people needing care, on the one hand, and useful technology on the other – without considering the everyday context of domiciliary care;
- Barriers on the part of technology: lack of real life suitability and user friendliness, no compatibility of different solutions due to lack of norms and standards, no proven reliability;
- Barriers on the part of the care recipients: general lack of information, reluctance to use technology, lack of skills or competences, lack of financial resources or of willingness to purchase expensive technology;
- Barriers on the part of family carers: lack of information on available technologies, lack of time (work overload), lack of adequate products;
- Barriers on the part of outpatient care service providers and care workers: traditional structures, segregated competences and responsibilities (see above), partly reluctance to technology.

However, there are positive tendencies as well. The main drivers are ...

#### ...The ageing people themselves

The *Federal Statistical Office* estimates that the percentage of single person households in 2025 will be over 40%. In urban contexts, the percentage will be even higher. In other words, Germany will have 16.7 million single person households and 15.0 million households with two people in 2025. Households with three or more people will diminish over the years (Federal Statistical Office, Press release No.402 / 2007-10-05, [http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/EN/press/pr/2007/10/PE07\\_402\\_12421.psml](http://www.destatis.de/jetspeed/portal/cms/Sites/destatis/Internet/EN/press/pr/2007/10/PE07_402_12421.psml)). This means a high proportion of older individuals living alone who cannot rely on a caregiver sharing their home as is the case for couples, or people living with their adult children or other potential carers. However, if we look at singles in German society today, we also find a growing group of people with good social networks, who use modern, innovative ICT as an important tool for communicating (and a status symbol; Horx, 2009). These singles are experienced with telephones, mobile phones, internet, e-mail – and quite often, they are well off. Therefore, we can assume that these singles – who will be 60+ in 2025 – will be more open minded towards technology than today's older individuals.

In addition, in the near future we can generally assume a higher use of ICT in older age, due to the experience with these technologies at work, as well as in everyday life today. Technical solutions like Vitaphone, SOPHIA or the devices used in Güstrow correspond to what many adults know and use nowadays: internet platforms like Facebook, Xing and others for business and private networking, internet search machines for information, internet sites for shopping, travelling etc., internet sites and e-mail for contacting, sharing and exchanging information, pictures, or data.

With advancing age, these people will continue using ICT to organise everyday life, to guarantee access to information and to stay in touch with all people who are important to them, whether they are acting as an informal care giver or are themselves in need of care. This will also be a chance for a broader use of ICT in domiciliary care.

#### ...Housing organisations

To meet the needs of the growing group of older tenants, architects and housing organisations are increasingly trying to consider their needs. Many barrier-free apartment buildings and houses have already been adapted to changing living situations and related needs. Recently, apartments and blocks of flats, even complete neighbourhoods, have been equipped with connections for technical devices (e.g., BUS systems), flexible features and ICT-based networks which also enable older people in need of care to maintain their independence through connected service and care providers. As outlined in Section 4.3, the government is supporting several initiatives in this field of action.

#### ...Innovative business and organisation models

Services like those offered by SOPHIA or the Güstrow model, which aim to enable independent and self-determined life in old age, show that economic success and user satisfaction is achievable if the services are well adapted to the clients' needs.

In the case of SOPHIA, the main success factors are flexible financing models, tailor-made service components and the combination of professional care work, voluntary supporters for social interaction and case-oriented technical applications.

In the case of the *Güstrow* model, it is the flexible combination of and soft transition from living autonomously in one's own home, sheltered housing and, if necessary, a nursing home. The self-determined living of the inhabitants of the centre is supported by household assistance, professional healthcare workers and innovative technology. This type of organisation could be transferred to domiciliary care in general.

#### ...Reform of the German Long-term Care Insurance

The adjustment of the German Long-term Care Insurance in 2008 is suited to promoting the integration of ICT in the above mentioned kind of innovative organisation models further. People in need of care who are entitled to receive benefits from care insurance (at least care level I) can 'pool' their benefits, i.e. finance, for instance, a caregiver jointly with the total amount of their benefits. Regardless of whether these people share one household, live in independent apartments in one apartment building, or in various houses in the close neighbourhood – systems like SOPHIA, Vitaphone or technical devices like those used in Güstrow will guarantee better organisation of everyday life and – if needed – of care.

#### Implications for caregivers

Given the present conditions in Germany, caregivers – both professional care workers and informal caregivers – are faced with a fragmented, confused situation. This holds for legal regulations, organisational segregation of health and care and the access to information, consultation and benefits – and, as a result, suitable technological support.

## 5 ICT USE IN HOME CARE

This chapter provides some insights into the ways in which Information and Communications Technologies (ICT) are currently used in home care or could be used in the near future. The findings presented here are based on desk research and on the interviews conducted and analysed in Phase II of this study.

### 5.1 General Dissemination of ICT Applications

#### 5.1.1 Common (mainstream) devices

ICT is playing a more and more important role in every day life and also in care. In *professional outpatient care*, the use of devices like (mobile) phones, (different types of) computers and GPS/navigation systems are quite common. They are used for better communication between care providers and their employees to achieve better organisation of the care required. Quite often, the person in need of care is not involved in the use of these technical devices. Instead, the focus of communication lies within the care organisation.

The information provided by the BAGSO member organisations and other experts in the field of outpatient care (for details, see Annex 1: Methodology) shows the almost complete dissemination and application of modern (DECT-) telephone systems and mobile phones. Equally, e-mail is seen as an indisputable means of communication between the organisations and their members or employees and volunteers. The use of a Notebook, PDA, Blackberry or SmartPhone is still the exception and seems to be highly dependent on the individual interests and competencies of the person in charge of the service. Among those who use these appliances, the respective acceptance and appraisal is high. Advantages are seen particularly with respect to better planning and organising the care work and employment of personnel and documenting and controlling care performance and benefits. Furthermore, the people needing care and/or their family and other informal caregivers can reach the service round the clock.

Communication and networking through Internet sites seems to be usual and well accepted *among the care organisations and professionals*. They use both services provided by their umbrella organisations and professional associations (such as, e.g., [www.DiakonischesWerk.de](http://www.DiakonischesWerk.de), [caritas.de](http://caritas.de), [kfd.de](http://kfd.de), [bpa.de](http://bpa.de)) and general sites (such as, e.g., [xing.de](http://xing.de)). Concerning health and care questions, they draw on general information (such as, e.g., from [www.bmg.bund.de](http://www.bmg.bund.de), [fogera.de](http://fogera.de), [pflegewiki.de](http://pflegewiki.de) or [kda.de](http://kda.de)) and on specific information (such as, e.g., from [deutsche-alzheimer.de](http://deutsche-alzheimer.de)).

*Informal caregivers* are usually not part of a formal organisation and therefore the communication takes place mainly between the caregivers and the people in need of care or the caregivers and other informal or formal caregivers involved in the care of the person concerned. In such cases, ICT is used, for example, for staying in touch with the person needing care (social bonding), surveillance and control of the person in need of care (for example, while the caregiver is at work), contact and information exchange with doctors and other caregivers.

### **5.1.2 Assistive technical devices (AT)**

Assistive technologies (AT), comprise social alarm systems, video-monitoring, fall detectors, door monitors, bed alerts, pressure mats, smoke- and heat alarms, electronic sensors of all kinds. All these devices send or exchange information that is needed for adequate care.

Social alarm systems are a generally accepted service for people in need of care or surveillance who want to stay in their home. However, people in need of care use these less often in Germany than in other European Countries – even when a person classified as needing care is entitled to receive the basic equipment (for details, see Section 4.1).

Whereas technical devices like video-monitoring, fall detectors, door monitors, bed alerts, pressure mats, smoke- and heat alarms, and other electronic sensors are already used in institutional care, they are less common in private households with a person in need of care at the moment. However, all these devices with their (positive and negative) effects will probably become more common in in-home care in the future (and thus will concern informal caregivers more than today) because of:

- the possible reimbursement of technical devices within the German Long-term Care Insurance (see again Box 1);
- the important role the Government allocated to informal care (see again Box 1);
- the growing interest of the industry in developing technical systems for a growing ‘silver market’;
- the lower barriers against the use of technology in general, because future generations of older people will be far more used to computers and technology than ever before.

## **5.2 The Impact of ICT on People Receiving and Providing Care**

In the following, we would firstly like to highlight the effects of communication technologies and assistive devices on people in need of care, on caregivers and on the care market in general as they are discussed in scientific and professional literature. Secondly, we describe the views we could derive from the answers received from expert questionnaires and phone and personal interviews.

### **5.2.1 The view on ICT in scientific research and in specialist publications**

Scientific research like the SENTHA project (‘Everyday Technologies for Senior Households’; Mollenkopf et al., 2000) shows that older people perceive technologies as helpful and useful only if these technologies can be inserted without major changes in every day life and if these technologies serve a certain purpose, i.e. support the maintenance of an independent lifestyle (Mollenkopf, 2003).

Experts in the domain of care discuss the effects of technology and ICT on people in need of care and on caregivers. The following sections refer to contributions in specialist journals for care personnel like ‘Pflege Aktuell’, ‘Altenheim’ and ‘Forum Sozialstation’ and to publications which deal with whether and how caregivers and caretakers are concerned (e.g., Gronemeyer, 2005; Garms-Homolová, 2007; Gogl, 2006; Heeg & Volpp, 2008).

In the cases where *people in need of care* use certain ICT or deal with the possibility of integrating ICT into their every day lives, they seem to deduce clear advantages from these technologies. Major advantages for people in need of care are seen in:

- the maintenance of the ability to cope at home;
- less dependence on caregivers;



- more flexibility concerning support (getting support only when needed).

The positive effects on people in need of care are:

- more self-confidence (in sense of ‘I still can do!’, ‘I’m still able to cope at home’);
- the feeling of ‘being safe’ if there is an emergency.

Even when considering the advantages, technology and ICT in care cause fear as well. Possible negative effects on people in need of care are seen in:

- the loss of privacy (i.e. through surveillance with video cameras);
- the possible loss of social contacts due to the replacement of people through technology;
- the feeling of being dependent on technology;
- the worry about not being able to learn or to know how to handle the device.

The effects on *people giving care* somehow reflect the attitudes of the people in need of care (and vice-versa). The advantages for caregivers are:

- more efficiency and flexibility due to a) the availability via ICT of people in need of care and (for professionals) of the organisation and b) the fact that care is given when needed and not due to a fixed time-schedule;
- more capacity for other or new services due to the fact that technology can take over routine and/or surveillance tasks.

