

User needs in ICT Research for Independent Living, with a Focus on Health Aspects



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USER NEEDS IN ICT RESEARCH FOR INDEPENDENT LIVING, WITH A FOCUS ON HEALTH ASPECTS

**Report on a joint DG JRC/IPTS-DG INFSO workshop held in Brussels,
24 – 25 November, 2005**

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PREFACE

The Commission Communication “i2010-A European Information Society for growth and employment”¹ proposes the launch of **flagship ICT initiatives** on key social challenges. One of these initiatives concerns **caring for people in an ageing society**, and the use of technologies for wellbeing, independent living and health

As a consequence of the post-war baby boom and continuous improvement of health conditions, Europe is indeed about to face an important demographic challenge. Figures collected in various Member States and outlined in this report indicate the dimension of the situation. In summary, the dramatic increase in the number of elderly people as compared to active workers raises concerns about our European societies’ capacity to sustain our social and healthcare systems.

The financial challenge is certainly one of Europe’s major concerns. However, this should not hide the human dimension, or prevent us from questioning our societies’ ability to integrate elderly people. First of all recent changes in our ways of living, due in particular to urban development conditions, have progressively isolated elderly people. Social isolation is often increased by health conditions such as chronic diseases, the incidence of which increases with age and leads to restricted mobility. It becomes difficult for elderly people to maintain their former levels of activity, leading sometimes to them living in extremely restricted situations such as hospitals or specialised institutions.

The workshop ‘User Needs in ICT Research for Independent Living, with a Focus on Health Aspects’ aimed to better understand, on the one hand, how Information and Communication Technologies (ICT in short) can help in solving some age-related problems and, on the other hand, to identify actions which the Commission could initiate accordingly. The health and healthcare domain has been targeted because of its impact on the quality of life of the elderly and with a view to getting concrete, implementable results. Nevertheless, it should be clear that we cannot completely isolate healthcare from other social or economic fields and that we have to include, for instance, the interaction between healthcare and social care.

We are aware of the difficulty of the challenge. We are not claiming that ICT can replace the human factor, which is certainly more important than anything else in the support of elderly people. A chat with a neighbour or a nurse’s visit are important interventions which have to be maintained and even encouraged. But ICT as a tool can provide complementary support, give new opportunities, like homecare and support to mobility, and remove the social or geographic distances between elderly people and their families. It can also reinforce older people’s involvement in the community through the development of new activities, and through new ways of becoming part of human networks. By identifying the needs of elderly people, we hope that we will address more effectively the ways in which ICT can be integrated into their lives in order to provide the best possible support for their health and well being.

This workshop has given a good insight into the needs of the elderly for support to independent living through ICT from a health and healthcare perspective. The results of the workshop will be the basis for further work and initiatives. Such work and initiatives will support priorities defined in the Commission’s policy document i2010, particularly those regarding the "flagship initiative on caring for people in an ageing society".

Gérard Comyn
European Commission, DG INFSO, ICT for Health Unit

¹ “i2010- A European Information Society for growth and employment”. Communication from the Commission to the Council, the European Parliament, the European economic and social Committee and the Committee of the Regions, COM(2005)229 final

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EXECUTIVE SUMMARY

The ICT for Health Unit of the Directorate General Information Society and Media (DG INFSO) and the Institute for Prospective Technological Studies (IPTS, DG Joint Research Centre) of the European Commission organized a joint workshop on "User Needs in ICT Research for Independent Living, with a Focus on Health Aspects". The objective of the workshop was to identify and discuss the main issues, from a user's perspective, regarding ICT for Independent Living with focus on health aspects in the ageing society. This report on the workshop aims to contribute to a clearer needs-oriented focus of the Ambient Assisted Living (AAL) initiative, a 5 year R&D project involving the European Commission, the Member States and European industry.

Understanding the needs of different users is crucial for the success of Independent Living Services (ILS), as it is in all ICT application areas. Older users are not a homogenous group and their needs vary significantly according to the socio-demographic and socio-economic characteristics of the group. This report focuses on the different target groups of Independent Living Services, active older people who prevent themselves from getting diseases through 'wellness' activities; older people with slight physical and/or mental handicaps, informal carers such as relatives of the older people. Understanding the needs of other ILS user groups such as professional carers and a broader group of professionals in the health system would also be required, but this has been excluded from this study in order to better focus on older users and informal carers.

Independent Living and Goals of ILS

The World Health Organisation defines independence as the ability to perform the activities of daily life with little or no help from others (living independently). It is generally regarded as having a positive impact on quality of life. Health, impairment and functioning are important determinants of independent living. The notion of independent living services can, in very general terms, be identified as "*enabling services*". ILS are designed to assist people with chronic health conditions or disabilities to gain independence and assist communities in eliminating barriers to independence. Supportive environments can prevent the future development of disease and the resulting disabilities by making the healthy choices the obvious and easy ones.

The goals are to maximise empowerment, independence and productivity of individuals and their integration and inclusion into the mainstream of society. Keeping links to the social networks and places where older people have progressively built their lives is crucial for healthy ageing. The notion of independent living is strongly connected to the idea of "community integration", implying that people should not be subjected to disruptive institutionalised care, unless this is absolutely necessary. As regards people suffering from chronic diseases and being cared for in hospitals, it can be argued that, while hospitals aim to deliver acute treatment, in some ways they also isolate people and do not allow for community integration.

ILS User Needs

Barriers to independence are numerous. Frail physical and/or mental health, housing conditions, lack of transportation facilities, community information and communication services, and low income levels are the main ones for older people. The most common physical health barriers are low mobility levels, impairments (e.g. vision, hearing), pain, sensory loss, fall-related injuries, chronic illness and adverse drug reactions, while loneliness, dementia and cognitive impairments are the main mental health issues.

In order to understand and cluster the specific needs of the older population, detailed research has been carried out in a number of EU projects, such as SHARE (Survey of Health, Ageing and Retirement in Europe) and ESAW (European Study of Adult Well-Being²), and SeniorWatch surveys. These Surveys revealed that most of the population aged 50 and older are receiving medication for at least one long-term condition. High blood pressure and joint, bone or muscle diseases have the highest prevalence. Consequently, more than one in three senior citizens consult with a doctor more often than once a month. For all EU Member States, the 20th Century 'epidemiological transition' has brought changes in the main causes of death. Now degenerative disorders, especially cardiovascular diseases and neoplasms, increasingly take the place of infectious diseases as major causes of death.

Around 40% of people older than 50 have some degree of activity limitation due to health problems, and almost 50% report that they have some long-term health problems. Due to a substantial decline in the age-specific mortality of the oldest-old (80+) within the last 50 years, this age group has become the fastest growing age segment in most European populations. With advancing age, older people are increasingly likely to suffer from various conditions which can impair independent living, e.g. cognitive impairment, visual and hearing impairments, and frailty due to disease.

Mobility restrictions are a very significant issue among older Europeans. 10.6% of the survey population find it very difficult to walk long distances, climb stairs or get onto a train. Problems with vision are also quite frequent. Many older people (40.8%) have at least some difficulty with seeing fine details, even when using glasses.

The prevalence of cognitive impairment increases sharply with increasing age, throughout Europe. Depression is a key issue in older people's health status. Some experts have forecast that depression will be the second most burdensome condition globally, taking into account the associated disability risks and the high mortality rates associated with depression. Diseases causing dementia are closely related to old age, with prevalence doubling every five years of life beyond 65, leading to a situation where half the population over 85 suffers from these diseases. In 2002, it was estimated that 18 million people were affected worldwide, a number that is expected to rise to 34 million in 2025. Alzheimer's disease, for example, which affects memory, gestures, language, visio-spatial and organization functions, can lead to agitation or apathy, somatic complications and modification of behaviour and personality. This diversity and range of possible complications translates into a long list of Alzheimer sufferers' needs and concerns that range from security, living at home, social life, communication and mobility to cognitive assistance, nursing and medical care. Risks associated with Alzheimer patients living at home include falls, getting lost, nocturnal pacing, motor agitation and aggressiveness.

Of those older than 80 who took part in the SHARE survey, more than 56% live alone, while around 27% live as a couple. The remaining 16% live with their family, most often with one of their children, but these proportions vary across countries surveyed by SHARE (Denmark, Sweden, Austria, France, Germany, Switzerland, Belgium, Netherlands, Spain, Italy, Greece, and Israel). A higher incidence of chronic illnesses in old age means that a fifth requires regular help with the activities of daily living. Family care is the predominant model of support for older people across Europe, due not only to economic constraints and community care policies but also to socio-cultural values regarding the role of the family. The core needs of family carers consist of information, education and support. The needs for information and education centre on practical caring skills in daily life. Family carers need knowledge about their relatives' illnesses, common problems and treatment. Family carers also need to be supported in their role. Both formal support from professionals and informal support from other

family members, friends, neighbours or members of voluntary organisations are crucial for carers' well-being and also help them to carry on caring for their relative.

ILS Solutions

A wide range of existing and emerging devices for independent living can support these needs. Assistive devices from simple alarm bells to fully equipped smart rooms, telemedicine solutions and prevention of risks in daily activities through re-design of everyday tools can improve the autonomy of patients and the care they receive. With regard to monitoring activities and devising automated alarm systems, for example, R&D activities are exploring infrared rays and web, smart carpets, mattress and over-mattress pressure, magnetometers and accelerometers.

Information and Communication Technologies (ICT), in tandem with technological innovations in other fields, offer opportunities for independent living to older people (and also to those with disabilities). Generic ICT products, services and applications such as mobile telephony or e-mail and the Internet can open up many new opportunities for social, professional and political participation for people who have restricted mobility. In addition, specifically designed ICT-based assistive technologies can be of great benefit to older people who are increasingly at risk of having functional difficulties in areas such as mobility, vision, hearing and in some aspects of cognitive performance. Smart home and consumer electronic developments can make management of the home and everyday living a lot easier for older people. Healthcare technologies can help in prevention, early detection and cure, and in the management of chronic conditions.

Challenges

ILS could offer solutions but an important factor is the readiness and acceptance of older people to use ILS services. The health and social care sectors have been relatively slow in the utilization of ICT tools. ICT use in the health sector lags behind the other sectors (e.g. business, chemicals, transport) in general, making it one of the least connected sectors, with great disparities across countries. Many older people use some sort of new ICTs, but the number of users is lower than in the younger age group. A number of factors influence the perceived utility of ICT solutions. ILS, for example, are seen as less useful, when their benefits to users are not clear and when they are more complicated, difficult, inconvenient, and awkward than alternative arrangements. ILS can also be perceived as a threat to human contact, privacy or personal control. It is generally accepted that due to health professionals' mistrust or scepticism of ICT services, they often fail to inform carers of the availability of these types of services and/or they fail to support carers in their willingness to try out new ICT products and services. Clearly, not all professionals fall into this category, nevertheless, it is one the significant barriers to the take up of ILS for older people and their carers.

With regard to technologies for the ageing population the match between technologies on offer and actual user needs is viewed as far from optimal. Despite attempts of developers and manufacturers of technical devices and systems to make products as user friendly as possible, technological devices or particular features thereof could not be adequate for the needs and abilities of older people. It has been estimated that there are currently more than 20,000 assistive technology products available in Europe; however, although there is no reliable estimate of the numbers of people actually using those technologies, it is widely accepted that there are significant market and supply failures in Europe in this domain.

ILS also raise a number of ethical challenges. Widespread sharing and consolidation of patients' records by ILS providers is important to avoid duplication and medical error, and to achieve seamless care solutions. But this information exchange of what is very detailed data

about personal matters comes with serious concerns about infringing the privacy of the user. Full respect for the personal autonomy of a potential ILS user requires that they be granted the right to overrule the services and intelligent switch-off features should be built in. It also requires that the right to opt-out is respected, and that potential users should be given the choice not to use these services, if that is their wish.

The availability of fewer adult women to act as carers due to the increasing numbers of women in the workplace, and the extension of the retirement age, are two important future challenges for family care. Changing family patterns due to increasing divorce rates blur the responsibilities for caring and greater family mobility can make it unfeasible to provide care. Support is most often provided in the form of respite care services which give carers the opportunity to take a short break from their duties. A key problem is that professionals tend not to work together with carers to help them manage their situation. Relatives frequently nurse a demented patient until the strain exceeds their strength. Thus, there is an increased risk of the carers also becoming ill. Relatives providing care frequently suffer from emotional disorders with symptoms of anxiety, depression and exhaustion.

Policy Options and Future Research Needs

In order to maximise the potential of independent living services, it is expected that innovative organizational models will be needed to support their implementation. For example, closer co-ordination between all service providers and stakeholders of independent living services is essential, such as health and social services providers' coordination for early detection of risks and preventive interventions. ICTs have a central role to play in these new models of health care, since they allow the networking and sharing of citizen information among all stakeholders that underpin a more integrated care provision. These new models also allow the continuity of care, avoiding unnecessary hospitalization or intrusive surgery, minimizing the disruptive effect of healthcare interventions on patients' daily lives. However, it is also expected that these new forms of collaboration and joint service provision will come with shifts in responsibilities and a different distribution of service costs among health care providers, which will need to be encouraged with incentives. Specific research to better understand how ICTs can contribute to enable independent living through new models of (health) care would be needed.

The important role of informal carers should be recognized, and ways to support them should be devised to interlink them effectively with formal care systems. Local support services should play key roles for family carers. ICT-based support services for carers have the potential to provide flexible forms of support that meet the individual needs of carers.

Current models and solutions for care provision need to take better account of user-contexts. There is a persisting need for research into methods on how to integrate users in research and development process generally, i.e. not only the older citizens but also all other actors in the ILS area including formal and informal carers. There is significant demand for a European-wide harmonization and co-ordination of specific ILS-related measures, such as the development of common definitions and quality standards, quality certificates or trustmarks. Awareness about ILS and its opportunities is limited among potential users, professional organisations and policy makers alike. Outreach strategies that familiarize all stakeholders with technological options already available and under development are required.

Market forces alone will not ensure that the best outcomes from the intersections between ageing and ICT developments are achieved for older people and for European society as a whole. Public policy will be required that helps to shape developments in the ways that are needed to exploit the positive potential and reduce the likelihood of negative impacts. Policy makers need to pay attention to affordability and inclusion issues, in order to spread the benefits

of ILS widely and to avoid emerging ILS solutions being exclusively geared towards the needs of high-income users.

Ageing is a major challenge for European societies and active ageing with the help of ILS presents a major opportunity to harness technological progress for individual autonomy and dignity, for social inclusion and for establishing an effective and sustainable health system attuned to the challenges of the next decades.

1. BACKGROUND / INTRODUCTION

Demographic change and ageing of the population is one of the socio-economic challenges European societies have to face in the 21st century. Of all world regions, Europe has the highest proportion of population aged 65 or over; only Japan has a similar age structure. Currently about 16% of the EU15 population is aged 65 or over. According to the baseline projection of Eurostat, this percentage will almost double to more than 28% in the year 2050.³ This means there will be more than 80 million people with various needs for care by 2050. It is estimated that the cost of this care will range from 5% to 20% of GDP by 2025.

Rapid innovation in the field of Information and Communication Technologies (ICTs), in conjunction with significant advances in micro and nanotechnologies, offer tremendous opportunities to improve the functionality of everyday tools and to make the built environment more responsive to individual human needs and capabilities. Innovations in areas such as remote sensors, embedded systems, robotics or wireless mobile networks provide building blocks for intelligent ambient systems⁴ that can support citizens in a wide variety of their day-to-day activities. Examples of such systems include portable or wearable devices for health care applications, or remote sensors and alarm installations that can detect and alert us to health emergencies in the home environment.

This application area, referred to as “ICT for independent living”,⁵ or “Independent Living Services” (ILS) can be of particular relevance for citizens with special needs that result from temporary or chronic illness, disability or the impairment of physical and cognitive capabilities that often comes with old age. In short, new ICT, in tandem with technological innovations in other fields, offer great opportunities for bringing independent living in old age (and also in disability conditions) closer to reality and driving down costs in the health care sector. The goals of such ILS are to maximise empowerment, independence and productivity of individuals and their integration and inclusion into the mainstream of the society.

These opportunities have been recognized by European policy-makers. The European Commission adopted the initiative “i2010: European Information Society 2010”⁶ to foster economic opportunity and social cohesion in the information society across all European countries. i2010 is a comprehensive strategy which aims to promote an inclusive European information society with a high quality of life and excellence in public services. “Technologies for an ageing society” is one of the three “quality of life” ICT flagship initiatives in the i2010 framework. All this puts ICT-enabled independent living at the centre of a policy strategy to maintain and strengthen social inclusion and opportunities for all in an ageing European society. The recognition that health is an important factor in the realisation of independent living is directly inspired by the encompassing definition of health by the World Health

³ (as quoted in the Survey of Health, Ageing and Retirement in Europe, SHARE, 2005).

⁴ Ambient systems are those enabled by the so-called Ambient Intelligent (AmI) Technologies. AmI is a vision of the Information Society, elaborated by the Information Society Technologies Advisory Group (ISTAG) where the emphasis is on user-friendliness, efficient and distributed service support, user empowerment, and support for human interactions. ISTAG reports are available at <http://www.cordis.lu/ist/istag.htm>

⁵ “Other similar concept to ILS is “Ambient Assisted Living” (AAL). AAL Art. 169 initiative defines AAL as a concept which aims to prolong the time people can live decently in their own homes by increasing their autonomy and self-confidence. This may involve the discharge of monotonous everyday activities, or monitoring and caring for the elderly or ill person, in order to enhance their security and save resources. (<http://www.aal169.org/>).

⁶ http://europa.eu.int/information_society/europe/i2010/index_en.htm

Organization in 1946 and widely adopted since then: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.⁷

Emanating from this definition is a set of more concrete principles for active healthy living. These include maintaining the links to social networks and places that older people have built up over the years; and allowing older people to live in their preferred environment, maintaining a degree of independence, autonomy and activity while preserving their quality of life. This set of objectives should also include the improvement of the quality of healthcare in tandem with new technological opportunities, and also the strengthening of the social infrastructure for informal care. This last point is essential since technology should not be viewed as a substitute for informal care networks. These networks play a vitally important role in mitigating social isolation for many care recipients. Technology on its own cannot tackle this isolation, but it can, in the form of networking and communication tools, help to address it.

1.1. Rationale of the Workshop

ICT can provide services to older people (and citizens in general) that keep disruption of their lives through hospitalization or third-party care to a minimum. ICT can enable them to continue carrying out their daily activities, both in their home environment and in public, with the greatest degree of independence and autonomy. All these opportunities are of specific importance against the backdrop of the ageing society and a collective health system in structural crises.

With regard to technologies for the ageing population, the match between technologies on offer and actual user needs is far from optimal. Lack of acceptance, lack of usability or even of usefulness, are often diagnosed as reasons for limited technology diffusion in this area. They are also indicators of the mismatch between technologies supplied and technologies needed. For example, for people with reduced physical capabilities and growing sensory loss, adequate technological appliances are increasingly important. Nevertheless, despite attempts of developers and manufacturers of technical devices and systems to make products as user friendly as possible, all too frequently technological devices or particular features thereof are not adequate for the needs and abilities of older people.⁸ It has been estimated that there are currently more than 20,000 Assistive Technology⁹ (AT) products available in Europe. However, although there is no reliable estimate of the numbers of people actually using AT, it is widely accepted that there are significant market and supply failures in Europe in this domain.¹⁰ This mismatch is particularly unfortunate in the context of an ageing population. Despite the incidence of improved health in later life, there will be an increasing demand for care and support for older people.

This all suggests that the user perspective matters. Involving users early on in the design process is increasingly recognized as crucial for successful innovation processes. These should address concrete needs in independent living and produce practical applications which are

⁷ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946.

⁸ Mollenkopf & Kaspar, (2005) “Elderly People’s Use and acceptance of Information and Communication Technologies” in *Young Technologies in Old Hands*, Birgit Jaeger (ed). DJOF Publishing Copenhagen.

⁹ We usually understand by an assistive technology any device, or equipment that is used to maintain, increase, or improve the functional capabilities of individuals with disabilities.

¹⁰ “The Demographic change – Impacts of New Technologies and Information Society”, European Commission, Employment And Social Affairs DG, Social protection and social integration, Social and demography analysis, available at: http://europa.eu.int/comm/employment_social/social_situation/docs/lot7_ict_summary_en.pdf

eventually widely embraced. These applications should harness the full potential of new technologies for active ageing and independent living.

So far, this user-centric approach for technological products and services, envisaged in the Ambient Intelligence (AmI) paradigm, has only been partially realized. Compounding the problem is the fact that both awareness of the status quo in user involvement, and understanding of the institutional mechanisms and practical policy options available to enhance communication between user and technology development communities, are limited. In short, the central role that user needs and priorities *ought* to play all along the innovation chain from research and development to implementation is well established, but actual implementation lags behind. User needs are ill-understood, existing mechanisms for their articulation and integration into the technology development process are insufficiently mapped, and new strategies for more user involvement have barely been elaborated.

The innovation processes that are needed to bring technological developments from RTD through to widespread take-up and deployment, by health and care services and by older consumers themselves, are not functioning effectively at present. These innovation and supply chain failures need to be given a lot more policy attention. The market alone will not deliver. It is noted in a recent EC report that market forces alone will not ensure that the outcomes from the interaction between demographic ageing and ICT developments are optimal for older people and for the European society as a whole. There is a need for public policy that helps to shape developments in ways that exploit the positive potential and reduce the likelihood of negative impacts.¹¹

In order to close this gap, the ICT for Health Unit of the Directorate General Information Society and Media (DG INFSO) and the Institute for Prospective Technological Studies (IPTS, DG Joint Research Centre) of the European Commission organized a joint workshop on "User Needs in ICT Research for Independent Living, with a Focus on Health Aspects". This workshop aimed to contribute to a clearer needs-oriented focus of the Ambient Assisted Living (AAL) initiative, a 5 year R&D project involving the European Commission, the Member States and European industry. It sought to achieve this objective by involving the user communities and inviting them to formulate, from their perspectives, their needs with regard to active ageing and ambient assisted living. The workshop also explored how these needs translate into concrete demands in the wider health, social and technology policy fields.

¹¹ "The Demographic change – Impacts of New Technologies and Information Society", European Commission, Employment And Social Affairs DG, Social protection and social integration, Social and demography analysis,

2. A CONCEPTUAL FRAMEWORK OF INDEPENDENT LIVING

Independent Living has been used to describe a philosophy, a movement, and a service programme. At a philosophical level, independent living addresses the question of autonomy and equity in the right to participate in society and share in the opportunities, risks, and rewards available to all citizens. The *Independent Living philosophy* promotes full participation of people with functional impairments in our society. The main objective is to prevent or mitigate the physical, economic and attitudinal obstacles that functionally impaired people face, ultimately allowing their integration into society.

A social model of disability has emerged from disability studies which sheds a different light on the issue of dependence and independence. This model or approach can also be applied to other groups at risk of exclusion such as the older people, socio-economically marginalized groups, etc. The *International Classification of Functioning, Disability and Health (ICF, 2001)* is based on ideas from this theoretical approach and emphasises the impact of the society on the ‘functioning’ of an individual. The ICF endeavours to link the individual with physical and psychological constraints with the context in which he/she lives, namely personal and environmental factors.

The notion of independent living is strongly connected to the idea of “community integration”, implying that people should not be subjected to disruptive institutionalised care, unless absolutely necessary. As a concept, community integration incorporates ideas of both place and participation, in that community integration not only recognizes that a person is physically located in a particular community but also that integration depends on the practices and possibilities for participation in community activities. The case of people in hospital for chronic diseases shows that, while hospitals offer these patients intensive treatment, they also isolate them to some extent and do not provide community integration.

Community integration also opens up a different perspective on how support services are offered. A range of services and programmes are designed to support individuals with disabilities to live in their communities. For instance, individuals who need assistance with activities of daily living (ADLs), such as bathing, dressing, and mobility often need personal assistance services. These services are already on offer, but they are typically not attuned to the daily schedules of individuals and their demands. In the traditional service delivery models, professional health care providers and their managers have a major impact on what and how services are offered within time frames determined by the agency. Independent living aims at a more flexible support model, shifting the locus of control to the consumer, who is responsible for contracting and requesting, services on demand. In this framework, innovative thinking about the potential role of ICT is particularly needed.

To sum up, the following aspects of independent living can be differentiated: control of one’s life and empowerment, integration and full participation in society, independence, autonomy, self-determination, self-respect and self-reliance. All these aspects relate, in one way or another, to the values of human dignity as a universal right.