The positive effects for *informal caregivers* are:

- reduction in the time they have to be present and thus an increase in their leisure time
- reduction of responsibility and ‘stand-by-time’ for an emergency;
- delegation of responsibility (in the sense of ‘I have to be present’) to technology;
- reduction of control and authority over the person in need of care – often seen as negative and straining.

The positive effects for *professional caregivers*, in particular, are:

- change of job content and, associated with this aspect, higher (job) satisfaction due to the delegation of routine tasks and/or surveillance to technical devices.

An aspect to worry about *for professional and informal caregivers* may be the possible complexity and difficulty of learning and handling the technology.

For *professional caregivers*, a new level of control through the organisation could be another possible negative effect of ICT – resulting in less self-determined time to spend with the people in need of care. For example, conversation and socialising might no longer be possible – an important aspect for people in need of care and often a contribution to the job satisfaction of professional caregivers.

*To sum up the desk research* on the role of ICT in home care: experts in care and scientists seem to be highly aware of the positive and also the negative effects of ICT in home care. There seems to be agreement that people involved in care will increasingly have to deal with ICT and other technologies in the future. The desk research also showed that – because many technologies are still at pilot project level – information about use and experience in everyday life situations seem to be sparse.

In the next section, we compare these findings with the views of the experts we consulted.

## **5.2.2 The view on ICT derived from expert questionnaires and interviews with professionals in outpatient care**

This section draws on the responses we received through questionnaires sent to member organisations of BAGSO e.V. and other experts in the field of outpatient care; complementary face-to-face or phone interviews with selected respondents (mainly leaders of old people's associations, outpatient care services of non-statutory welfare organisations and private outpatient care services); and additional expert interviews.

### **5.2.2.1 How ICT applications affect those receiving and providing care**

In order to receive information on the possible impact of ICT on the people needing and receiving care on the one hand, and on those providing care on the other, we asked the following questions, as part of the questionnaires and in the course of the in-depth interviews with experts in the field of outpatient care:

What is your experience?

- Has the application of ICT been more likely to improve or aggravate the conditions of domiciliary care among people in need of help or care or among family members of people in need of help or care?
- How did the people needing help or care and their family members react to ICT interventions?
- Has the implementation of ICT contributed to more social contact among people in need of help or care?
- Has the implementation of ICT contributed to more safety and security among people in need of help or care and their relatives?

To investigate how the use of ICT is mediated by carers and care workers, the following questions were posed:

- Has the application of ICT been more likely to improve or worsen the work conditions in domiciliary care in general / in particular for informal caregivers / for professional care workers and care assistants / for care workers from migrant backgrounds / for migrant care workers?
- How did the informal caregivers / professional care workers and care assistants / care workers from migrant backgrounds and migrant care workers react to ICT introduction?
- Has the deployment of ICT contributed to more (or less) social contact among informal caregivers / professional care workers and care assistants / care workers from migrant backgrounds and migrant care workers?

### *Effects on the quality of domiciliary care by ICT*

Actors involved in the management and in the practical work of outpatient care predominantly state that the application of *ICT improves the conditions of domiciliary care* in general and of the people needing help or care, their families, informal caregivers and professional care workers in particular. The reasons are attributed to the technologies themselves (more, better and more reliable ICT available); to improved organisation and documentation of care (see again Section 4.1); more independence for informal caregivers and professional care workers; faster information and communication between all actors involved; and more transparency and accessibility of information.

Some *concerns* relate to very old people who have difficulties accepting and handling modern technologies, to the slow-moving achievements regarding the willingness of care personnel to

use new technologies, and the frequently ignored ethical questions connected with care. Another concern is that ICT might raise too high or wrong expectations that cannot be fulfilled.

A clear improvement is ascribed to ICT with regard to *safety and security*. Mobile or service phones and safety alarm systems, in particular, contribute to reassuring people in need of care and their family caregivers alike. “*They have become vitally necessary*,” an expert said. Less frequent, but also mentioned in this respect were health monitoring after a heart attack, sensor-based fall prevention and recognition, movement detectors for lightning and GPS.

#### Reactions when introducing ICT

Experiences with acceptance of and reactions to the introduction of ICT are less uniform. Answers range from ‘in general positive’ to ‘half-half’ and ‘in general sceptical’. According to the experts’ statements, the latter holds especially true for the care recipients, and also for family carers. They emphasised that the systems are often not accessible and affordable for the potential users, that people feel uncertain about them and, again, that many old people are not used or not able to use new ICT. Even the experts who report positive experiences qualify this statement by saying that the implementation of technology has to be accompanied by substantial consultation and training and by further services for housekeeping, emergencies, technical help or company.

As for *informal (family) caregivers*, there seem to be great differences. Some accept technical appliances gradually when they realise the improvements connected with their implementation. For others, an outpatient service seems to increase in value (compared to other service providers) if it provides the latest technologies.

*Professional care workers and care assistants* seem to accept ICT more readily, albeit with initial scepticism. Experts stress that substantial time and effort has to be invested to convince and train care workers.

#### More social contact through ICT?

Opinions are not unanimous about ICT communication potential either. A considerable share of experts states that service phones, websites, e-mail, safety alarm systems, call centres and video conferences have contributed to more and better communication among the people in need of care and their relatives, informal caregivers, professional care workers, friends, doctors etc. On the other hand, some experts clearly say that this is not the case or that they cannot judge it. Answers related to *professional care workers and care assistants* show a similarly diverging pattern. On the one hand, the experts stress the positive aspects associated with the use of ICT: fast, relevant and direct communication between all people involved; easy exchange of information; simplified planning of one’s rounds; and the possibility to be reached or to get in touch round the clock. On the other hand, these benefits do not always materialise and ICT can even be seen as a pressure and/or a means of control.

#### **5.2.2.2 Training of care assistants and care workers in the use of relevant technologies**

All the experts state that their organisations are providing training to their employees or members (regardless of their German or migrant backgrounds) in the use of technologies when they are introduced. Some of them just explain the functioning of a mobile phone or of new software such as, e.g., MediFox (care management software; [www.medifox.de](http://www.medifox.de)). For others – mostly large regional care services with several branches, numerous staff and advanced technologies – training includes consultation, explanation, trying out, instruction,

evaluation and inclusion of practical experiences. These organisations also offer training for caring family members.

With regard to dealing with the technologies, the experts found no differences worth mentioning between native care workers and care assistants compared to employees from migrant backgrounds. In their opinion, this is more a question of personality and of general interest in technology than of cultural background.

#### **5.2.2.3 Future opportunities for using ICT and the potential for development**

The experts' opinion on the potential of ICT for supporting domiciliary care is generally positive. Even today, ICT improves and speeds up communication and information among all the people involved. It conveys a feeling of safety and security to the people in need of care, their caring relatives and the care workers and/or care assistants in charge of older people's care. Similarly, where care workers and other informal caregivers (like migrant care workers or other 'household assistants') work as complementary support in a care recipient's household (which is often the case; see Neuhaus, Isfort & Weidner, 2009), ICT is suited to fostering the cooperation between them, thus enabling older people in need of care to stay longer independently in their homes.

*Future opportunities* for the deployment of ICT in home care are envisaged concerning:

- *older people in need of care*: environmental control systems to cope with everyday demands;
- *communication between older people in need of care and their families and/or other informal and professional caregivers, doctors, physiotherapists etc* : direct visual and auditive contacts (video-phone, skype, etc.) at reasonable costs;
- *exchange of information and data related to the care case*: standardised input of and access to data for all authorised actors, bridging at the same time the gap between health and care sectors (electronic care file, electronic health card);
- *outpatient care organisations and their staff (care workers and care assistants)*: transparency, quality control, easier documentation and efficient organisation.

Again, experts found no differences between native care workers and household assistants compared to staff from migrant backgrounds.

The general *preconditions* for developing the potential of ICT to the full are, however:

- user friendly design, barrier-free, accessible, affordable and reliable technologies;
- intensified training of potential users and further vocational training of outpatient care staff;
- accessible, objective information and advice, independent of manufacturers, traders, care providers and financial or funding authorities;
- turning away from technology-driven research towards needs- and user-driven research and developing a better understanding of the context and circumstances of caregiving in domestic settings;
- public campaigns for increasing awareness of the consequences of demographic change, the shortage of care personnel and the needs and burdens of home care on the one hand, and the available technologies and potential benefits of their implementation on the other;
- collaboration between all stakeholders in the field of domiciliary care.

Important *additional conditions* for ICT use by caregivers from migrant backgrounds are:

- developing and providing comprehensive training material with explanations in both German and native languages, if possible supported by pictures or videos;
- systematising the bulk of information available on the internet about health, specific illnesses and other medical issues.

As a result of their knowledge of the living and working circumstances of migrant care and/or household assistants, the experts discern *future opportunities* of ICT applications for:

- *migrant care and/or household assistants*: supporting direct and easy communication and information between migrant care assistants, the care recipients, their relatives and possibly professional care workers.

In this case, a particular *additional precondition* is:

- user-friendly design – for instance handling via icons, independent of language skills.

Considering all these conditions might well foster the deployment of ICT to improve the complex and difficult circumstances of people in need of care, their family caregivers, professional care workers and care assistants and also informal caregivers and (migrant) household assistants to avoid transfer to a nursing home.

### **5.2.3 ICT use by informal caregivers with particular attention to migrant care workers**

Only little is known about how ICT might support informal caregivers with their caring tasks and how technology could enhance their social integration. This holds for both German native family carers and family caregivers from migrant backgrounds, and even more so for migrants who are illegally employed as home carers and/or household assistants. To narrow this knowledge gap, we carried out a few personal interviews with the most typical cases of informal caregivers in Germany, that is: family caregivers with and without migrant backgrounds and migrant care assistants from Eastern European countries. We draw additional information from the statements made in the interviews with outpatient care providers and experts who have insight into the situation of care households and from a study carried out by *Deutsches Institut für angewandte Pflegeforschung* (Neuhaus, Isfort & Weidner, 2009).

The interviewed people involved in domiciliary care are four migrant care assistants (a Romanian and three Polish women) and two family caregivers (a daughter and a daughter in law), one of them of German origin and one from a migrant background (a second generation of Turkish immigrant). As the personal and/or family relationships with the person in need of care and the different reasons for taking on the responsibility of caring can influence the role ascribed to ICT, we differentiate in the following between family caregivers and migrant caregivers without family relationship with the person in need of care.

#### **5.2.3.1 Family caregivers' use and views on ICT applications**

For family caregivers, it is natural to take care of their relatives in need of care. They either assume this role through a slow process or are prompted by a sudden event, caused for instance by an operation or an accident of their relative. Regardless of how these situations emerge, family carers tend to cope with demands and strains the moment they occur or look for information and support the moment it is needed.

Family caregivers' readiness to take on care tasks is clearly based on the social bonds and feelings of responsibility related to the person in need of care. Concerning the introduction of ICT, the preferences, needs and competences of the person cared for are consequently at least

as important to them as their own needs and competences in this field of action. Thus, family caregivers tend to assess ICT from the point of view of the person in need of care. They either know that their relatives do not (like to) adopt unfamiliar technology or they do not have the time or competence to convince or train their older relatives in new technologies. This is why family caregivers tend to focus and rely on the technologies that are present in the older relatives' households: the telephone and sometimes a mobile phone. The use of a computer and the internet is not very common for the present generation of older people in need of care. Therefore, for the organisation of care and for communication with and supervising the person in need of care, they are restricted to these already well-known technologies. In some cases, babyphones are used as 'emergency call' or in-house communication in addition to the phone. Hence, it is no surprise that family caregivers' priorities regarding ICT is to optimise these devices rather than to introduce technology that would be completely new to their older relatives in need of care.

It is not that family carers do not see the positive effects ICT could have on the people in need of care, like the feeling of 'being safe' in case of an emergency, the positive effect on self-confidence in the sense of 'I still can do' – with its positive consequences on their mental health or the reduction of feeling dependent. They can also envisage positive effects of more sophisticated ICT for themselves: first of all the possibility to meet the needs of the older person needing care (e.g., supervision, availability in case of emergency) without the need of being present all the time. Second, the possibility to delegate control and focus on the social aspect of their relationship (including a reduction of authority or of feeling responsible as a counterpart of feeling dependent on the side of the person in need of care). However, despite this positive potential, family carers seem to put more weight on the possible negative effects for the person in need of care, like loss of privacy, loss of social contacts, and/or the feeling of dependency on technology. This attitude seems to be related to the social bonds between the caregivers and caretakers.

Moreover, as family caregivers know the older people and their competences and capabilities, they assume emotional barriers as well as difficulties in handling and using innovative ICT due to the unfamiliarity with such devices. They fear a reduction of the older people's self-confidence – a result they do not want.

Where caring relatives are familiar with computers and the internet and these devices are available in their own households, they use them for communication with other relatives of the person in need of care and with medical personnel involved in the care process.

#### *Family caregivers from migrant backgrounds*

With regard to the view on ICT of family caregivers from migrant backgrounds, some special aspects have to be considered. The interview with the woman from a Turkish background caring for her mother-in-law contained some particularly interesting comments.

According to her experience, the situation of family carers from migrant backgrounds is especially stressful and associated with great burdens, because there are only sparse experiences in migrant families with caring for older relatives, mainly due to the age structure of this cohort.

On the whole, knowledge about care needs in old age and the possibilities for information and support seems to be rather low in families from migrant backgrounds. Their ignorance and uncertainty is particularly high with respect to dementia, which results in discussions and even conflicts among the caring relatives. "Nobody really knows how to cope with it and where to get information."

So far, the Turkish community and Turkish media have rarely dealt with this issue. Therefore, the caregiver interviewed emphasised the need for information and support especially in this area in order to reduce the uncertainties and to increase the readiness to take advantage of advice and support. She also suggested showing short movies on Turkish television, similar to the movies related to the Aids prevention campaign.

Moreover, although she and her family are very openminded about new technologies and although they use ICT at work and private contexts naturally, they are not informed about the potential of technical support in home care, e.g. where to get it and where to get the respective information. She very much appreciates the internet, but thinks that the available sites are too complicated, and not inviting or very informative. Information should be shaped in a more attractive way, for instance with pictures, movies and/or interviews. Listening to reports and interviews would also be helpful. Forums and chatrooms seem to be a communication platform for the younger migrants and for those with lower education.

#### **5.2.3.2 Migrant care assistants' use and views on ICT applications**

For migrant caregivers/household assistants who are not part of the family, the care they give is a job which enables them to improve their living conditions and those of their families in their home countries. Usually, they are restricted to the technical resources available in the households of the people in need of care – and they take them for granted. Moreover, they do not develop requests for ICT to support their tasks as they are used to making do with what is given. Thus, in most cases they handle the various organisational and communication-related tasks associated with their job – communication with relatives of the people cared for, with doctors, hospitals, possibly other informal caregivers, frequently with complementary outpatient care services, physiotherapists – with very limited technology.

A crucial factor hindering the deployment of ICT by migrant care workers is their own (lack of) ICT knowledge and competence on the one hand, and their employment situation on the other. In many cases, migrant care workers do not have adequate knowledge or the competence to use, for example, the internet or e-mail. In the cases where they do have the knowledge and competence to use ICT, they are not, or do not feel, in a position to suggest innovative ICT to the people they care for or to the relatives of these people.

In cases where the migrant care workers are familiar with computers and the internet and these devices are available (seldom in the households of the care recipients, but sometimes in those of the responsible relatives), these ICT are used for communication with other relatives of the person in need of care, with medical personnel involved in the care process, and/or for private communication.

Migrant care workers show two – comprehensible – differences in comparison to informal care workers from migrant backgrounds:

- They prefer to learn and use ICT in their native languages: For example, the internet as a possible source of information and support concerning the caring process would be helpful in general. However, it would be even more helpful, if information sites or specific training (e-learning) were available in their mother tongues (e.g., behaviour in case of emergency, information about health, care, cultural peculiarities and legal issues). The possibility to fall back on one's mother tongue gives more certainty in the understanding of the problems discussed and the learning content.
- They would like to improve their private communication possibilities in order to stay in touch with their family and friends at home.

The interviews with recruitment agencies revealed further clues regarding the potential of ICT for supporting migrant care workers:

- For the training of migrant care workers, training material in native languages on CD or DVD would be very helpful. Similarly, short movies for mobile phones or smart phones with MDA (model driven architecture) and SDA (smart digital assistants) features would also be suited for the purpose of short (10 to 15 minutes) training units.
- A training programme would be useful which includes the possibility for the user to insert questions and to receive corresponding answers. This should be very easy to use with respect to both the handling and the content (basic knowledge).
- In general, electronic learning programmes are seen as helpful, but as complements to learning on courses. Personal meetings and interchange are more important and better meet the needs of migrant care workers.

#### **5.2.3.3 Future opportunities for using ICT and the potential for development**

*All groups of informal caregivers* see future opportunities for ICT in home care. They expect a steady increase in ICT use for communication among the people and organisations involved in the caring process (apart from the people in need of care).

For future communication with people in need of care, informal caregivers emphasise the better and always reliable communication with well-known technologies like (mobile) phones. Due to their experiences with older people in need of care, they stress the importance of age-related design and operating instructions (e.g., large keys, easy to use). Especially in the eyes of family caregivers, this would keep the emotional barriers for older people low and increase the opportunities and chances for proper use.

For *care workers from migrant backgrounds* the availability of information and operating instructions in their mother tongue is important – at least at the beginning of their working career.

In detail, *family caregivers and migrant care workers* see future opportunities concerning:

- *communication between older people in need of care and their informal caregivers:*
  - control systems to protect people in need of care and give the informal caregivers more security in times of absence (GPS mobile phone, fall detector);
  - age-related communication devices to give older people the opportunity to communicate and stay in touch;
- *communication between informal caregivers and other people involved in the caring process:*
  - software and databases that allow information access for all people authorised at any time (electronic care file, electronic health card – also available for informal caregivers from migrant backgrounds in their native languages).

Informal caregivers believe this would enable outpatient care organisations and doctors to better organise their work, and it would save time and costs.

- *communication of informal caregivers from migrant backgrounds:*
  - All software and all information databases should be provided in native languages and should be available at any time when needed. This would give them more security in their daily work.
- *Reliable and accessible communication and control systems:*



- In general, the specific deficits of a person in need of care lead to specific requests concerning ICT. Informal caregivers with experience of dementia, for instance, are interested in GPS systems to find the person with dementia wherever he or she is.

The *preconditions* for developing the potential of ICT, identified by informal caregivers, are quite similar to those mentioned by professional care workers in outpatient care (see again Section 5.2.2.3):

- User-friendly design: barrier-free, easily accessible – ‘age-proof’;
- affordable;
- training of informal caregivers and people in need of care;
- independent, objective information and advice concerning suitable technical devices and their application;
- integration of the ‘social environment’ of the person in need of care in the consultancy process in order to find the most suitable technology for the individual case (because of different competences and capabilities of the people involved in the caring process);
- systematic, reliable and trustworthy information on the internet about health, specific illnesses and other medical issues;
- public campaigns to open up the opportunities and chances of ICT in domiciliary care to informal caregivers and older people;
- collaboration of all stakeholders in the field of domiciliary care to inform and advise informal caregivers about ICT.

The aspects listed here were mentioned by all groups of informal caregivers. In addition, informal caregivers from migrant backgrounds would generally prefer

- information or handling instructions in their mother tongue.

#### **5.2.4 Support and information for informal caregivers**

In Germany, there are various opportunities for informal caregivers to get individual support and consultation at regional and local level via ICT (e.g., Landesstelle Pflegende Angehörige in NRW [[www.lpfa-nrw.de](http://www.lpfa-nrw.de); [www.koskon.de](http://www.koskon.de)]; [www.sekis-berlin.de](http://www.sekis-berlin.de); [www.hilfe-hd.de/seniorhd.htm](http://www.hilfe-hd.de/seniorhd.htm); [www.seniorenlotse.bremen.de](http://www.seniorenlotse.bremen.de), etc.). ICT-based support, information and networks are also offered by professional (commercial) suppliers (e.g., [www.lifesensor.com](http://www.lifesensor.com); [www.sophia-tv.de](http://www.sophia-tv.de); [www.vitaphone-telecare.de](http://www.vitaphone-telecare.de)), non-statutory welfare organisations (e.g., [www.caritas-frankfurt.de](http://www.caritas-frankfurt.de)) and senior citizens’ organisations ([www.seniorenrundschau.de](http://www.seniorenrundschau.de)).

Further information is provided on specific illnesses or diseases (e.g., [www.schlaganfall-hilfe.de](http://www.schlaganfall-hilfe.de); [www.deutsche-alzheimer.de](http://www.deutsche-alzheimer.de); [www.demenz-ostfildern.de](http://www.demenz-ostfildern.de)), and another category of portals is based on initiatives of individual professionals in the field of domiciliary care (e.g., [www.pflegeberatung24.de](http://www.pflegeberatung24.de); [www.pro-pflege-selbsthilfenetzwerk.de](http://www.pro-pflege-selbsthilfenetzwerk.de) linked with [www.werner-schell.de](http://www.werner-schell.de)). However, no fundamental changes have taken place since 2001 when Germany was classified as a country without an explicit policy or initiatives for the use of ICT as an empowering tool for family carers in any policy area (Malanowski, Özçivelek & Cabrera, 2008).