2.1. A Holistic View of Independent Living

Independent Living and human activity in older age groups are closely interconnected. Indeed, active lifestyles have been widely recognized as determinants for good health and more independent lives. The World Health Organization, amongst other major agencies, supports Active Ageing policies all over the world, arguing that ageing societies everywhere require

governments, international organizations and civil society to enact “active ageing” policies and programmes that enhance the health, participation and security of older citizens (WHO, Active Ageing, A Policy Framework, 2002).

2.2. Independent Living and Older Age Groups

A striking feature is that the notion of “independent living” is now being used for different age groups and for a broad range of problems (varying from young criminal offenders with complex backgrounds to mentally or physically disabled people). As regards the older age groups, the concept of *independence in later life* is freely and widely used, but not explicitly defined. Independence is a complex and subjective concept. It is generally regarded as having a positive impact on the quality of life of older people. The WHO defines independence as the ability to perform the activities of daily life with no or little help from others (living independently)¹². The barriers to independence for older people are immediately obvious: frail physical and/or mental health, housing conditions, lack of transportation facilities, community information and communication services, and low income levels are the main ones. The most common physical health barriers are, for instance, low mobility level, impairments (vision, hearing...), pain, sensory loss, fall-related injuries, chronic illness and adverse drug reactions, while loneliness, dementia and cognitive impairments are the main mental health issues.¹³

Independence in older age groups will be most effectively enhanced by achieving healthy ageing. This in turn is made more likely by a supportive environment with sound economic, social and environmental conditions, including adequate income and equitable income distribution through paid employment and social security provisions. Well developed, cohesive communities, high levels of accessibility of the built environment and appropriate living situations increase the level of independence of older people, while a wide range of health and community service programmes can effectively support healthy ageing, hence independence.

As indicated above, active ageing policies are public policies that affect the level of independence in individual lives. For this reason, international agencies have firmly opted to elaborate and support these policies from a public health perspective. A major actor in this realm is the WHO.¹⁴ The WHO Policy Framework on Active Ageing is intended to inform discussion and the formation of action plans that promote healthy and active ageing. It explores the challenge of a rapidly ageing population and discusses the concept and the rationale of the active ageing paradigm. The WHO defines active ageing as “the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age”. The policy framework takes into account the determinants of health throughout the life course, in order to understand the social roles and opportunities for older age groups in future society.¹⁵ They are represented in the figure below.

¹² WHO, 2002 “Active Ageing: A Policy Framework” World Health Organization, 2002. This document as well as more WHO information about ageing is available at www.who.int/ageing/en/

¹³ Source: Presentation by L.Plouffe, “Canadian Perspectives on Older Adult User Needs: ICT Research for Independent Living”, EC Workshop, Brussels, Nov 24-25, 2005.

¹⁴ WHO, 2002 “Active Ageing: A Policy Framework”

¹⁵ Mark Leys, Sofie De Rouck, “Active Ageing and Independent Living Services: Core Propositions Leading to a Conceptual Framework”, IPTS Project Report, 2006, <http://fiste.jrc.es/pages/ehealth.htm>.



Figure 1: Determinants of Active Ageing, WHO, 2002

Active ageing also plays a role in employment policies. The fact that the population is ageing also implies a series of risks and opportunities for the labour force and for the sustainability of the social security and pension systems. From a health point of view, active ageing is linked to the notion of health as a cumulative state that rewards healthy lifestyles and early preventive measures with good health and less age-related problems in old age. Research is increasingly showing that the risk of developing a chronic condition, such as diabetes and heart disease, originates in early childhood or even earlier. This risk is subsequently shaped and modified by factors, such as socio-economic status and experiences, throughout an individual's life.

2.3. ICT-based Independent Living Services

The notion of independent living services can be identified in very general terms as (*culturally adapted*) “enabling services”. *Independent Living Services* (ILS) are designed to help people with disabilities to gain independence and communities to eliminate barriers to independence. Any product, application or service that enables people, whose independence in daily life is challenged, to lead a more independent and participatory life fall under the ILS label. ICT-based ILS refers to ICT products and applications as well as services based on a salient deployment of ICT.

It is important to note that many ILS are available (or will be available soon) to a large market audience today, and are no longer in the pilot phase. There are already a myriad of mainstream, everyday products, services and applications that could also help older people to live independently. Generic ICT products, services and applications such as mobile telephony or e-mail and the Internet can open up many new opportunities for participation for people who have restricted mobility, for example. Participation here can comprise all realms of social and economic life, for instance the enhanced opportunities for social contact with distant family or kin and in friendship networks, but also participation in cultural and political life, and improved technical preconditions to retain work.

Specifically designed ICT-based assistive technologies can be of great benefit to older people who are increasingly at risk of having functional difficulties in areas such as mobility, vision,

hearing and in some aspects of cognitive performance. Smart home and consumer electronic developments can make management of the home and everyday living a lot easier for older people. Workplace technologies and tools can help to prolong working life. Healthcare technologies can help in prevention, early detection, cure, and management of chronic conditions.

Many of the challenges of old age require support from the health and social care services as well as assistive technologies. Telemedicine opens up new opportunities for providing medical care to the home and there are many new developments in ICT-based home care, including ways of monitoring well-being and providing a secure home environment. Future developments in many of these areas are underpinned by some key emerging technologies. These include robotics, new materials and biosensors. In addition, the emerging concept of Ambient Intelligence offers great potential, with the possibility for the whole environment (at home, on the move, in the street, whilst driving or during transportation, in public buildings and so on) to have embedded intelligence that helps with everyday life. Some of these technologies are on the market today and could be used to support ILS.¹⁶

Different kinds of independent living programmes to support disabled and older people can be identified. These programmes differ on several dimensions: the service setting may range from residential to non-residential; and the *service delivery* method may range from direct to indirect, or a combination of both.

ICT based ILS services enhance older people lives and enable them to share their knowledge and wisdom. It enhances sense of community as opposed to alienation. For example, peer elder computer education programmes such as SeniorNet¹⁷ enables its members to learn and teach others using computers and communications technologies to accomplish a variety of tasks. Also, ICT based ILS services help foster inter-generational relationships, such as, facilitating contact between grandparents and grandchildren who live some distance away from each other, and between school children and elders via online education projects.

It is very important that the features of an independent living programme are adapted to the needs of the clients served, the availability of existing community resources, and the physical and social makeup of the community.

¹⁶ Kubitschke and Hüsing “Inventory of ILS related policy, applications and contextual factors”, IPTS Project Report, 2006, <http://fiste.jrc.es/pages/ehealth.htm>.

¹⁷ <http://www.seniornet.org/php/default.php>

3. DIFFERENTIATING USERS

Understanding the needs of different types of users is crucial for the success of Independent Living Services. Users are not homogenous group and their needs vary significantly according to socio-demographic and socio-economic characteristics. The broadly defined 'older age group', can include the 'younger old', the 'middle group', and the 'oldest old'. In addition, a specific category is devoted to the 'frail elderly' and elderly with chronic health conditions. Other characteristics to be taken into account to differentiate the groups and understand their needs are gender, socio-economic differences or cultural area. As the older age group becomes more diverse, this has to be taken into account in order to prepare a needs-oriented approach for (ICT supported) service development.¹⁸

Other target groups for Independent Living Services can be defined as active older people who protect themselves from disease through wellness activities; older people with slight physical and/or mental handicaps, informal carers such as relatives to the older people or family carers, professional carers and a broader group of professionals in the health system.

It is important to understand the needs and incentives that shape the work of these specific ILS beneficiary groups in order to make ILS most effective. Broader societal dynamics that have an impact upon these groups must also be kept in mind when designing ILS strategies. These dynamics include increasingly mobile and precarious employment arrangements, pluralisation of lifestyles, changes to retirement regulations, the trend towards living alone, reduction in household size, and shrinking family networks - all of which shape the needs and available support structures for independent living.

To understand and cluster the specific needs of the older population, more detailed research has been carried out in a number of EU projects, such as SHARE (Survey of Health, Ageing and Retirement in Europe)¹⁹ and ESAW (European Study of Adult Well-Being²⁰), and SeniorWatch surveys. ESAW proposes a time-oriented perspective on how activity patterns change with age in developed countries. Europeans on average work up to the age of 60. When they retire, their levels of activity drop. Once their mobility is reduced, old people tend to limit their activities to the home. Importantly, activity levels are correlated not only with age, but also with income and education. Groups with higher incomes and education levels exhibit more active lifestyles.²⁰

The health of older people has steadily improved in recent decades. In the last quarter of this century, older people have enjoyed substantial health gains. Explanations for this development vary and may be jointly attributed to improvements in health education, health services, medicine, public health and in the general standard of living. Forecasts predict that these contextual factors will continue to improve in the future, though it remains to be seen whether age-specific health status will continue its positive development in tandem. It is reasonable to assume that some older people will be healthier and be able to maintain a health status equivalent to that of younger individuals in the previous generation. Others, however, may be able to go on living longer because of improved medical technology, even though their health status along the way may still be relatively poor for their age.²¹ Differences in self-assessed

¹⁸ Mark Leys, Sofie De Rouck, "Active Ageing and Independent Living Services :Core Propositions Leading to a Conceptual Framework", IPTS Project Report, 2006, <http://fiste.jrc.es/pages/ehealth.htm>.

¹⁹ www.share-project.org/

²⁰ www.bangor.ac.uk/esaw/

²¹ Mestheneos, E. et al. (1999) The health of older people in the European Union: current state and future trends. Report prepared for the CEC, DG V (Public Health). Athens.

health and physical functioning are also evident across countries. *Figure 2* shows the self-assessed number of limitations that older people report with regard to a set of basic physical activities such as climbing stairs or lifting a 5kg weight.

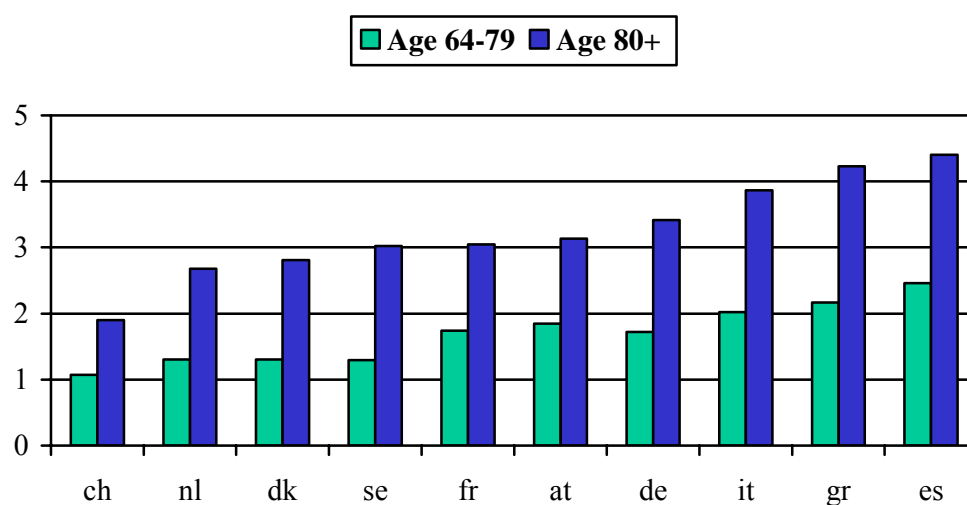


Figure 2: Reported self-assessed number of limitations²²

3.1. Older People's Health Needs and Illnesses

Evidence clearly shows that older people today enjoy generally better health than ever before. Nevertheless the SeniorWatch surveys in 2001 found that a majority of the then EU-15 population aged 50 and older were receiving medication for at least one long term condition. Among the conditions surveyed, high blood pressure and joint, bone or muscle diseases were most prevalent. Consequently, more than one in three senior citizens sees a doctor more than once a month.

Table 1: Prevalence of some frequent diseases by age

Currently treated for	Age				Total
	50 - 59	60 - 69	70 - 79	80+	
High blood pressure	23.1	34.8	44.9	41.7	33.7
Joint/bone/muscle diseases	18.9	27.0	30.3	35.2	25.6
Heart disease	7.4	14.5	27.4	35.7	16.8
Diabetes	6.8	9.4	12.2	10.1	9.2
Chronic respiratory disease	5.4	8.8	11.5	11.4	8.5
Any of these (at least one answer yes)	41.7	58.5	68.6	69.9	56.0
Other long term condition (n.o.s.)	16.7	18.5	20.9	22.2	18.7
Any of these (incl. other long term condition)	49.0	64.2	73.5	74.0	61.9

Base: All respondents (N=9661)

Source: © SeniorWatch, 2001

²² Source: Presentation by Hendrik Juergens, "Ageing and Differences Across the EU: The SHARE Survey", EC Workshop, Brussels, Nov 24-25, 2005.