In the following, we present a few examples of the various initiatives that aim to improve the circumstances of domiciliary care and to support caregivers.

#### **5.2.4.1 Association 'Wir pflegen' ('We care'; [www.wir-pflegen.net](http://www.wir-pflegen.net))**

As mentioned above, there are various opportunities for individual support and consultation for informal caregivers at regional and local level. However, until 2008 no national organisation representing the common interests of informal caregivers existed. The Association 'Wir pflegen' (We care) is the first representative of informal caregivers' interests in Germany. It is a result of the international research project EUROFAMCARE ([www.uke.uni-hamburg.de/eurofamcare](http://www.uke.uni-hamburg.de/eurofamcare)) on the situation of informal caregivers. In the context of long-term care reform, a workshop was held in October 2007, to discuss the fact that planning and discussion of changes in social law did not sufficiently take into consideration the situation of informal caregivers. In March 2008, the national association 'Wir pflegen' was founded as a registered society, and in May, the managing committee, mostly informal caregivers, started working. The most important aim of 'Wir pflegen' is to support informal caregivers, relatives and friends, give them a voice and increase their impact on the debate on social care.

In addition, 'Wir pflegen' wants to announce local and regional initiatives, emphasise their political importance, and make initiatives better known. The internet site offers news, information concerning care and a forum for exchange of experiences, discussion and mental support. According to a board member's statement, a broader information portal would be desirable and useful. However, as the association is based on voluntary work and does not receive public funding, it cannot perform such a task.

#### **5.2.4.2 Internet sites offered on regional and local level**

##### ***Example SEKIS (Self-Help Contact and Information Centre) Berlin ([www.sekis-berlin.de](http://www.sekis-berlin.de))***

SEKIS in Berlin is a centre of self-help and self-help organisations, formed by citizens of Berlin. The body responsible for SEKIS is the "Dachverband der Berliner Selbsthilfekontaktstellen selko e.V." (Governing Body of self-help contact points selko – a registered association). SEKIS is supported by the Senat of Berlin, especially by its Health- and Social Departments, the Consumer Protection Authority and by several semi-public bodies, such as Medical Insurance Plans in Berlin and Brandenburg.

The centre supports self-help groups and initiatives, people who want to commit themselves or those who are looking for specific help for their own needs, and professionals, who want to encourage and promote self-help and individual initiatives by concerned people. In the social and health domain, SEKIS is a link between lay people and professional assistants. The contact centre develops approaches for new forms of collaboration and teamwork.

The internet site serves as a contact- and information 'market' for all those in and around Berlin who try to deal with problems. The internet site is available in German, English, Polish, Turkish, French and Russian and is a good example of the kind of multi-language information source that informal caregivers from migrant backgrounds are looking for. Beyond the information about the offers and services available in Berlin, SEKIS offers a data bank system with different self-help groups. Useful addresses for informal caregivers are available as well.

##### ***'Seniorenlotse' Bremen ([www.seniorenlotse.bremen.de](http://www.seniorenlotse.bremen.de))***

This site offers information gathered by the community projects AWO Bremerhaven (Arbeiterwohlfahrt: [www.awo-bremerhaven.de](http://www.awo-bremerhaven.de)) and Bremen.online ([www.bremen.de](http://www.bremen.de)). Medical information about Alzheimer, care, leisure activities and facilities, a data bank with addresses of experts, services and public authorities are provided. People over 55 living in the area of Bremen are the main target group. The layout of the site is adjusted to this target

group, i.e. it is possible to enlarge the text easily or to navigate with tab-keys. An internet-based forum for older people and informal caregivers (relatives) complements the site.

### **5.2.4.3 Internet sites offered by professional (commercial) suppliers**

Example: LifeSensor ([www.lifesensor.com](http://www.lifesensor.com))

LifeSensor is a product of InterComponentWare AG (ICW) in Walldorf, Germany. ICW, founded in 1998, develops and sells information technology in the health sector. Like Vitaphone ([www.vitaphone-telecare.de](http://www.vitaphone-telecare.de); see again Box 5), LifeSensor uses personal computers and internet for collecting information about the health status of a person and relays this information to everyone involved in the medical treatment and care of this person. Both LifeSensor and Vitaphone are business models, offering services for a fee to be paid per month or year. Whereas Vitaphone focuses on elderly people who want to maintain their independence, LifeSensor is a tool *for everyone, regardless of their age*, based on a lifelong concept and created to accompany the member through all stages of his or her life.

Available since June 2000, LifeSensor is a web-based file containing all relevant medical data of a person or a family. The person concerned and the doctors the person is consulting continuously add to the database. The LifeSensor member chooses who is authorised to access this database: for example, professionals, informal caregivers, relatives, doctors, etc. The member can allow access to the database to further people involved in his or her healthcare and to others, i.e. partner, relatives, carer givers. Possible offers by LifeSensor are:

- health management;
- fitness management with individualised training and training documentation concepts;
- risk prevention, i.e. blood pressure check and evaluation of the relevant data;
- emergency case file, i.e. in case of emergency the medical team has access to all relevant data;
- information database in cases of needing care (for details see *LifeSensor and Care*).

Costs for the ‘start file’ are € 60 per year, for the ‘fitness file’ € 54 per year. The service centre is available Monday to Friday from 8 a.m. to 8 p.m. from the German fixed line network (for details, see [https://www.lifesensor.com/fileadmin/user\\_upload/ls\\_german/de/documents/lpk/lifesensor-icw-lpk-de.pdf](https://www.lifesensor.com/fileadmin/user_upload/ls_german/de/documents/lpk/lifesensor-icw-lpk-de.pdf)).

LifeSensor is also a tool *for care professionals* to maintain the quality and continuity of care. It helps to prevent gaps in information or care because it is possible to connect all the institutions and people involved to exchange relevant information concerning the person in need of care. Authorised professionals are able to take a look at all the information they need at any time – but are responsible for keeping the information up to date.

The advantages of this information collection for healthcare professionals are: better case history (Pflegeanamnese); relief of reception process, of transition between different carers or between domiciliary care, institutional care and/or hospital; guarantee of quality and continuity of care; reduction of gaps in care etc. LifeSensor enables care advice centres to inform and select the adequate care concept for every individual. For people in need of care and their families or other informal caregivers, LifeSensor offers the possibility of maintaining an overview of health status and care needed. LifeSensor can also be used like an electronic calendar with a reminder function for appointments, medicine etc. Access via internet enables relatives – if they are given access – to be informed at any time. All authorised people involved in care have the same information level.

#### **5.2.4.4 Internet sites of welfare organisations and senior citizens' organisations**

Example: Caritasverband Frankfurt/Main: Internet site as 'bulletin board' for informal caregivers ([www.caritas-frankfurt.de/](http://www.caritas-frankfurt.de/))

The non-statutory welfare organisation Caritas in Frankfurt offers on its internet site various materials for informal caregivers. The organisation addresses particularly family caregivers as an important group with special needs due to the immense physical and psychological strains they suffer. The offers are varied:

- a pdf 'Stress-Test' for informal caregivers, through which they can find out whether they can accomplish the care themselves or whether it would be better to look for support;
- a writers' workshop (Schreibwerkstatt) for informal caregivers to give them the opportunity to take a break doing something completely different to their duties in everyday life and, at the same time, meet other informal caregivers;
- Talking / discussion groups to exchange experiences, to learn from other informal caregivers;
- Telephone consultation. This offer financially supported by Frankfurt and can be used anonymously if necessary. The consultants indicate alternatives and give practical information concerning care. They can arrange learning and training courses and relief for informal caregivers.

#### **5.2.4.5 Internet sites provided on specific illnesses or diseases**

Example: Deutsche Alzheimer Gesellschaft (German Alzheimer Society; [www.deutsche-alzheimer.de](http://www.deutsche-alzheimer.de))

Support and help for people with dementia and their relatives, friends and neighbours is offered by the German Alzheimer Society. It focuses on how dementia or Alzheimer changes the every day life of the person concerned and their next of kin and friends; what support is given by whom and where; and which financial support is available. The German Alzheimer Society publishes brochures and – with one phone number valid for all over Germany – offers information through consultants (01803/171017 – 9 cent/minute).

The internet site offers a forum, a 'meeting point' for people who are concerned or interested. They can exchange their experiences, tips for coping in every day life, etc. It also offers a blog for people with dementia, their relatives and all people engaged in dementia or Alzheimer. This blog is an online project for self-help ([www.alzheimerblog.de](http://www.alzheimerblog.de)).

Example: Ostfildern ([www.demenz-ostfildern.de](http://www.demenz-ostfildern.de))

Since September 2007, a campaign in Ostfildern near Stuttgart has been offering an internet site with information about dementia: addresses of experts, consultants for dementia, references to events and training offers, information about and links to nursing homes and day care centres, with the possibility to book accommodation for limited periods of time in the area of Ostfildern.

'Demenzkampagne Ostfildern 2007/2008 – Wir sind Nachbarn (We are neighbours)' is based on the fact that, when the campaign started, 600 people with dementia were living in the area of Ostfildern. Ostfildern is a relatively rural area where people know each other. The local government sets great store on offering support and information. With society growing older it is expected that more people will suffer from dementia. The basic idea for the campaign is that dementia is a disease which interferes with the social life of everyone involved. The campaign aims to make every citizen aware of the condition of dementia and give everyone

the chance to be prepared to cope with people with dementia in everyday life. At the same time, the people concerned get the chance to stay in their own environment as long as possible. Back up and financial support has been donated (Erich und Liselotte Gradmann Stiftung). The Ostfildern campaign is part of a Germany-wide initiative ‘Aktion Demenz – demenzfreundliche Kommune’ ([www.aktion-demenz.de](http://www.aktion-demenz.de)).

#### **5.2.4.6 Internet sites offered by professionals in the field of domiciliary care**

*Example: Pflegeboard* ([www.pflegeboard.de](http://www.pflegeboard.de))

This internet site was created by a non-profit, independent and non-party organisation (club: Pflegeboard e.V.). The site is financed by advertising or donations given by participants in the forum or members of the club.

The internet site offers information, forum and blogs for professionals and a special forum for informal caregivers. The contributions deal with problems concerning every day life with relatives in need of care. ICT was not mentioned in the period of time we visited the forum to read the contributions open for the public (May and June 2009).

*Example: Pflegeberatung24* ([www.pflegeberatung24.de](http://www.pflegeberatung24.de))

This web forum was created by a care professional (E. Böttger-Böhlen) for professional care personnel, informal caregivers and doctors. Among others, it indicates new literature. Access is for members only. Registration as a member is free of charge.

From our point of view, the level of information on similar websites is comparatively low. Such sites appear to rely on the contributions of their members who seem to look more often for emotional support than for reliable information.

#### **5.2.4.7 Implications for informal caregivers**

The examples given mirror the great diversity of possible ICT-based sources of information and support for home care and carers. Many of the sites are perfectly suited to meeting the needs of people in need of care, of caregivers in general and of informal caregivers in particular. Authorised sites offered, for instance, by Caritas, Diakonisches Werk, the German Alzheimer Society and municipalities provide at least information on local or regional support initiatives, refer to useful addresses, inform about special health- or illness-related issues and give people the security of valid and high quality information.

In other cases, it is sometimes difficult to judge the quality, validity and seriousness of information given on internet portals. The language of private comments is often very basic or shortened. This may lower the threshold for people who just want to exchange experiences concerning their stressful situation and get emotional support. However, for *migrant care workers* these kinds of portal will not be helpful.

Another problem for family caregivers, which is even more acute for migrant caregivers, is the great variety of ways in which content is organised and presented. Moreover, each provider focusses on different information, which means that somebody looking for comprehensive information and support would have to research the internet extensively in to obtain an overview. A central national internet site containing systematically organised information, databases with key addresses and significant links does not, as yet, exist.

However, in a stressful situation, people do not want to ‘look around’ for information. What they need is centralised, qualified and easy-to-get information that shows how available services could connect to meet their needs. In the future, ‘long-term care support centres’ (Pflegestützpunkte) should be able to meet this need. Part of their work should also be to

signpost relevant internet sites, a suitable forum or chat rooms for informal caregivers. Doctors, hospital staff, domiciliary care services and care workers should equally know appropriate internet addresses and forward them to people in need of care and their caregivers.

### **5.3 Can ICT Support Migrant Care Assistants?**

Finally, we would like to directly address the question on what opportunities ICT offer for migrant care workers, in particular. We do this based on extensive expert interviews and personal (face-to-face) in-depth interviews with carers from migrant backgrounds.

As set out in Chapter 3, the living and working conditions of migrant care assistants in Germany are characterised by high legal insecurity, reduced social rights, a great variety of tasks, irregular working hours, little free time and limited social networks. They are often well educated, but not necessarily trained as nurses. According to an investigation among outpatient care providers (Neuhaus, Isfort & Weidner, 2009), in about two thirds of the households in which outpatient care is provided, the care needs are complemented by a migrant care assistant. 85% of the care providers estimate that the tasks the migrant care assistants perform are essential for avoiding the care recipient's transfer to a nursing home.

The migrant care assistants' language skills depend very much on previous learning opportunities and on the chances they are given with their employers. Most of the families (69%) regard their assistants as part of their family and support them in maintaining contact with their relatives in the home countries – for instance by providing ICT (internet, skype; Neuhaus, Isfort & Weidner, 2009: 61). Some of the migrant care assistants participating in our study were able to profit from their care work insofar as they started the training as geriatric nurse or nursing assistant as soon as they were able to legalise their stay in Germany.

ICT applications might well support migrant care assistants' tasks, meet their various needs and enhance their opportunities for information and training. Migrant care assistants themselves expressed the wish for:

- easy to understand and handle ICT applications to support their communication with all people involved in the care of the people they are responsible for;
- centralised portals where they can find trustworthy and comprehensive information on legal and health and care issues in their mother tongue;
- training programmes, also in their native languages, for improving their performance of care and for preparing and accompanying an eventual training as a geriatric nurse.

However, in view of:

- the present legal regulations;
- the widespread digital illiteracy of the present generation of older people in need of care and their holding to conventional technologies;
- the lack of time and opportunities among migrant care workers to acquire computer and internet skills; and
- the lack of adequate training material in native languages...

it seems there is a long way to go before ICT is able to unfold its potential for the benefit of migrant care assistants. On the other hand, experts in the field of home care suggest that computer-supported learning might well accompany and reinforce migrant care assistants' training but that real training courses near their work and living place, providing the opportunity to meet other people living in the same region, would contribute more to migrant care assistants' integration than remote e-learning courses.



## 6 CONCLUSIONS AND RECOMMENDATIONS

With respect to the potential of ICT, we can record that the importance of ICT in both institutional care and home care is growing steadily in Germany. Conventional technical devices like telephones, mobiles and computers have for a long time been the basic ‘tools’ to organise and handle every day care-related tasks for professional care workers. Informal caregivers and people in need of care also use the phone and mobile and are gradually beginning to use the PC to exchange information between themselves, their relatives, and other people involved in particular care cases.

Nonetheless, and despite various current initiatives, the deployment of ICT in Germany is not very advanced. Particularly in home care, the diffusion of assistive technologies has been relatively limited so far. The same holds for ICT-based information systems suited to empowering and supporting informal caregivers in general and migrant care workers in particular.

In the following sections, we summarise the main barriers and drivers for ICT in domiciliary care. We begin with general barriers and drivers in Germany and continue with the main barriers and drivers for professional care workers and informal caregivers, paying particular attention to caregivers from migrant backgrounds. Each section concludes with recommendations for policy action and support.

### 6.1 General Barriers and Drivers with Implications for Domiciliary Care

As mentioned above, telephones, mobile phones and PCs are quite common devices in institutional nursing and professional outpatient care. Informal caregivers use telephones and mobile phones as well. However, assistive technologies are more common in institutional care – although people in need of care and their caregivers could profit from the advantages these devices offer. Social alarm systems, video-monitoring, fall detectors, door monitors, bed alerts, pressure mats, smoke and heat alarms, various electronic sensors can send and/or receive information about the care recipient – without a caregiver being present. ICT for assessing and sharing information, for enhancing social relations and/or training could also relieve the strain on informal caregivers and improve the situation in home care. However, these opportunities are not used as frequently as one might expect.

The reasons for the rather limited deployment of more advanced technologies for communication, information and support are manifold. We distinguish two main categories of barriers: structural barriers including legal, organisational and financial aspects, and emotional barriers at the individual and societal levels.

#### 6.1.1 Structural barriers

The main structural barriers to broader dissemination of ICT in home care in Germany are the segregation of competences, the differentiation between the health and care sectors, the diversity of authorities in charge of care, the reimbursement conditions, the lack of centralised and systematic information and the barriers as regards housing and technology design.

##### Segregation of competences

The segregation of competences among Federal Ministries – for Family Affairs, Senior Citizens, Women and Youth, for Health, of Labour and Social Affairs, of Education and Research, of Transport, Building and Urban Affairs – is not conducive to the development of holistic ICT and care concepts and their translation into action. The German federal system

intensifies the segregation further by conceding own areas of responsibility to the Federal States. This hinders strong concerted action and results instead in numerous single initiatives and a broad range of approaches.

#### *Segregation between Health Care and Social Long-term Care*

Another barrier is the segregation of responsibilities between healthcare and long-term care. This results in confusion about competences and responsibilities and consequently in uncertainty about entitlement, reimbursement and legal possibilities for receiving both support for care and support for technological equipment.

#### *Lack of centralised and systematic information*

The segregation between responsibilities and between healthcare and long-term care leads also to a *diversity of information*. People in need of care and their next of kin are confronted with various authorities in charge: doctors, nurses, social services in hospitals, outpatient care providers, etc. Quite often, the professionals in medical and social care themselves do not have sufficient information about suitable technologies and reimbursement possibilities, or the information they have is only partial, depending on the respective professional's expertise. This is supposed to change with the new long-term care support centres. It is still questionable whether these centres will be able to provide adequate and reliable information about ICT.

Similarly, there is no centralised ICT-based information system available targeted at older people in need of care or their informal caregivers. Ministries, municipalities, non-statutory welfare organisations, commercial suppliers and many others offer numerous portals, but again it is difficult to find the information one needs in a systematic way.

#### *Financial aspects*

Furthermore, the reimbursement situation in Germany makes the diffusion of ICT-supported care difficult. Although it is possible to get some reimbursement for assistive devices within the German Long-term Care Insurance, this insurance covers devices only for people in need of care according to Grades 0 to III. Moreover, the subsidy is limited to the applications listed in the official catalogue of assistive devices.

#### *Housing stock and technology design*

One more barrier is the condition of the buildings many older people live in: these houses were often built fifty or more years ago and infrastructure like the electrical cabling is not suitable for ICT. People would have to re-construct their houses or apartments to meet the technical requirements of modern, innovative technology.

Concerning the devices themselves, the lack of everyday suitability and user friendliness of ICT, and the lack of norms and standards of the technologies are conditions that hinder the use of ICT in domiciliary care.

#### *Structural drivers*

The adaptation of the German Long-term Care Insurance to new life styles and household structures – initiated with the Long-term Care Further Development Act in 2008 – could work as a driver for ICT in domiciliary care as it promotes independent living in new forms of housing and pooling of funds.

Industry and service providers are getting more and more interested in the growing 'silver market'. Housing organisation also have an interest in older people, which can be observed in their provision of technical equipment and services for their older tenants. These initiatives



are supported by the recent research and development programmes of Federal Ministries and the ministries of some Federal States.

The further diffusion of adequate technical devices and services for the target group of older people will have a stimulating effect on people in need of care and caregivers. Once adequate services and devices are available, once more and more people have had (positive) experiences, and once advertising has spread the news about these opportunities, the interest in and use of assistive devices and ICT-supported services will grow.

### Emotional barriers

As in other fields like the production process in the industry for example, people are suspicious of a possible substitution of human resources (in this case, of personal care work and informal care giving) through technical devices. Moreover, the general discussion about surveillance and intrusion, of ethical concerns and protection of data provokes the idea of loss of personality and of control associated with some of the assistive monitoring and control technologies used in care. This scepticism about technology in general has an adverse effect on the assessment of ICT in care.

## **Box 8: General recommendations for policy action and support**

It seems to be more important than ever to bring together all the responsibilities, competences and knowledge needed for coping with the subject of ageing and care, in order to enable the growing proportions of older people to maintain an independent life even if they need care and to relieve at least some of the burden on care workers and informal caregivers. To overcome the general structural and emotional barriers, we suggest:

### Synergies

For successful implementation of ICT in domiciliary care, it is first necessary to establish overarching collaboration between all the stakeholders concerned. The recent programmes launched by the Government (presented in Chapter 4) constitute important steps towards overcoming the fragmentation of responsibilities.