For all EU Member States, the 20th century ‘epidemiological transition’ has brought changes in the main causes of death. Degenerative disorders, especially cardiovascular diseases and neoplasms, are increasingly taking the place of infectious diseases as major causes of death.

According to SHARE's findings, around 40 % of older people have some degree of activity limitation due to health problems, and almost 50 % report that they have some long-term health problems. Around 40 % of respondents rate their health as less than ‘good’, and 10 % even rate their health as ‘poor’ or ‘very poor’. Although almost all physical health problems are strongly age-related, some variations by gender and country of the respondents have also been found.²³

Oldest-old Group²⁴

Due to a substantial decline in the age-specific mortality of the oldest-old (80+) within the last 50 years this age group has become the fastest growing age segment in most European populations. With advancing age, older people are increasingly likely to suffer from various conditions which can impair independent living, e.g. cognitive impairment, visual and hearing impairments, frailty due to disease.

According to the results from the SHARE project, a little more than half (56%) of the SHARE oldest-old population live alone, while around one fourth (27%) live as a couple. The remaining 16% live with their families, usually with one of their children. These percentages vary across SHARE countries, where a North-South gradient can be observed. The percentage of oldest-old who live with their families is lowest in the northern SHARE countries, middle range in the more continental SHARE countries and highest in the southern-most SHARE countries (SHARE, 2005, P.35).

The SHARE results confirm that morbidity increases with advancing age, and more so in females than in males. In the SHARE study about 1/3 of the oldest-old report having no long-term health problem/illness. It is well recognized that cognitive functions decline with advancing age. Being healthy can be defined in many ways, but using the definitions of being independent in ADL, I-ADL, and mobility (healthy), around 16% of the SHARE oldest-old are healthy, but with significant differences between men and women.

In line with the gender-specific differences regarding self-reported chronic diseases and symptoms, oldest-old men according to the above definition of being healthy are in a healthier state than their female counterparts, 21.9% and 12.5% respectively. However, wide variations exist cross-nationally. 40% of Swiss men, but only 14 % German men and 15 % of Greek men, can be defined as healthy. According to SHARE results, Swiss women are again the healthiest (22.8 %) and Greek women the least healthy (4.1 %). Although only a small proportion of the oldest-old can be defined as unhealthy, a rather large proportion of oldest old can manage activities of daily living (ADL) without limitation, in other words, a large proportion of oldest-old is not severely disabled.

²³ SHARE notes that age and gender variation is probably even underestimated due to the exclusion of the over proportionally very old aged institutionalised population. Further, SHARE rightly observes that the so-called age-gradient actually mixes age and cohort effects due to the differential gender proportions per age.

²⁴ SHARE (2005) “Who Are Our 50+ Olds?”, Ed. Axel Börsch-Supan, Karen Andersen-Ranberg, Inge Petersen, Jean-Marie Robine, and Kaare Christensen.

Mobility Restrictions, Impairments and Dependency

Mobility restrictions are a significant issue among older Europeans. 10.6% of the survey population find it very difficult to walk longer distances, climb stairs or get on a train. Another 19.7% report some difficulty, and 0.4% state they cannot walk at all. From the distribution across the age groups one can see the increasing mobility restrictions with age (see Table 2).

Table 2: Mobility restrictions by age

Do you find it easy, somewhat difficult or very difficult to move around - I mean, for example, walking longer distances, getting on a train, climbing stairs?	Age				Total
	50 - 59	60 - 69	70 - 79	80+	
easy	81.7	69.9	53.6	34.5	67.2
somewhat difficult	12.5	18.9	27.8	29.7	19.7
very difficult	4.5	9.1	15.1	30.1	10.6
Have not tried / no experience	1.0	1.9	2.7	5.4	2.1
cannot walk at all	.2	.2	.8	.3	.4
Total	100	100	100	100	100

Base: All respondents, DK/refusal excluded (N=9607)

Source: © SeniorWatch, 2001

Sensory restrictions, understood here in terms of vision, hearing and dexterity, trigger special access-related needs as regards information and communication technology. These impairments inter alia affect the human senses necessary to utilise standard technologies. As a consequence this calls for an enhancement and adaptation of user interfaces of standard technologies. It also requires the provision of dedicated services and technologies to alleviate functional sensorial impairments and enable people with these restrictions to participate in an active life.

Problems with vision are also quite frequent among European senior citizens according to the SeniorWatch surveys. Many older people (40.8%) have at least some difficulty with seeing fine details, even when using glasses. 27 % state they have *some* difficulty reading small print or seeing fine detail, and 12 % report this to be *very* difficult. Another 0.3 % of the survey respondents are blind.

At least some difficulties in hearing were reported by one third, of which 5% had severe problems. Interestingly, only 37% of those who report severe difficulties with hearing wear a hearing-aid. 4% of the population as a whole wears a hearing aid. With regard to tactile functions, more than one quarter of the older population are reported to have tactile problems, when using ICT. This problem becomes significant among the very old.

Table 3: Tactile functions

Difficulties using touch-screens, using a credit card, typing on a keyboard	Age				Total
	50 - 59	60 - 69	70 - 79	80+	
At least one of the above: somewhat difficult	17.4	18.1	20.4	27.3	19.2
At least one of the above: very difficult	6.0	9.9	12.6	15.9	9.7
Total	23.4	28.0	33.0	43.2	28.8

Base: All respondents, (N=9661)

Source: © SeniorWatch, 2001

Finally, if one looks at the interrelationships between different types of impairments there is, of course, some degree of correlation between the four functions observed. At the same time, however, the findings also show that there is not a very clear concentration in some people, but rather that many people suffer from one restriction or another. A total of 21 % suffer from at least one severe impairment. This proportion increases with age, reaching 39% among people over 80.

Table 4: Impairment

Impairment: vision, hearing, tactile functions	Age				Total
	50 - 59	60 - 69	70 - 79	80+	
At least one: somewhat difficult / little trouble	41.1	43.9	44.6	39.7	42.7
At least one: very difficult / lot of trouble	16.7	19.3	25.1	38.6	21.4
Total	57.7	63.2	69.7	78.3	64.1

Base: All respondents, (N=9661)

Source: © SeniorWatch, 2001

Cognitive Functions and Mental Health of Older People

According to the SHARE project, the prevalence of cognitive impairment increases sharply with age, across the whole of Europe. Some of the variations in cognitive performance, particularly amongst the younger age groups, may relate to how intelligence and other cognitive abilities are acquired in early life, and may be affected by the benefits of education, and social and socio-economic advantage. Cognitive ability is strongly associated with education – the more educated are more cognitively able than the less educated. Differences between countries in cognitive impairment rates seem in line with the differences between countries in education levels. Many of the differences between countries in cognitive performance shown in SHARE are explained by differences in educational experience. The Mediterranean countries have the highest relative cognitive impairment and also the lowest levels of education. But although differences in the provision of education account for some of the North-South gradient they do not completely explain it.

SHARE has also identified a strong and fairly consistent association between cognitive impairment and impaired functioning (limitations in ADL and IADL), poor self-reported health, and changes in the dynamic of giving and receiving support. The data suggests that kin and

non-kin social networks of support may be more intact in Southern Europe, and this allows older people with cognitive decline to function at a higher level.

Depression

Depression is a key issue in older people's health status. Some experts forecast that depression will be the second most burdensome condition globally, taking into account the associated disability risks and the high mortality rates (SHARE). SHARE findings suggest that, consistent with previous observations, depression is more prevalent among women, older people, those who are not married, and those who live alone. These associations are broadly consistent across Europe, although there is an overall North-South gradient with higher prevalence of old age depression in Southern countries.

3.2. Family Care in Europe

Increased longevity and improved living conditions have led to an improved quality of life for many older people. However, a higher incidence of chronic illnesses in old age means that a fifth require regular help with the activities of daily living. Family care is the predominant model of support for older people across Europe due to economic constraints and community care policies and also socio-cultural values regarding the role of the family. Family carers are often spouses/partners, but adult children also play an important role.²⁵ Women take caring responsibilities more often than men. The availability of fewer adult women to care due to increasing numbers of women in the workplace, and the extension of the age of retirement are two important future challenges for family care. Changing family patterns due to increasing divorce rates blur the responsibilities for care and greater family mobility makes it unfeasible to provide care.

Co-residence among adult family generations has decreased massively in all western societies. There are, however, great differences with regard to the average age of children leaving their parental homes. In Southern Europe, young people tend to live with their parents longer than in many central and northern European countries.

The SHARE study found that in Denmark and Sweden, 13 and 15 % respectively of survey respondents (i.e. the population aged 50 and older) who also have at least one living child, live with the child in the same household. In the 'central' countries this rises to 20 - 27 %, and in Italy and Spain to 49 -52 %. This reflects the southern European inclination to leave the parental home very late: Among those aged between 50 - 59, 79% of Spaniards and 77% of Italians live in households with children, while only 24% of Danes and 35% of Swedes do so. In continental Europe, this figure is around the 40% mark.

The core needs of family carers consist of information, education and support. Family carers also need information and education on practical caring skills in daily life. They need knowledge about the relative's illness, common problems and treatment. Local support services should play key roles for family carers.

Carers' needs change over time - the needs of novice carers differ from those who have been caring for their relatives for a long time. Experienced carers can often be seen as the experts with regard to the care of their own relative. Support is most often provided in the form of respite care services, which means giving the carer an opportunity to take a short break from the

²⁵ Source, Presentation by Lennard Magnuson, " The evolving needs in family care' EC Workshop, Brussels, Nov 24-25, 2005.

caring duties. This respite support mainly consists of day services (day centres); institutionally-based respite care (nursing homes), holiday respite (a care setting at a holiday resort) and home-based sitting services.

Family carer support groups and services could take the form of educational groups, training programmes/courses in caring, counselling services and services such as informal 'drop-in centres' or family carer cafés and family carer resource centres.

A key problem is that professionals tend not to work together with carers to help them manage their situation. Also, traditional services often lack sufficient flexibility and quality to meet the needs of individual carers. There is a strong need for policies to support and encourage professionals to work together with carers. The important role of informal carers should be recognised and ways should be devised to support and interlink them effectively with formal care systems.

ICT-based services for family carers (informal care) are very important and connected with the claim that it is much better to support informal care than replace it with expensive formal care. Historically, services are telephone-based and led by professionals. They focus on providing counselling and support to reduce carer stress and promote optimal coping.

There are a number of telecomputing services that provide information and support to carers (e.g. REACH for TLC intervention in the US).²⁶ There is also evidence of Internet-based information and support services for family carers, such as the pioneering US based Computer Link programme. Within Europe, this concept was further developed to incorporate videophone-support in addition to Internet-based information and some specific service initiatives were researched and developed together with carers.²⁷ In the last few years, there has been growth in the research and development of user friendly websites for carers, mainly from the US and Britain. 'Design for all' or more accurately 'user sensitive inclusive design' is one of the critical success factors for ICT services for older people and their family carers. Understanding older people's attitudes toward technology is important for successful applications and training always has positive effects.

ICT-based support services for carers have the potential to provide flexible forms of support that meet the individual needs of carers, provided they are researched and developed with the direct involvement of a range of carers across the member states and include specifically challenged groups such as working carers and carers from ethnic minority groups.

According to the national correspondents in the SeniorWatch project, in 2001, only two member states make specific reference in policy documents to the use of ICTs as a means of empowering family carers. In the UK, a reference appears in the 'National Strategy for Carers' (1988), which recognises the important role of carers in providing care and support to frail and disabled people. It is government policy to support carers through better information, support and care services and, as part of this, the Strategy makes significant reference to the use of new technology as an important means to help carers. In Belgium, a regulation exists that addresses the use of personal alarm systems in providing homecare. This regulation has been adapted to the context of homecare and now permits the use of a wider variety of emergency alarm systems, such as video telephony, thus providing more choice to family carers.

²⁶ <http://www.clinicaltrials.gov/ct/show/NCT00178165>.