### Transparency

The mechanisms of the Healthcare Insurance and the Long-term Care Insurance, the related legal regulations and the available options for support and also the reimbursement possibilities and conditions should be simplified and systematised. The respective information should be clearly laid out; published in an easily readable and accessible format; translated into the languages of the major population groups from migrant backgrounds; and disseminated via various media.

Likewise, the general information on available technologies and the potential of ICT for supporting home care must be improved. Every possibility of providing objective and reliable information should be used.

### Mainstreaming of products, universal design and business models

Industry and service providers need to make their offers more useful and suitable for everyday life— aspects that turned up repeatedly as barriers for ICT in domiciliary care. In particular, the needs of care recipients and care givers need to be better addressed; the interaction of the different actors in the care context needs to be better supported. New business models including different providers, technologies and services for the benefit of the clients are possible (as the SOPHIA telecare service showed).

### Norms and Standards

One of the main goals should be the development of norms and standards for ICT in order to ease their interoperability in domiciliary care. Steps in this direction have been taken by the VDE/VDI AAL innovation partnership ([www.ambient-assisted-living.info](http://www.ambient-assisted-living.info)) and the AALIANCE project ([www.aaliance.eu](http://www.aaliance.eu)).

### Considering emotional and ethical aspects

Justified concerns about ethical aspects, about the loss of privacy, the replacement of personal care by technology and the possibility of data misuse must be taken seriously. Appropriate measures must be put in place to avoid any misuse.

## **6.2 Main Barriers and Drivers for People in Need of Care**

### Structural barriers

The vast majority of the current cohort of older people in need of care rely on the telephone as the main communication technology in their everyday lives. They do not often use computers, which constitute the most common tool for present ICT applications. Beyond this, the knowledge about availability and benefits of innovative technology is generally scarce.

Furthermore, older people, especially when they are in need of care, often do not have the skills, financial resources and/or opportunities to purchase, learn to handle and use innovative ICT. In addition, the intention and the capability to learn something (completely) new are rather low, except for emergency call systems once these devices have become generally accepted. Against this background, it is not surprising that, for the time being, older people prefer human resources in care.

The preconditions for accepting and using ICT are even more difficult when *older people from migrant backgrounds* are concerned. They often come from an even more technology-averse cultural background and some of the very old migrants are illiterate.

### Emotional barriers

The main emotional barrier is the fact that older people do not anticipate the possibility that some day they might need support or care. Therefore, their general knowledge about the circumstances of home care and the options for support is low. In particular, many older people do not know anything about appropriate technical solutions or reimbursement possibilities in case of needing support.

This unawareness of the possibilities can also lead to diffuse fears and scepticism about technology: fears of becoming dependent on technology and of handling it wrongly. Moreover, the general concerns about ethical issues are also relevant for older people.

### Drivers

The idea of living a self-determined life in one's own home remains important when care is needed. With the increase of single-person households and – at the same time – the decrease of care personnel in the near future, technology promises a solution for this dilemma. Therefore, the development of society will be one important driver for ICT in domiciliary care.

Another driver is the fact that, in the near future, more older people will be experienced with and open minded towards ICT – due to their lifelong use of ICT for work, leisure, information

and networking. For many of them, the adaptation of ICT to the situation of being in need of care will be just a small step. However, the danger of a digital divide will remain as long as there are different levels of education, income and opportunities.

### **Box 9: Recommendations with respect to people in need of care**

#### Increasing general awareness

Public information campaigns on television and internet (spots, short movies) should be used in order to destigmatise the issues of old age, care, illness and dementia and to reduce the reservations and information deficits related to these topics.

#### Providing information and learning opportunities

The benefits of ICT – for instance, GPS for people with dementia – should be shown and explained in everyday life situations to provide knowledge about available solutions and to avoid the image of ‘something special’.

Moreover, policies are needed to support learning, as the implementation of technology has always to be accompanied by substantial consultation and training. Easily accessible opportunities should be provided at public agencies, offering at the same time advice and training. Likewise, a cautious introduction and accompanying will back up the adoption of ICT and prevent technology of getting a ‘technical ruin’.

Due to the high credibility of people of the same age and in the same living conditions, positive experiences with ICT of these groups of people should be disseminated to convince others without experience.

#### Usability and business models

An important prerequisite for accepting and using ICT is the simplicity of the appliances and their handling: the size of keys, the size of letters or labels, the installation process and using procedure should be ‘plug-and-play’. Norms and standards that allow an easy transfer of knowledge and competence from one appliance to another one would be helpful as well and are a precondition for combining different devices and systems. As mentioned before, industry and service providers need to increase the usefulness and everyday suitability of their offers.

Business models suited to combining different financial sources and providing not only technical support but also social contact, training and client-oriented help with everyday tasks should become standard.

#### Considering emotional and ethical aspects

Again, concerns about ethical aspects, the loss of privacy, the replacement of personal care by technology and the possibility of data misuse have to be taken into account. Appropriate measures must be implemented to avoid any misuse. The *Charter of Rights for People in Need of Long Term Care and Assistance* points toward this necessity.

## **6.3 Main Barriers and Drivers for Professional Care Providers**

### **6.3.1 Structural barriers**

The main barriers for outpatient care providers and professional caregivers (care workers and care assistants) are the traditional structures of home care associated with fragmented competences and responsibilities.

For both management and care workers, another barrier is permanent lack of time. For all people involved in care, time is limited and split up into small units of action. Getting information and making decisions about new technology has to be done in addition to everyday tasks of management and care. The integration of ICT solutions in daily practice and the training of the staff needs extra time and costs.

This leads to the next barrier: budget resources are tight and new technology – at first sight - is an investment with uncertain outcomes in view of the high fluctuation and frequent part-time jobs of the employees.

With regard to dealing with technologies, no differences worth mentioning were found between German care workers and care assistants and employees from migrant backgrounds.

### **6.3.2 Emotional barriers**

Care workers and care assistants seem to accept ICT after initial scepticism. Some of them, however, tend to remain reluctant to using technology, due partly to the necessary training in addition to their work duties and partly to the fear of losing their jobs and being replaced by technology. Moreover, the possible control through the organisation, less time to spend with the care recipients, lack of knowledge of ICT and general feelings of uneasiness with technology play a role.

### **6.3.3 Drivers**

Generally, the offices of professional care services are fitted with modern computer equipment. Organisation software, e-mail, telephones and mobile phones are used permanently. The use of personal computers in central offices enables the centralisation of knowledge and permanent availability of information about the people in need of care to all the people involved in a care case and fast communication between central office and employees. The advantages of ICT are recognised particularly with respect to better planning and organising care work and employment of personnel and also to documenting and controlling care performance and benefits.

The positive experiences gained in this respect are the main driver for management and staff to look for more advanced ICT solutions for improving both their work conditions and the situation of domiciliary care. Large regional care services with several branches, numerous staff and managed by young, open-minded (often male) professionals are especially interested in modernising their organisation and service.

### **Box 10: Recommendations with respect to professional caregivers**

#### Overcoming the fragmentation of the care system

For successful implementation of ICT among outpatient care providers and their staff, it is first necessary to overcome the fragmentation of responsibilities and to establish collaboration between all stakeholders concerned with domiciliary care.

#### Improving products

Also with respect to ICT implementation in professional care work, industry is called upon to increase the usability and suitability of their offers. The development of norms and standards for ICT in order to ease their interoperability in domiciliary care is an urgent need.

#### Training

Education and vocational training of professional caregivers should integrate the use of innovative ICT from the beginning to make these technologies natural working tools and material. For this purpose, adequate training material and accompanying e-learning concepts have to be developed. It is also true for care workers and care assistants that just providing ICT does not automatically ease their work or increase its quality.

For care workers and care assistants *from migrant backgrounds*, training and information should be available in their mother tongues. Cultural peculiarities need consideration as well.

#### Considering emotional and ethical aspects

Concerns about intrusion and control, about the loss of jobs due to the replacement of personal care by technology have to be seriously taken into account.

## **6.4 Main Barriers and Drivers for Family Caregivers**

### **6.4.1 Structural barriers**

#### Segregation of responsibilities and competences

Given the present conditions in Germany, informal caregivers are faced with a fragmented, confused situation. This applies to legal regulations, the organisational segregation of health and social care and the limited access to information, consultation and benefits. As a consequence, there is a lack of technological support as usually, people affected by care – people in need of care as well as their informal caregivers, relatives and friends – are unaware of the legal, organisational, medical, financial and social context of home care before they are directly concerned. When they are confronted with a situation or have to take on care tasks, lack of time and work overload hinder comprehensive information research about the potential of ICT.

Moreover, according to seniorwatch 2 data (empirica & wrs, 2008b), half of the family carers do not have access to digital information. Hence, the individual preconditions for a more extensive implementation of ICT have not been favourable until now and the digital divide may have a negative effect on the provision with suitable ICT for home care as well.

#### **6.4.2 Lack of information and support**

The lack of adequate support mechanisms and of systematic, centralised information constitutes an additional barrier. Although domiciliary care is generally seen as the ‘core’ of care and the Long-term Care Further Development Act suggests a range of important measures to improve the situation of family caregivers, there is no central policy for fostering the use of ICT as an empowering tool for family carers.

The fact that, before 2008 when the Association ‘Wir pflegen’ was founded, there was no national organisation representing the interests of informal care givers is similarly unfavourable.

#### **6.4.3 Drivers**

The necessity to stay in touch with the person in need of care and to organise care in addition to everyday tasks, and the wish to support the independent and self-determined life of an older relative in need of care are basic drivers for family carers to search for information on assistive ICT use or on ICT in care.

#### **Box 11: Recommendations with respect to family caregivers**

##### Lost in fragmentation

As for the other actors in the domain of home care, overcoming the fragmentation of responsibilities is the most urgent action needed for improving the situation of family caregivers and for seizing the opportunities ICT can offer. Informal caregivers are concerned by the diversity of actors, regulations and information.

##### Need of centralised advice and support

Policy action is needed to strengthen the rights and interests of informal caregivers in general and with regard to advice and access concerning ICT in particular. Initiatives like the national association ‘Wir pflegen’ should be encouraged and empowered. A centralised and systematised portal informing people about the potential of ICT would be equally helpful. This database should be available at all official websites provided by Federal and State ministries, municipalities and non-statutory welfare organisations.