²⁷ Source: Presentation by Lennard Magnuson, "The evolving needs in family care'.

Dementia-specific Needs

The prevalence of diseases causing dementia symptoms will soon reach epidemic levels. This will prove very difficult for the patients, the surrounding social and informal care networks, formal care providers and the health system in general to cope with.

In 2002, it was estimated that 18 million people were affected worldwide, a number that is expected to rise to 34 million in 2025. Diseases causing dementia are closely related to old age, with prevalence doubling every five years beyond the age of 65, leading to a situation where half the people aged over 85 suffer from these diseases. In Europe, the number of people suffering dementia symptoms is currently estimated at 5.5 million. The range of mental and physical functions that can be lost through dementia is wide. For Alzheimer's disease, for example, it affects memory, gestures, language, visio-spatial and organization functions, and it can lead to agitation or apathy, somatic complications and modification of behaviour and personality. This diversity and range of possible complications translates into a long list of Alzheimer user needs and concerns that range from security, living at home, social life, communication and mobility to cognitive assistance, nursing and medical care. The risks associated with Alzheimer's disease for patients living at home include falls, nocturnal pacing, motor agitation and aggressiveness. A wide range of existing and emerging devices for Independent Living can respond to these needs. Assistive devices from simple alarm bells to fully equipped smart rooms, telemedicine arrangements and prevention of risks in daily activities through re-design of everyday tools can strengthen the autonomy of Alzheimer patients and the care they receive. With regard to monitoring activities and devising automated alarm systems, for example, R&D activities are exploring infrared rays and web, smart carpets, mattress and over-mattress pressure, magnetometers and accelerometers. Similarly, a range of context-aware assistive devices are being developed and already deployed as *Figure 3* illustrates:

Context-aware assistive devices for older adults with dementia

Alex MIHAILIDIS, G.R. FERNIE, *Gerontechnology* 2002; 2:173-88.

- ◆ For 20 years
- ◆ Help people to take medications at the appropriate time
 - From Plastic segmented pillboxes to Electronic systems
- ◆ Electronic cognitive devices
 - IQ Voice Organizer (Voice Powered Technology)
 - ISAAC (Cogent Systems)
 - PEAT (Attention Control Systems)
- ◆ Softwares products
 - Easy Alarms (Nisus Software Inc.)
 - Essential Steps (MASTERY Rehab. Systems)
 - Softwares of the Institute of Cognitive Prosthetics

Figure 3: Context-aware Assistive Devices²⁸

Tele-applications can also be used in the treatment and care of diseases with dementia symptoms. Screening for these diseases by telephone interviews, for example, has been successfully trialled in a pilot programme in the U.S. Similarly videophony applications, such

²⁸ Source: Presentation by Alain Franco, "Alzheimer's and user needs", EC Workshop, Brussels, 24-25 Nov, 2005.

as the ViSaDom Network illustrated in *Figure 4* below have been found to significantly reduce the anxiety of patients.

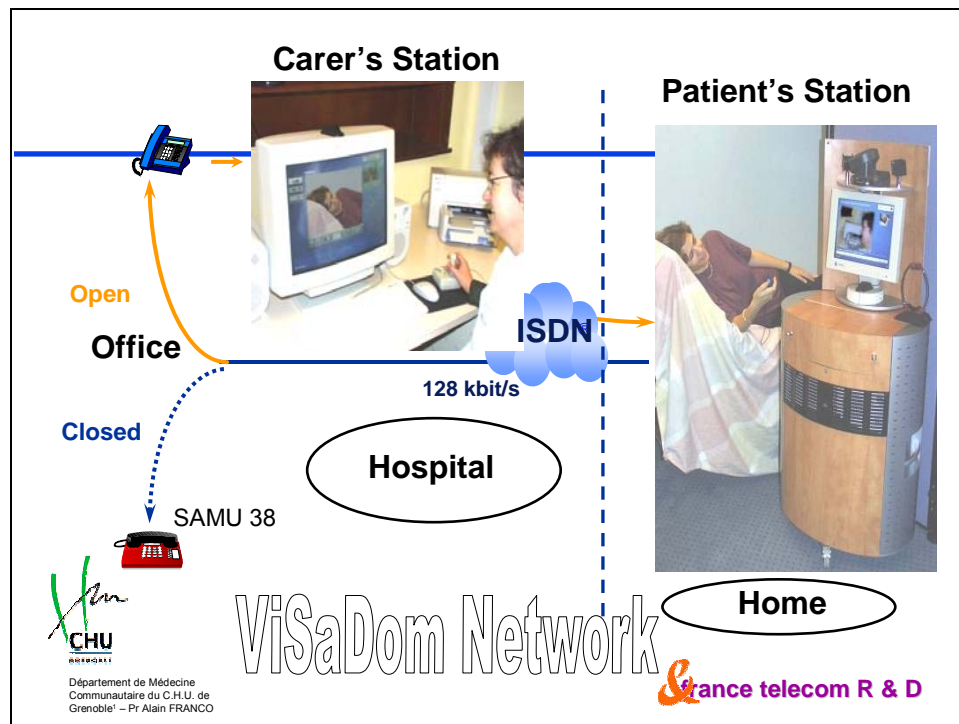


Figure 4: ViSaDom Network²⁹

Dementia symptoms put particular stress on care and support systems. According to the results of Switzerland National Research Program NRP 32 'Ageing'³⁰ research project, the majority of patients (sufferers from Alzheimer's and other diseases causing dementia) are cared for at home by relatives (mainly partners, daughters, daughters-in-law). Care of a patient with dementia requires an extremely intensive commitment and it can push partners— frequently old —to their limits. The progressive course of dementia means that relatives continually have to adapt to changing situations. The patient loses more and more of his/her intellectual abilities and autonomy in everyday life. This causes a change in the relationship between the person with dementia and the relative responsible for their care. Dementia symptoms, such as depression, aggression, anxiety, restlessness, confusion of night and day, hallucinations, etc. are a further strain on patients and relatives. This can restrict the social life of relatives acting as carers, especially if 24-hour care is necessary. Frequently dementia not only affects the sick person but changes the whole family system. It results in high morbidity (50%) and mortality (20%) for the carers, and affects many daily activities. The current coping strategy is for a career to continually provide verbal reminders to the patient with dementia.³¹

Relatives frequently nurse a patient with dementia until the strain exceeds their strength, thus increasing the risk that they too become ill. These relatives frequently suffer from emotional disorders with symptoms of anxiety, depression and exhaustion. It is therefore a central task to identify the problems which put strain on nursing relatives and look for solutions to alleviate it. This is also significant from a socio-political point of view, as only support which is tailored to

²⁹ Source: Presentation by Alain Franco.

³⁰ Alter - Vieillesse - Anziani – (1999) Ageing Main results and findings from the National Research Program (NRP 32) <http://mypage.bluewin.ch/hoepf/fhtop/Age-english.pdf>

³¹ Presentation by Alain Franco, "Alzheimer's and user needs".

the requirements of the carer can make homecare more effective and prevent the premature committal of dementia patients to a home. Studies show that psycho-social measures (perhaps in the form of a memory clinic) can delay, or even prevent, placement in a home.

It is essential for the relatives to have support and counselling sessions with experts. Counselling sessions, in which the relatives are given information about the illness and practical help in managing the effects of dementia symptoms, contribute to calming their fears in the early stages of the illness. Counselling can also help relatives plan care adequately. As modern diagnostic instruments enable doctors to make ever earlier diagnoses of illnesses causing dementia, early information provision and counselling of the relatives becomes more and more important.

A wide range of services is necessary for the relief of relatives – e.g. community services (day-care facilities), respite stays to relieve the carers (medically-indicated short stays in hospitals or homes, holidays for dementia patients), well-devised counselling and therapy facilities (memory training) and well-organized relatives' associations (for example, the Alzheimer's Association). There is an urgent need for integration of all health and social services and closer cooperation between different services.

3.3. Readiness, Use and Acceptance of Technology

The health and social care sectors are relatively slow to use ICT tools. ICT use in the health sector lags behind the other sectors in general, making it one of the least connected sectors, with great disparities across countries.³²

Household		Health Care		ICT	
Non-Impaired	Impaired	Non-Impaired	Impaired	Non-Impaired	Impaired
Dishwasher (57); 19%	Tumble-dryer (69); 21%	Blood pressure/ Pulse meter (49); 16%	Blood pressure/ Pulse meter (66); 30%	Cordless phone (107); 32%	Cordless phone (86); 28%
Tumble-dryer (53); 15%	Dishwasher (64); 21%	Hometrainer (47); 11%	Massage device (48); 14%	Cellular phone (64); 14%	Answering machine (37); 10%
Microwave (29); 12%	Microwave (32); 14%	Massage device (38); 9%	Lifting gear (43); 11%	Answering machine (44); 11%	Cellular phone (36); 9%

Table 5: Wish for more domain-specific devices

The German Centre for Research on Ageing (2005)³³ is one of the very few organizations working on how technology-based options would simplify life at home for older people. In a survey on older people's attitudes to technologies, the respondents expressed strong preferences for a variety of devices, as *Table 5* and *Table 6* show:

³² E-business watch@2004.

³³ Presentation by H. Mollenkopf "Future Societal Trends and Older Technology Users' Needs, EC Workshop, Brussels, 24 – 25 Nov, 2005.

Security Devices		Comfort Devices	
Non-Impaired	Impaired	Non-Impaired	Impaired
Secure door (225); 44%	Secure door (208); 51%	Noise-adjusting doorbell (213); 39%	Noise-adjusting doorbell (189); 43%
Self-deactivating cooker (213); 40%	Self-deactivating cooker (203); 46%	Automated light in entrance area (183); 49%	Motion detector in hallway (174); 44%
Smoke detector (144); 28%	Personal emergency call (149); 34%	Motion detector in hallway (181); 39%	Automated light in entrance area (164); 53%

Table 6: Wish for more domain-specific devices

Actual equipment with many of these devices, however, was reported to be very low as *Figure 5* shows.

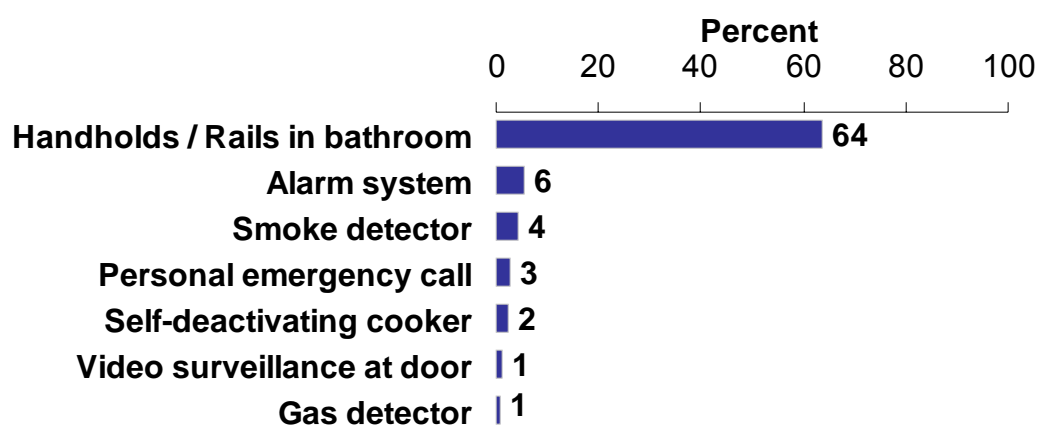


Figure 5 Equipment with security devices³⁴

³⁴ Source for Table 5 and 6, Figure 5 and 6: Presentation Heidrun Mollenkopf (Database: Sentha Survey-1999).

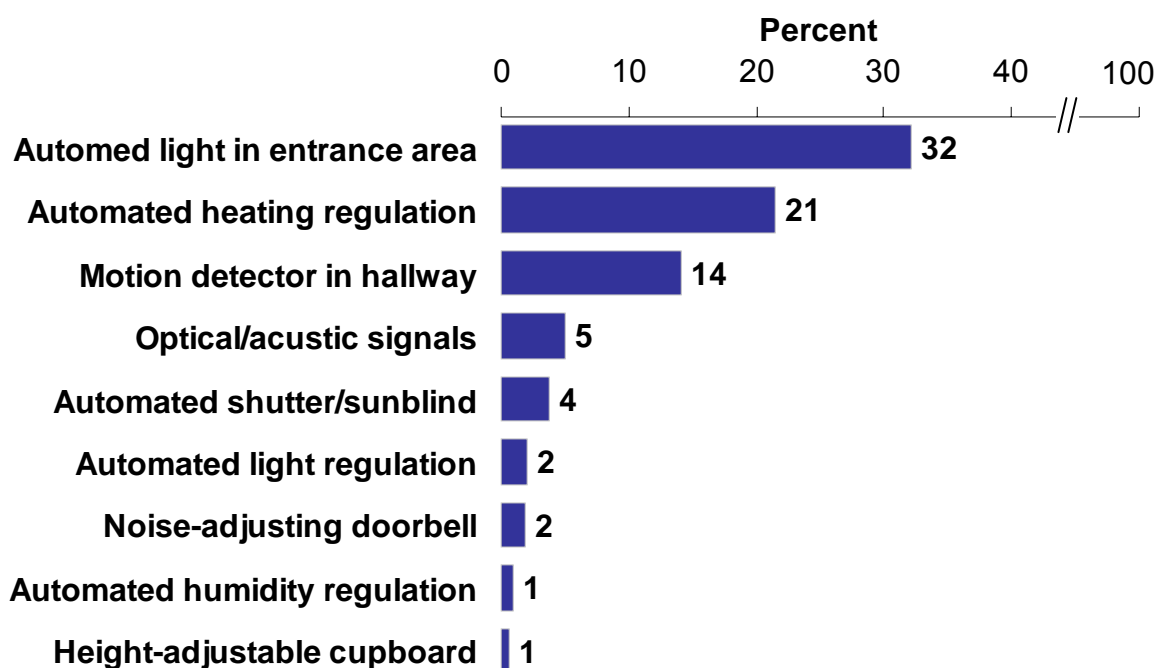


Figure 6: Equipment with comfort devices – Items

The same organization also studied which activities were perceived to be the most difficult. The results can be clustered under the headings “household”, “body care” and “leisure time”.

The most difficult household activities were “hanging up the curtains” (55% of the older people interviewed mentioned this), “fixing household devices” (51%), “cleaning the windows” (45%), “ironing” (34%) and “making the bed” (34%). For body care tasks, the most mentioned ones were podiatry (29%), gymnastics, including sports and fitness (28%), see *Table 7*.

According to the German SENTHA study, 67% of older people in Germany view ICT devices as a major support to their independence. Barely 15% of the respondents expressed fears of ICT. Almost half stated that they always liked to use ICT, while 45% preferred to use it as little as possible. About one third thought that it was no longer worth while buying new ICT.³⁵

Many older people use some sort of new ICTs, but their numbers are lower than in the younger age group. In 1998, mobile phones were owned by 37% in the 35-44 age group and by 10% of respondents in the 75+ age group; 74% and 5% of these groups respectively owned PCs.³⁶ Age has a major impact on PC adoption. Over 50% of older people experience problems in using PCs, and mobile phones. In several studies, age was the most important predictor of usage, followed by education and gender. Older people complain about having difficulties with user interfaces.³⁷ Dutch research in 2002 showed that half the older people did not use modern

³⁵ Mollenkopf & Kaspar, (2005) “Elderly People’s Use and acceptance of Information and Communication Technologies” in *Young Technologies in Old Hands*, Birgit Jaeger (ed.), DJOF Publishing Copenhagen.

³⁶ Klerk M de. *Rapportage ouderen 2001, veranderingen in de leefsituatie* (Report on older people 2001, Changes in Life situation). The Hague: SCP 2001.

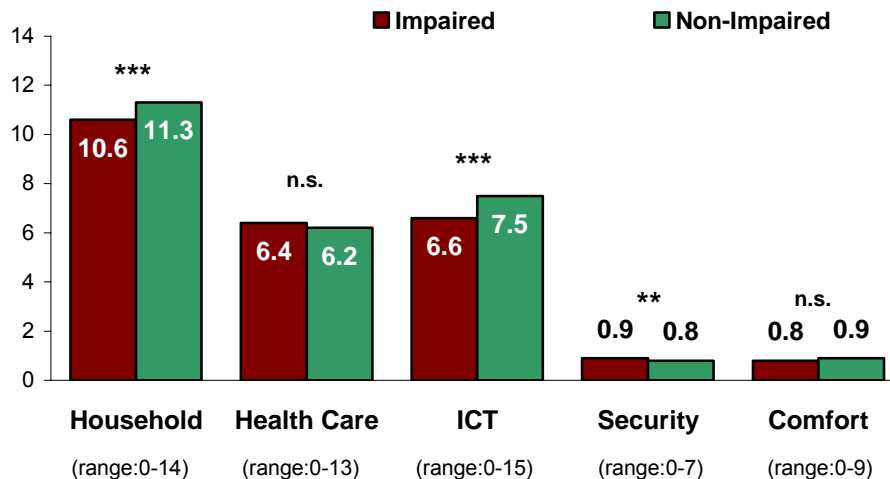
³⁷ Docampo Rama M. *Technology generations handling complex user interface*, PHD Thesis University of Eindhoven, 2001.

technology that could make life easier.³⁸ The factors affecting acceptance and rejection of technical aids (true for technological devices in general) are described as:

- (i) fear of the new;
- (ii) lack of motivation for use; often demand is lacking for this specific function or people are unwilling to try them out;
- (iii) ease or complexity of use
- (iv) advice, training, and encouragement or the lack thereof.

According to the European study "MOBILATE-Enhancing mobility in later life",³⁹ access by older people to modern technologies appears strongly dependent on income, education, experience, and attitudes (Tacken, Marcellini, Mollenkopf, Ruoppila, Széman: 2005, p. 128).

People could use ICT to compensate for physical deficiencies. It is noted that mobility-restricted people are significant users of tele-shopping, mainly over the telephone. However, people in poor health use mobile phones and Internet even less than people in good health. In general, the use of technology is lower and the perceived problems with technology are higher for old people with impairments compared to old people without impairments, as *Figure 7* and *Figure 8* indicate.



*Figure 7: Equipment with domain-specific devices*⁴⁰

³⁸ Kuiper I. Je moet wel met je tijd meegan (One has to cope with the present). Special of Nestor, Journal of KBO; 2002;50/24-27.

³⁹ Tacken, Marcellini, Mollenkopf, Ruoppila, Széman (2005) "Use and acceptance of new technology by older people. Findings of the international MOBILATE survey: Enhancing mobility in later life", in *Gerontechnology*, March 2005, p 126-137.

⁴⁰ Source: Presentation by Heidrun Mollenkopf, (Database Sentha Survey 1999).

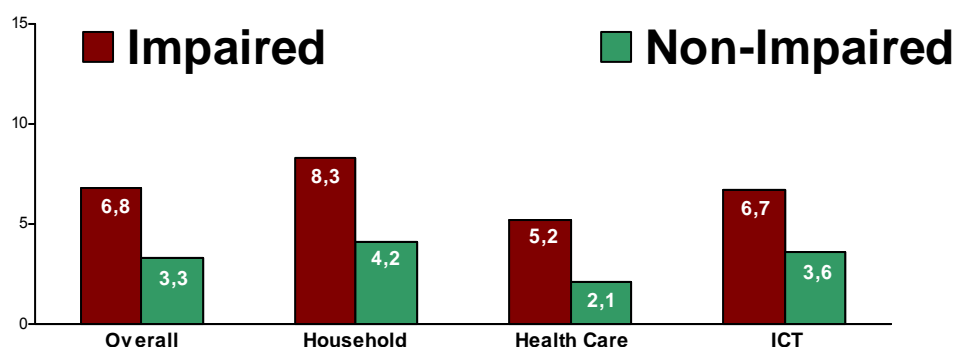


Figure 8: Bad experiences with domain-specific devices⁴¹

Innovative options that go beyond increasing the human resources or technologies available need to be considered, as the composition and characteristics of the ageing population change. Today's older people are generally better educated than in the past and have a strong desire to remain independent. Keeping older people integrated within their community as far as possible, so as to preserve their personal autonomy and quality of life, while ensuring their personal security and protection, becomes the obvious main goal. Inevitably, there will be a certain gap between the pace of technological innovation and the acquisition of technology skills by the ageing population, leading to a persistent risk of their exclusion. Therefore it is important to attempt to predict future user groups' (today's net generation) needs. Related innovation processes should try to anticipate these future needs. Today's "computer generation" has a friendly attitude to technology and is likely to demand increased technology-supported services in their old age. This means that those who are in their forties today will ask for these services in two decades from now. This coming generation of older people will be more acquainted to changes in their professional lives (fragile careers, life-long learning) and social relationships than former generations. What's more, the increasingly intercultural mix of older citizens is another factor that needs to be considered in the design of technologies for future older age groups.⁴² Ongoing socio-economic and socio-cultural dynamics lead us to expect that the next generation of ILS users will have somewhat different expectations and attitudes towards technology.

First, these future user groups will have more widespread experience with extended periods of living alone. This translates into increased independence and expectations of freedom of action, but at the same time leads to an increased need of social, practical and technical support in case of frailty and chronic illness. Second, the improved standards of living that these user groups enjoy generate high expectations with regard to comforts of housing and technological amenities, specifically in terms of convenience, support and security. Third, future user group will enter old age with increased experience with new technologies and can therefore be expected to be more open to technological advances. To sum up, future older user groups of ILS can be expected to be more technology savvy but also more demanding in terms of the autonomy they seek, and the convenience they expect from technological solutions.

⁴¹ Source: Presentation by Heidrun Mollenkopf, (Database Sentha Survey 1999).

⁴² Monteagudo and Redondo (2004) "eHealth and the Elderly: a new range of products and services?" The IPTS Report, <http://www.jrc.es/home/report/english/articles/vol81/ICT6E816.htm>

4. IMPLICATIONS FOR TECHNOLOGY DESIGN AND IMPLEMENTATION STRATEGIES

4.1. Preferred Functionalities and Characteristics of ICT Solutions

A number of factors influence the perceived usefulness of ICT solutions. ILS, for example, is seen as less useful, when their benefits to users are not clear and when they are more complicated, difficult, inconvenient, and awkward than alternative arrangements. ILS can also be perceived as a threat to human contact, privacy or personal control. Unattractiveness and threat to personal image are other possible factors that affect usefulness of ILS (Plouffe). Specific needs of user groups should be taken into consideration in the design of ILS.

All this translates into a long list of desired features for new devices in this area. For a start, the design of new products should take into account the “old” habits of the users. Simple and intuitive handling is required. Multi-functionality of physical and electronic user interfaces can be an important issue for acceptance. Reliable confirmation of remote handling activities needs to be provided, protection against unauthorized intrusion and use of data have to be guaranteed. Fast and secure error diagnosis and error removal are important for technologies that contribute to services of vital importance to the users and their health. Affordability can be an important barrier, especially for low-income older people. Integration and adaptation of devices to the user’s living environment should be easy and technology-based solutions should not generate new risks.

4.2. Ethical Considerations

ILS raise a number of ethical challenges. In the case of cognitive impairment such as Alzheimer’s disease there is a fundamental concern about who takes decisions. How can claims to self-determination and autonomy best be fulfilled, when a patient’s information processing and decision-making power is deteriorating? This requires a responsible balancing of a patient’s articulated wishes, with her interests and needs.

Widespread sharing and consolidation of patients’ records by ILS providers is important to avoid duplication and medical error, and for achieving seamless care solutions. But this information exchange of what is very detailed data about personal matters comes with serious concerns about infringing the privacy of the user. Strong data protection laws that lay out clear quality guidelines for secure data storage, authenticated access and permissible sharing can address some of these concerns. Another important remedy would be to reinforce the patient’s rights to his/her own health data. He/she should be able to inspect, copy and, if required, correct records, and be alerted to sharing arrangements, retaining the right to authorize or reject specific sharing practices.

Bringing technology with monitoring functions into a person’s home also raises important ethical questions with regard to possible conflicts with principles of dignity, independence and privacy. The appropriate choice of technology can help to mitigate some of these concerns. For example, monitoring a patient’s well-being at home might not require video-cameras, but can be done less intrusively through tactile carpets that detect when a person falls. Technology implementation and careful application of social norms can also reduce a sense of intrusion and loss of privacy. In telemedicine consultations, for example, it is very useful to enhance the sense of reciprocity and communication by presenting an image of the doctor to the patient, although functionally only the transmission of the doctor’s voice would suffice. The intrusive aspects of tele-consultation can further be minimized by respecting social norms. In a tele-

consultation it would be important to include a facility which would allow the doctor, for example, to ‘knock before entering’ a consultation session, since entering also implies virtually entering the patient’s house.