##### Awareness campaigns, design of products, business models and training

Regarding these issues, we can repeat all the suggestions made for the actors mentioned before:

Information campaigns on television and the internet to raise awareness and acceptance of care, illness, dementia and the situation of informal caregivers; to reduce information deficits concerning these issues; and to provide information about possible solutions to problems would give people the chance to prepare for decisions they have to make. *The importance of such awareness raising is equally necessary for caregiving in families from migrant backgrounds.*

In this context, the benefits of ICT, for example, GPS for people with dementia, internet platforms for information research or for the exchange with people in similar situations, should be introduced as well.

Again, the implementation of innovative ICT has to take the technologies people are accustomed to as a starting point. Successful business models like the SOPHIA telecare service need to be shared more systematically. Training for family caregivers should include training with innovative ICT.

And finally: Concerns about ethical and emotional aspects must be taken seriously into account.

## 6.5 Main Barriers and Drivers for Migrant Care Assistants

### 6.5.1 Structural barriers

The main barriers for illegally-employed migrant care assistants and household assistants is their uncertain legal situation as regards their living and working conditions in Germany. Their situation is further aggravated by irregular working hours, manifold tasks, limited free time and the risk of isolation.

Additional thresholds for accessing and using ICT are their lack of experience with innovative ICT and language problems. Short-term work contracts and uncertainty about the duration of their stay in Germany can further reduce their interest in learning something new.

### 6.5.2 Drivers

The main driver to use ICT is the migrant care assistant's private situation – being a stranger in a foreign country and having family members who stayed in the country of origin.

A further important issue is communication with all the other people involved in the caring situation, i.e. the person in need of care, family members, outpatient care workers, doctors etc. A major task of household and/or assistants is to stay in touch. For the time being, phone and mobile phone are the first choice, because these are the technologies available in the households of older people.

Another driver for the use of ICT is the wish for more safety and security. Migrant care assistants would highly appreciate suitable emergency call systems.

#### **Box 12: Recommendations with respect to migrant caregivers**

##### Protecting illegal immigrants

Family caregivers as well as outpatient care providers consider the tasks that migrant care workers perform in home care essential for the well-being of the people in need of care. As the living and working conditions of migrant care assistants – or other household assistants – in Germany are characterised by high legal insecurity and reduced social rights, a great variety of tasks and irregular working hours, little leisure time and limited social networks, a legalisation of this societally important work is most urgently needed.

The European Parliament adopted new measures to fight illegal immigration in February 2009. The 'Sanctions Directive' lays down standard penalties and seeks to discourage clandestine working procedures, while protecting illegal immigrants ([www.europarl.europa.eu/sides/getDoc.do?pubRef=-//Text+IM-Press+20090202FCS479460+DOC+ML+VO//EN](http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//Text+IM-Press+20090202FCS479460+DOC+ML+VO//EN)). *This protection should be applied particularly to migrant care assistants.*

*All further suggestions are similar to those given before:*

##### Transparency and information

The mechanisms of the Healthcare Insurance and the Long-term Care Insurance, the related legal regulations and the available options for support and also the reimbursement possibilities and conditions should be simplified and systematised. The respective information should be available in the most common languages for caregivers from migrant backgrounds and disseminated via various media.

The general information on available technologies and the potential of ICT for supporting domiciliary care must be improved as well. Communication aids and programmes on the

Internet should specifically address people needing care and informal caregivers, enabling mother tongue exchange of experiences to extend their knowledge concerning care.

#### Improving products

With respect to ICT for supporting migrant care workers, industry is again called upon to increase the usability and suitability of their products. Instructions for ICT and technical applications should be multilingual or independent of language to meet the needs of migrant caregivers and household assistants who are not fluent in German. The development of norms and standards for ICT to ease their interoperability in domiciliary care is an urgent need.

#### Training

Multilingual courses for vocational training of migrant care workers, adequate training material and accompanying e-learning concepts have to be developed. Cultural peculiarities need consideration as well. To support social integration and societal participation, ICT-based learning must always be accompanied by personal courses. What Ala-Mutka et al. (2008) claim for older people's learning holds also for migrant care workers: In order to encourage them to participate in the information society, ICT literacy courses and formal and also informal learning opportunities are increasingly important. There is a need to bring learning opportunities closer to migrant care workers and special attention should be paid to course content. Easily accessible opportunities should be provided at public agencies, offering at the same time advice and training.

#### Considering emotional and ethical aspects

Ethical aspects, fears of failure and misunderstanding and cultural aspects have to be taken seriously into account.

## **6.6 Final Remarks**

ICT display a huge potential for enabling better quality of life for older people in need of care and supporting care workers and informal caregivers (whether they are from migrant backgrounds or not). However, some general obstacles and constraints for effective deployment of different technologies and ICT-based services have to be overcome and the special needs of different groups and actors in the field have to be considered and addressed.

First of all, the competences fragmented between different ministries, at State and Federal level, and the segregation of responsibilities between healthcare and long-term care in Germany are not conducive to the development and dissemination of advanced technologies and need to be better co-ordinated. Relatives and other informal caregivers looking for support and advice, especially when the care situation first arises or changes, are confused about competences and responsibilities and consequently uncertain about entitlements, reimbursement and legal possibilities for receiving both support for care and support for technological equipment. Additionally, the knowledge about available ICT solutions and the options they offer for supporting care workers and informal caregivers in home care is limited among professionals, informal caregivers and the people in need of care.

Therefore, the mechanisms of the Healthcare Insurance and the Long-term Care Insurance, the related legal regulations and the available options for support and also the reimbursement possibilities and conditions should be simplified and systematised. The respective information should be clearly laid out, in languages and terms that people from migrant backgrounds can also understand, and be disseminated via various media. Strategies of awareness raising and training that familiarise all the people involved with the technological options already available are needed.



More efforts to raise awareness of the situation of home care on the one hand, and the potential of ICT for supporting professional and informal caregivers on the other, could also convey a more realistic image of ICT and relieve participants of some of their fears concerning possible negative impacts. At the same time, ethical aspects and data protection are a particular challenge and must be taken seriously.

Industry and service providers are called upon to increase the usefulness and everyday suitability of their products – aspects that turned up repeatedly as barriers for ICT in domiciliary care. Agreeing on common standards for the technologies and their interoperability can pave the way for easier implementation and acceptance.

As regards informal caregivers from migrant backgrounds, the legalisation of their important contribution to society is the most urgent action. In addition, multilingual services or interfaces for vocational training, adequate training material and accompanying e-learning concepts have to be developed. To support their social integration and societal participation, ICT-based learning has to be accompanied by personal courses.

Overall, strong efforts are still needed to unfold the potential of ICT for improving the situation of all actors involved in domiciliary care in Germany.



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## ANNEX 1: METHODOLOGICAL APPROACH

In order to elaborate the study on the potential of ICT in supporting the provision of domiciliary care, with particular attention to the case of immigrant care workers and informal carers, we used a multi-methods approach:

### 1. First phase of the study

For the first task: *Background information and statistics about the ageing population, especially about the older people in need of care, and the societal/legal context of care in Germany (socio-health care system and organisation, actors, services and customers)* we used official statistical data and information material of public bodies such as e.g.,

- *Bundesministerium für Gesundheit* (BMG; Federal Ministry for Health; [www.bmg.bund.de](http://www.bmg.bund.de))
- *Federal Health Monitoring* ([www.gbe-bund.de](http://www.gbe-bund.de))
- *Sozialgesetzbuch* ([http://www.sozialgesetzbuch-bundessozialhilfegesetz.de/buch/sgb\\_xi.htm](http://www.sozialgesetzbuch-bundessozialhilfegesetz.de/buch/sgb_xi.htm))
- *Statistische Ämter des Bundes und der Länder* (Federal Statistical Office; [www.destatis.de/jetspeed/portal/cms/](http://www.destatis.de/jetspeed/portal/cms/))
- *Statistisches Amt des Bundes und der Länder* (Federal Statistical Office) (Ed.) (2008a-c), Wiesbaden
- *Bundesministerium für Familie, Senioren, Frauen und Jugend* (BMFSFJ; Federal Ministry for Family Affairs, Seniors, Women and Youth; [www.bmfsfj.de](http://www.bmfsfj.de))
- *Bundesagentur für Arbeit* (Federal Employment Agency), Zentrale Auslands- und Fachvermittlung (ZAV), Bonn (<http://www.arbeitsagentur.de/>)
- *Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege* (Federal Association of Non-statutory Welfare (BAGFW; [www.bagfw.de](http://www.bagfw.de); BFW, 2003).

Based on these resources we can provide comprehensive information on the German health care system in general and on the outpatient care sector, in particular. Similarly, recent statistics about the personnel in outpatient care services were available.

Much less is known about the informal care in domiciliary settings and especially about informal carers with migration background. Up to now, there are no official data about this important field of activities. Instead, we had to rely on expert estimations and previous projects such as *EUROFAMCARE* ('Services for Supporting Family Carers of Elderly People in Europe'; [www.uke.uni-hamburg.de/extern/eurofamcare/](http://www.uke.uni-hamburg.de/extern/eurofamcare/)). Favourably, we could also draw information from a new study carried out by *Deutsches Institut für angewandte Pflegeforschung* (dip) for the *German Caritas Organization* (Neuhaus, Isfort & Weidner, 2009) and on our own enquiries to narrow the gap between assumptions and empirically based knowledge.

### ICT initiatives to support home carers

To complement this general information and focus on the main target groups of domiciliary /outpatient socio-health care (especially elderly people and disabled people) and ICT / telehealth/telecare applications being used to support domiciliary care provision in Germany we collected all available sources of scientific literature, statistics and projects in Germany dealing with the topics ‘older people / people needing help and/or care / technical devices / assistive technologies / information and communication technologies / ICT / health care / health care personnel’. Further information was gathered through systematic search of relevant *Internet Sources and Policy papers* such as ...

- Empirica & WRC (2008):
  - ICT & Ageing. European Study on Users, Markets and Technologies (2008a; [www.ict-ageing.de](http://www.ict-ageing.de));
  - Seniorwatch 2. Assesment of the Senior Market for ICT. Progress and Developments (2008b);
- the SHARE project: Health, Ageing and Retirement in Europe ([www.share-project.org](http://www.share-project.org));
- [www.aamee.de](http://www.aamee.de), [www.mgffi.nrw.de](http://www.mgffi.nrw.de) (Ministerium für Generationen, Familien, Frauen und Integration des Landes Nordrhein-Westfalen (MGFFI));
- [www.eds-destatis.de](http://www.eds-destatis.de) (Eurostat data);
- [www.destatis.de/jetspeed/portal/cms/](http://www.destatis.de/jetspeed/portal/cms/) (data from the German Federal Statistical Office);
- the German Socio-economic Panel (SOEP; [www.diw.de/english/soepoverview/33899.html](http://www.diw.de/english/soepoverview/33899.html); [www.bildungsbericht.de](http://www.bildungsbericht.de));
- Publications of the Federal Ministry for Family Affairs, Seniors, Women and Youth (BMFSFJ; [www.bmfsfj.de](http://www.bmfsfj.de)) and the Federal Ministry for Health (BMG);
- Ambient Assisted Living: congresses 2008 and 2009 ([www.aal-kongress.de](http://www.aal-kongress.de));
- additional sources found by an intensive literature search were used as far as they provided relevant data.

We got further reliable information in the context of the expert interviews within the second phase of the study. Answers from member organisations of the Federal Association of Non-statutory Welfare, in particular (some of which are members of BAGSO), were instructive.

The analysis of publications and broadcasts concerning domiciliary care in leading newspapers and TV stations complement the statistical, scientific and policy information. Beside the collection of latest information, the focus of interest here was on the *opinion* concerning this topic *to reflect public discussion*.

- <http://ard.de> / <http://zdf.de> / <http://faz.de> / <http://zeit.de> / <http://sueddeutsche.de>.
- Apothekenzeitung
- Stuttgarter Zeitung.

## 2. Second phase of the study: Understanding ICT use in home-care

In order to get deeper insight in questions like

- How do ICT applications affect those receiving and providing care?
- How is the use of ICT mediated by carers and care workers?
- Are carers and care workers in these settings receiving any training in the use of relevant technologies?
- What are future opportunities and the potential for development using ICT?

we used a mixed quantitative / qualitative approach and

- a) implemented a mail investigation among appropriate member organisations of BAGSO,
- b) carried out telephone and personal interviews (case studies) with selected actors in the domain of outpatient care services (e.g., with the most promising respondents out of the mail interviews) and further relevant experts
- c) carried out personal interviews (case studies) with typical informal caregivers with and without migration background.

(For details on the participating experts and caregivers, see Annex 2)

For the mail interviews and the case studies with experts we developed and provided a questionnaire (for mailing – see Interim Report, Annex) as well as a topic guide for in-depth interviews via telephone. For the case studies with informal caregivers, we developed appropriate interview guidelines. These guidelines were also translated into Polish by a native speaker who also carried out the interviews with the Polish women.

With this mix of standardized questions (e.g., concerning use of and experience with technical devices used and/or provided in the organisation) and psychological in-depth interviews (e.g., concerning motivations, opinions, psychological barriers) the result is a broad insight into this topic.

### Mail experts interviews

The questionnaires for collecting information from experts in the field of outpatient care were elaborated and sent out to the BAGSO member associations. Unfortunately, the returns were rather sparse. We made another attempt in the first half of March and extended the group of contact persons to get sufficient links for expert interviews and material in order to address the next tasks of this study.

- 17 questionnaires were suited to be utilized and analyzed.

### Phone interviews with Experts

- Complementary in-depth phone interviews with appropriate persons who had answered the questionnaires (or arranged an interview with a person with more expertise)
  - BAG LSV (Association of Seniors' Representatives of the Federal States), Berlin
  - Diakonisches Werk Hessen-Nassau, Frankfurt

- SOPHIA Franken, Bamberg.
- *In-depth personal or phone interviews with persons involved in domiciliary care (management and care work)*
  - IAV Heidelberg (Information, Assistance & Mediation Centre for persons in need of care and for informal caregivers)
  - Das Pfllegeteam, Heidelberg
  - Frauen pflegen Frauen, Heidelberg
  - Nurse, working in a private care provider.
- *In-depth phone interviews with persons involved in scientific projects or special issues concerning ICT / IEM care workers*
  - Institut für Pflegewissenschaft an der Universität Bielefeld (IPW)
  - Institut für Medizin-Soziologie, University Medical Center Hamburg-Eppendorf / National Association Representing Caring Relatives' Interests 'Wir pflegen'
  - Diakonisches Werk der Badischen Landeskirche (lecturer responsible for language training for care personnel with migration background)
  - Service4Home, Institut für Arbeitswissenschaften an der Ruhr-Universität Bochum
  - Senior Centre 'Viertes Viertel' Güstrow
- *In-depth phone interviews with job agencies for care workers and household assistants with migration background*
  - Bundes-Arbeitsagentur / Zentrale Auslands- und Fachvermittlung (ZAV), Bonn (<http://www.arbeitsagentur.de/>)
  - Agency "lebenswert24"
  - Agency "Pflege24Nord".

The mail interviews and case studies with experts cover the impact of the applications and the role of people providing care in domiciliary settings from their point of view and with their background knowledge as experts. Special consideration was given to the barriers to the deployment of ICT as well as to possible drivers.

Further, the output of this part of the mail and in-depths interviews helped to focus the questionnaire (topic guide) for the personal in-depth interviews with IEM carers.

#### *Case studies on ICT use and impact in care provision and informal caregivers (with specific attention to IEM carers)*

The main focus of this part of the study was on the role of people providing care in domiciliary settings, on how far IEM carers are already using ICT applications, the impact of ICT applications on their work and whether ICT is suited to meet their integration and professional development needs.

As only little information was available and accessible, we undertook a few case studies with most typical cases of informal care in Germany to cover the topic in its width and depth.

- *In-depth personal or phone interviews with persons involved in domiciliary care (care workers and carers)*

- Two family caregivers (daughter and daughter-in-law), one of German origin and one with Turkish migration background)
- Four informal caregivers with migration background (1 Romanian, 3 Polish women).

Based on this rich and broad material we can deduce thesis for the need for action concerning the applications and the improvement of ICT, on the one hand, and the competences and the performances of IEM care workers and carers in Germany, on the other.





## ANNEX 2: OVERVIEW ON CONTRIBUTING EXPERTS AND CASE STUDIES WITH INFORMAL CAREGIVERS

### 1. Associations and organisations who answered to the mail questionnaires

<b>Seniors' Associations</b>	<b>Additional in-depth interview</b>
BAG Landesseniorenverband (LSV) e.V., Berlin	★
Bundesforum Katholische Seniorenarbeit (BFKS)	
Deutscher Bundeswehr Verband e.V.	
Deutsche Alzheimer Gesellschaft e.V., Berlin	
Deutscher Seniorenring Mannheim	
Kath. Frauengemeinschaft Deutschlands, Bundesverband	
Kreisseniiorenrat Tübingen	
Kreisseniiorenring Forchheim	
Seniorenverband BRH (Ruhestandsbeamte etc. im DBB)	
Behinderten-Gemeinschaft und Behindertenbeauftragter, Bonn	
<b>Non Statutory Welfare and private outpatient care services</b>	
Albatros e.V., Berlin	
Diakonisches Werk in Hessen-Nassau, Frankfurt	
Diakoniestation Birkenfeld	
Diakoniestation Herborn (arranged by Diakonisches Werk in Hessen-Nassau)	★
Kreiskirchliches Diakonisches Werk (KDW), Demmin	
SOPHIA Franken, Bamberg	★
Sozialstation „Raum Weinsberg“	
Stift mobil Koblenz	

### 2. In-depth phone interviews with persons involved in scientific projects or special issues concerning ICT / IEM care workers

Institut für Pflegewissenschaft Universität Bielefeld	★
National Association Representing Caring Relatives' Interests c/o Institut für Medizin-Soziologie, University Medical Center Hamburg-Eppendorf / <a href="http://www.wir-pflegen.net">www.wir-pflegen.net</a>	★
Diakonisches Werk der Evang. Kirche in Baden (lecturer responsible for language training for care personnel with migration background)	★
Senior Centre 'Viertes Viertel' Güstrow	★
Service4Home, Institut für Arbeitswissenschaften an der Ruhr-Universität Bochum	★

**3. In-depth phone interviews with job agencies for care workers, homecarers and household assistants with migration background**

Bundes-Arbeitsagentur / Zentrale Auslands- und Fachvermittlung (ZAV)	★
Agency "lebenswert24"	★
Agency "Pflege24Nord"	★

**4. In-depth personal or phone interviews with persons working in domiciliary care (management and care work)**

IAV Heidelberg (Information, Assistance, Mediation Centre for persons in need of care / for informal caregivers)	★
Das Pflorgeteam, Heidelberg	★
Frauen pflegen Frauen, Heidelberg	★
Nurse, working in domiciliary care	★

**5. In-depth personal interviews with informal caregivers**

<b>Family caregivers</b>	
Daughter, German, caregiving since 2006	★
Daughter-in-law, Turkish migration background, caregiving since 2007	★
<b>Migrant carers</b>	
Female, from Romania, caregiving in Germany since 2005	★
Female, from Poland, caregiving in Germany since 2002	★
Female, from Poland, caregiving in Germany since 2000	★
Female, from Poland, caregiving in Germany since 2002	★

## ANNEX 3: FOTOS AND DETAILS ON INTERESTING CASES

### 1. Senior Centre 'Viertes Viertel' Güstrow

The fotos show the main buiilding from the street and the rear view from the garden.



This foto shows the open kitchen and dining area of each unit.



Touch screen in every room.

Map of Senior Centre Güstrow 'Viertes Viertel' (light blue = buildings).



Ground Floor Senior Centre Güstrow 'Viertes Viertel'.



Foto source: Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) (2008). Das intelligente Heim. Ablaufoptimierung, kurze Wege, Entbürokratisierung. Bericht über das Modellprogramm. Berlin: BMFSFJ, page 54ff

## 2. The SOPHIA Telecare Service



Foto source: [www.sohia-nrw.de](http://www.sohia-nrw.de)

### Example for emergency bracelet / wrist band



**Possibility: Several emergency bracelet / wrist band users in a house community are sharing the SOPHIA service.**

Foto source: Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) (2008). Das intelligente Heim. Ablaufoptimierung, kurze Wege, Entbürokratisierung. Bericht über das Modellprogramm. Berlin: BMFSFJ, page 54ff

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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, with particular attention to the case of immigrant care workers and informal caregivers in Germany. This country study was launched by JRC-IPTS in 2008 in parallel with two complementary country studies, assessing the situation in Spain 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 Germany, 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, so as to avoid and postpone their transferral into institutional care.

This report gives an overview on the situation of domiciliary care in Germany, outlining the current use of ICT in home care and by 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 reports and scientific publications; analysis of information and service web sites; and field work involving direct questioning of experts, service providers, and a sample of carers and care workers, including immigrants.

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