Another ethical challenge is to avoid the perception that the installation of ILS means that decision-making power is ceded to a heuristic machine or that it replaces human care and precipitates the erosion of social interactions. This perception is a major barrier to the uptake of ILS. It leads to the important ethical, as well as operational, principle that these services should not aim to substitute existing care networks, but that they should be promoted and implemented as complementary solutions. Smart home devices, for example, should be seen as a means to enhancing social care rather than as a substitute for it. ILS should not increase isolation. Instead they should be tools for maintaining and, ideally, even strengthening social networks.

Other adverse psychological effects of ILS can also be imagined. Having to rely on clunky, often unattractive technological devices in day-to-day life can do considerable harm to the self-image and confidence of the user. Efforts for better design, discreet ambient integration and the upgrading of conventional home devices with ILS capabilities can ameliorate this problem.

Implementing technologies that support life-critical functions also throws up a set of ethical challenges. Creating technologies for critical services requires built-in robustness, reliable maintenance and back-up infrastructures and clarification of legal responsibilities in case of failure.

Finally, if the personal autonomy of a potential ILS user is to be fully respected, the user must have the right to overrule or switch off the technology. These rights must be built into the services. Users should also have the right to opt out completely from using the services, should they so wish.

4.3. From High Tech to Appropriate Technology

It is widely agreed that technical aids could offer a multitude of benefits with regards to the preservation of independence, mobility, and social participation. However the design of these technical aids leaves much to be desired. The developers and suppliers of technology need to take the interests, needs, and possibilities of older people into greater account.⁴³

Table 7, for instance, shows the percentage of reported problems of German older people in performing everyday activities. According to the “Sentha” project results, hanging up curtains is the biggest problem for older people at home. The majority of the applications that would help with these activities require technologies which are already available on the market and are currently being introduced into many “smart” homes. Furthermore, it is important to keep in mind that innovation for ILS need not start from scratch. A large number of readily available off-the-shelf devices can be harnessed, as well as existing ICT infrastructures, such as TV or telephone. Designing innovative solutions that can be integrated with and built onto this installed infrastructure base and available devices is thus a key task for R&D in ILS.

⁴³ Mollenkopf & Kaspar, (2005) “Elderly People’s Use and acceptance of Information and Communication Technologies” p.56, in 'Young Technologies in Old Hands', Birgit Jaeger (ed.), DJOF Publishing, Copenhagen.

Table 7: Reported problems in performing everyday activities

Household	Health Care	ICT
Hanging up the curtains 55%	Podiatry 29%	Surfing the Internet 60%
Fixing household devices 51%	Gymnastics / Sports / Fitness 28%	Using the computer 58%
Cleaning the windows 45%	Sauna / Solarium 22%	Learning languages/Special interests 39%
Ironing 34%	Physiotherapy / Massages 21%	Taking courses /Attending roadshows 38%
Making the bed 34%		

Source: Database: Senta survey 1999; N=1, 417; weighted data

The responses collected in the Senta survey also affirmed that simple design with regard to ICT devices is a persistent concern, especially for older people with impairments as *Figure 9* and *Table 8* show.

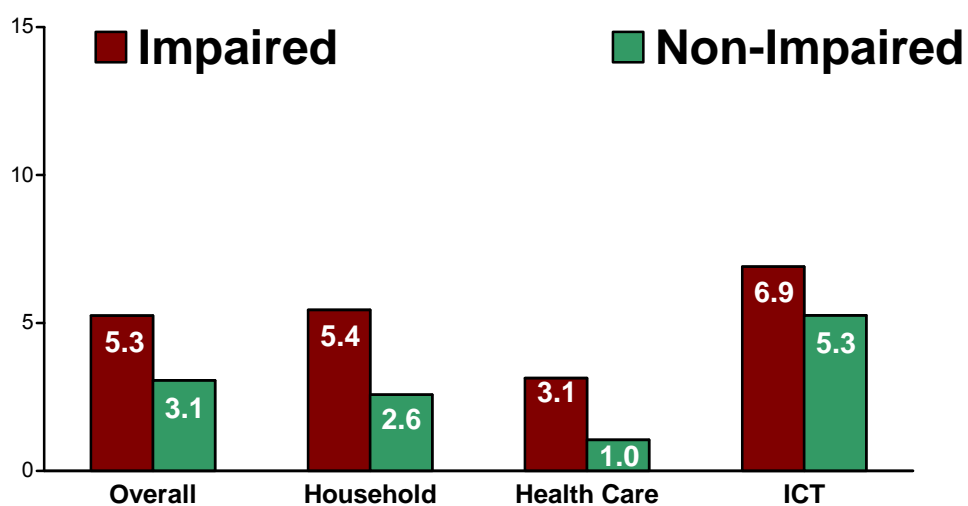


Figure 9: Wish for simplification of devices⁴⁴

⁴⁴ Source: Presentation by Heidrun Mollenkopf, (Database Senta Survey 1999).

Device	Equipment	Bad experiences	Fears	Need for simplification of use
Video recorder	52	23,1	16,4	33,2
Computer	11	18,0	19,3	24,8
Modem, Internet access	5	17,5	12,7	17,5
Video camera, Camcorder	13	16,3	12,5	19,0
Mobile phone	8	13,7	7,7	18,8
Answering machine	20	11,9	5,4	8,7
Fax machine	7	11,8	7,5	11,8
TV set	99	11,2	5,7	8,9
Cordless phone	30	10,3	4,9	6,8
Teletext	63	8,1	5,5	10,3
Stereo system	60	7,8	5,6	9,5
CD player	47	6,5	3,5	5,9
Cable connection	92	6,1	3,5	4,1

The percentages refer to the respondents who are equipped with the respective devices.
All further devices asked for (telephone with cord, radio) were mentioned by less than 5% in all aspects.

Table 8: Problematic Devices⁴⁵

4.4. Bundle Technology with Services

Developing useful technologies alone is not sufficient for their successful, widespread adoption for independent living. Familiarity with the technology and usability are major issues, which can be facilitated through bundling the technological application with specific services ranging from help with selection of appropriate solutions and their installation, to training and customer service and maintenance. This also opens up the opportunity for new business models around the provision of ICT-enabled independent living services.

4.5. Participatory Design and User Involvement

A consensus has emerged that user involvement is very important in the design and the development phases of novel applications and services, in order to develop solutions that are practical and address concrete user needs. Despite this, developers and users are very often disconnected. A good example of a research programme where user involvement is a reality is the Finnish *I-Well* initiative. The research projects Intelligent Moving Aid and Intelligent Rollator at Oulu University are also successful examples.⁴⁶ A number of interesting examples also exist in other countries, like Canada, (these include the National Participation and Activity Limitation Survey, the Health Canada Health Infostructure Support Program, the Canadian Standards Association Health Care Technology Program, Dr. Tong Louie Living Lab and Toronto Rehabilitation Institute). These could be a source of inspiration for European models. The James Lind Alliance⁴⁷ is a good example of a participatory approach to treatment evaluation and experience sharing.

However, there is a persistent need for research on how to integrate all users, i.e. not only the older citizens, but also formal and informal carers and other stakeholders in the ILS area. Moreover, new institutional mechanisms are necessary to make user involvement along the ILS

⁴⁵ Presentation by Heidrun Mollenkopf (Database Sentha Survey 1999).

⁴⁶ Presentation by Kalevi Virta "FinnWell and iWell technology programme experiences", EC Workshop, Brussels, 24 – 25 Nov, 2005.

⁴⁷ The James Lind Alliance <http://www.lindalliance.org/>

R&D chain sustainable and consistent, including the establishment of channels for user feedback and appraisal when technologies are already widely deployed. An interesting suggestion is that retired professionals could bring their professional experience to the innovation process. In addition to making use of their tacit knowledge and experience for the innovation process, their involvement, and the sense of social recognition and usefulness that would come with it, could help to alleviate problems of retirement. More active involvement of users in the design process would also help to raise awareness about available technologies and products within targeted user communities, and, at the same time, provide a seal of approval that could help to foster acceptability and trust in new technologies.

4.6. Smart Houses as an Socio-technological Option for Independent Living

Older people carry out most of their daily activities at home. The two models below, developed by the European Study of Adult Well-Being (ESAW), reflect this fact well.

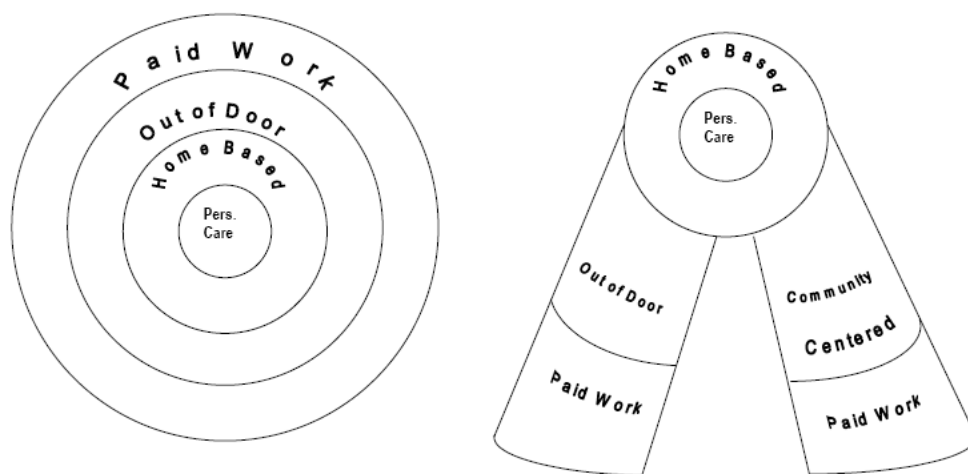


Figure 10: Contraction and convergence in activity patterns

Both models are placed in the context of participation of older people. Contraction and convergence of individual activities have a social as well as a spatial dimension. Several areas of more peripheral activities are gradually wound down in old age in consecutive stages, and daily life becomes more and more focussed on a cluster of core activities. The socio-economic and educational levels, as well as the degree of integration in the community determine the activity pattern model. But irrespective of these variations, home based care (and finally personal care) is at the end of all activity progressions.

Therefore, the home deserves special attention when seeking to foster independence in old age. Technologies that enable more independent (and safer and more comfortable) home-based activities are the focus of many research and implementation activities world-wide. Although the “smart house” is a widely used concept, its real meaning and relationship with the needs of older people is not so well understood. Leaving aside formal definitions and historical aspects, it could be said that the defining characteristics of a smart home are the interactive technologies that it contains. The technology can be used to monitor, warn and carry out functions according to selected criteria. Smart home technology also makes automatic communication with the surroundings possible via the Internet, ordinary fixed telephones or mobile phones.

It is important to note that usability has perhaps been the Cinderella in the conception of smart homes. This has crucial repercussions on acceptance by users with independent living needs,

and is perhaps the key reason why complex pilots, like those based on ubiquitous computing and ambient intelligence, are not the ideal homes for older people. A dramatic rethinking of services offered under the smart home concept might be in order to address real user needs on the one hand, and usability of independent living services on the other.



Figure 11: The case of Norwegian municipalities. Basic services in smart homes that can support independent living services: the bed-sensor registers when the person gets out of bed; and the light in the hall and toilet is switched on. If the person does not go back to bed within a set time; an alarm is sent to the carer (Norwegian experiences, the Delta Centre).

The above is a good example of the introduction of smart home technology as part of municipal services. These were introduced almost 10 years ago. Several municipalities have taken advantage of smart home technology in residential homes and nursing homes since then.⁴⁸ Several user groups are beneficiaries and stakeholders with regard to smart home technology as part of the municipal services: the residents, the home care staff; the technical services or management staff; and the municipality as an organisation and decision maker. The needs of all these groups must inform the planning of smart home implementation. Assessing the residents' needs is an important task. One should be aware that some residents may not need any smart home functions at all (no solution that fits all). On assessing individual needs for technology, it is recommended that municipalities follow the procedures and multidisciplinary approaches used in many other types of social need assessments. It is important that user requirements are developed in co-operation with the residents themselves, and sometimes with their relatives. As a guiding principle, the development of user requirements should be a dynamic process where assessments must be continuously re-evaluated and adapted.

Smart homes are being used today in Europe and in other countries. The AID House, Gloucester 'Smart' House for people with dementia and 'Dementia Friendly House' (UK), 'Smart model house' (NL), comHOME (Sweden), PROSAFE, Gardien, Grenoble HSH, Smardep (France) are some major examples of smart homes in Europe. The G.A.R.D.I.E.N. System in Grenoble is a successful application of a hospital smart room (Steenkeste, Banerjee et al., Toulouse – Grenoble). In this hospital smart room, 8 infrared sensors are linked to a remote computer for collecting data in continuous mode. Other examples from North America are Rochester's 'Smart Medical Home', Georgia Tech's Aware Home (USA), MIT's House of the Future, Sherbrooke's 'Smart' Home (Canada). 'Smart House in Tokushima' (Japan) is an example from Asia.⁴⁹ Inclusive design and user involvement are the key to smart home developments. Undertaking a full user needs assessment is essential in order to determine whether technology is appropriate and meets these needs. Such assessment should consider how

⁴⁸ Delta Center, 2005, Smart Home Technology, Planning and management in municipal services, http://www.shdir.no/vp/multimedia/archive/00004/IS-1216E_4103a.pdf

⁴⁹ Source: Presentation by Alain Franco, "Alzheimer's and user needs", EC Workshop, Brussels, 24–25 Nov, 2005.

the individual will interact with technology from a psychological, emotional, physical and social perspective (Cheverst et al, 2003, Design with Care: Moving towards Appropriate Technology, in Inside the Smart Home).

Older people with dementia symptoms form a special group with specific design requirements. Futuristic homes developed under the concept of Domotics are hardly appropriate for these special needs users. Furthermore, successful adoption of smart home technologies also requires that their usefulness is evident to the carers. Informal carers in particular should gain accessibility, and better interaction with the person with dementia. They should also feel confident about the dependability of the services. Neglecting the needs of informal carers and alienating them with smart house technologies can trigger more isolation for residents with special needs and result in higher costs for the social care systems, which have to step in and provide more formal care.

5. MOVING TOWARDS ACTION: INNOVATIVE ORGANIZATIONAL MODELS

In order to facilitate independent living and maximize the benefits of the services provided, innovative organizational models are needed to guide the implementation. Existing health systems also need to be transformed. A number of key messages emerged from the workshop and are briefly summarized as follows:

→ Incentives are needed to encourage the integration of all health and social services and to promote closer cooperation between them.

Closer co-ordination between all service providers and stakeholders that contribute to the independent living agenda is essential in order to put independent living into practice and make it as effective as possible. This means more information sharing and co-operation at several levels and a strong role for ICT-enabled interlinking of information networks and service provision:

- Linking health and social services for early detection of risks and preventive interventions

As emphasized at the outset, individual health and independent living are multi-dimensional concepts, inextricably linked to, and shaped by, social well-being, the appreciation of the social environment and the perceived quality of interaction, engagement and support that this environment provides. This interdependence between individual well-being and the social environment has two important implications. First, it means that risks to individual well-being, health and independent living can be triggered by events in the social environment that uproot established living patterns and social relations, such as death of a close partner, retirement, or the moving away of close family members. Second, it also implies that, a sudden deterioration in individual health or the capability to live independently can significantly affect the immediate social environment and put considerable pressure on the well-being of family members and their capabilities to cope with the new situation and provide effective social support. Many relatives of Alzheimer patients, for example, are found to be at considerable risk of experiencing a health crisis of their own due to the stress that the situation brings for them. A close synchronization between health-related and social support systems can help to break both of these adverse links. Information about disruptive life events, such as retirement, death of kin or onset of disease, that are first recorded in either the health or the social system, can be shared in order to trigger an integrated, preventive offer of social and health-related support services both to the affected individuals themselves and their immediate social support environment.

- Linking different health service providers for shared and seamless care with minimum disruption

The emerging paradigm of ‘shared care’ and, even more visionary, the scenario of seamless service provision, present a very promising reference for organizing health services for independent living. Both shared care and seamless care, as the most integrated, co-ordinated form of joint service provision, aim to avoid a duplication of efforts along the healthcare provision chain (prevention, diagnosis, treatment, rehabilitation) and strive to allocate different service functions to the provider best suited. They emphasize prevention and seamless provision of services in order to ensure the continuity of care, avoid unnecessary hospitalization or intrusive surgery. Thus, they seek to minimize the disruptive effect of healthcare interventions on patient’s daily lives. Above all, the paradigm of shared care aims to support the

information exchange and collaboration between different health care actors. Very importantly, the latter also includes the individual citizen, who ought to be made aware of different treatment options, health choices and their implications, and who should thereby be empowered to grow from passive recipient of ordered treatments to an active, responsible partner in the health care chain. New information and communication technologies also assume a central place in the shared care framework, since they afford opportunities to support the networking and citizen-centred information sharing among all stakeholders that underpins continuous, integrated care provision. As it aims to minimize the disruptive effects of addressing health issue, shared and seamless care lay the foundations for independent living in care situations. Furthermore, the potential benefits of the shared care paradigm both for controlling health care costs and enhancing the quality and accessibility of health care are expected to be enormous. Industry analysts, for example, reckon that redundancy and inefficiency in health care provision account for between 25% and 40% of the health bill world wide.⁵⁰

➔ Restructure payment and compensation incentives to make them fit with new care models

New forms of collaboration and joint service provision for independent living also come with shifts in responsibilities and a different distribution of service costs among health care providers. Adjusting purchasing, payment and reimbursement arrangements in order to bring everyone on board and provide incentives for co-operation is therefore essential. The shift to shared care and effective independent living arrangements needs to be encouraged with incentives. This puts health insurers, care purchasers and health policy makers in the spotlight and requires them to identify, together with healthcare providers and recipients, the necessary changes to the current payment and compensation systems. Different national approaches and organization of healthcare provision will require different strategies to catalyze the evolution of integrated services.

What all these strategies have in common is that they need to carefully re-appraise the current division of labour in the health sector. They must find incentives for co-operation at all levels - national, regional, local and between all stakeholders - if seamless care and effective independent living schemes are to be made reality. Irrespective of national specificities, a dialogue on financing and organizing shared care should also include hard questions on the right mix of public and private elements, both with regard to who will provide specific services and also who will pay for them. What risks and services under the independent living paradigm should be covered collectively and which ought to be left to individual responsibility is one key question, how to interlink public and private service provision in the most fruitful manner is another.

➔ Recognize the important role of informal carers, devise ways to support them and interlink them effectively with formal care systems

Informal care is becoming an increasingly important pillar of the health care system. Against the backdrop of an ageing population, tight public health budgets and people's growing expectations of health services, countries find it increasingly difficult to train and employ a sufficient number of professional carers, and provide broad access to a sufficient range of services at acceptable cost. Moreover, the notion of independent living and active ageing within one's own everyday environment is more attuned to community-based, social support services than large-scale formal care provision.

⁵⁰ "The No-Computer Virus", *Economist*, 28 April, 2005.

Strengthening this helping hand from the family and community and productively interlinking it with the formal care systems is a prerequisite for building sustainable and affordable arrangements for independent living. However, this is not easy for several reasons:

Informal care and carers are not sufficiently recognised and their work is little recorded in official statistics. We know that the high incidence of chronic illness in old age means that a fifth of people in this group need some sort of assistance with their daily activities and we know that the predominant source of support is the family. But the practical significance of this has not yet been translated into adequate recognition in policy and research. In the Netherlands, for example, the expression 'informal care-giver' is not very common and people in this group would often not even recognize themselves as such. Given this lack of even an established label, it is not surprising that very little robust official information is available on the scope and characteristics of informal care provision.

Smaller, more fluid family networks, as well as more mobility and higher labour participation rates thin out and put great strain on support provided through the family environment. This often leads to informal care arrangements, where care givers need to juggle employment with care commitments or childcare with care for older people, or where older people themselves assume care responsibilities for even older family members. These challenges are compounded by the great physical and mental stress that comes with certain forms of care. For example, Alzheimer patient carers' morbidity rate is 50% and the mortality rate is 20%.

Formal systems of care are typically not well-synchronized with informal care arrangements. Research indicates that formal carers often do not work together with informal carers. Moreover, informal care is provided on an ad-hoc, on-demand basis, but there is little in terms of a systematic training, recording and sharing of best practice or adequate financial support systems available to informal carers. In addition, informal care raises difficult issues of accountability and legal liability, as well as privacy and personal care, all of which grow in complexity the further informal care moves out of the immediate family environment.

All this suggests that much more attention needs to be devoted to informal care on the healthcare and independent living agenda. This starts with more systematic provision of training and learning for informal carers, both in terms of practical skills for caring and about the characteristics of the specific impairments, illnesses they need to deal with. It also involves expanding services for respite and advice on coping strategies, options for refitting the home environment to make it conducive to caring and on available financial aid. In addition, a strategy for strengthening informal care requires exploring opportunities for strengthening the cooperation between formal and informal carers and for informal-care giving from the wider social community beyond the immediate family network. ICT can also be used more intensively to support information repositories and information sharing networks for informal carers. Over the last few years, a number of encouraging initiatives have been set up in this regard, such as online information collections for informal carers, phone, online and even videophone help-lines. More needs to be done to expand these networks and support services and share experience about best practice initiatives in this area.

➔ Situate action at the most appropriate level

No single policy arena or community can lay the foundations for independent living single-handedly. Seamless care and effective provision of independent living services are jointly produced by a variety of stakeholders and require a number of policy measures at different levels.

Cities have proved to be good platforms to pull together local resources from several sectors, and launch multi-stakeholder dialogues on joining up services and technologies for prevention and care. Grenoble in France, for example, is piloting a project to fit rooms with assistive devices to support patients with dementia, while the city of Turku in Finland spearheaded an exercising and fitness initiative, as part of its preventive work on the Alzheimer disease.

The subsidiarity principle of the European Union places the responsibility for health policies at the national level. This makes the national and state level the principal policy arena for updating broader policy frameworks on collective health insurance, purchasing and compensation schemes or for establishing budget lines for financial support to pilot projects, lighthouse applications or ILS-related community initiatives.

In addition, there is room and significant demand for a European-wide harmonization and co-ordination of specific ILS-related measures. One example is the development of common definitions and quality standards, even quality certificates or trustmarks, that offer service providers and consumers alike a reliable reference point for what constitutes a wheelchair-friendly bus entrance, or what criteria a website needs to fulfil to call itself accessible to blind people. Establishing such standards at European level, economizes on co-ordination costs, creates an integrated market with economy-of-scale advantages and helps to build trust in the quality of devices and services, where error-free functioning can be critical to individual health. The EC can also act as a facilitator for sharing best practice examples in ILS across regions and for harnessing innovation capacities across Europe for pan-European R&D efforts for ILS.

➔ **Leverage action through user interest groups**

Efforts to more closely involve ILS users in the R&D and implementation process need not start from scratch, but can harness a well developed existing infrastructure of healthcare users' interest associations. *Table 9*, for example, shows the number patients associations for specific diseases in Spain.

Distribution of Patients Associations versus Illness (n=758)		
Illness	Number	%
Alzheimer-dementia	125	16.50
Mental illness	116	15.30
Diabetes	79	10.42
Cancer	55	7.25
Sclerosis	46	6.07
Kidney	37	4.88
AIDS	32	4.22
Rare illnesses	32	4.22
Source: Fundación Farmaindustria 2003		

Table 9: Patients Associations versus Illness

These groups can act as interlocutors with industry to ensure user-centric design, and also be involved to strengthen outreach and awareness about ILS solutions. End-users are often insufficiently aware of the technological possibilities available and do not know enough about the support services and financial aid that they can draw upon to make ILS more affordable and tailor it to their personal needs profile.

➔ Adopt appropriate research strategies to accompany ILS innovation, design, and implementation

Which research strategies are best suited to capturing the complexity and diversity of independent living services across Europe? Which approaches can best guide implementation and help to tailor the development of technology and services to user needs? Here are some elements for a suitable research agenda and strategy:

- A life course approach as a conceptual framework can provide the right level of granularity to account for the diversity of experiences and conditions for independent living. This concept embeds individual health and well-being in particular socio-economic contexts, where it is influenced by individual life events and histories. This offers promising entry points for effective interventions and guidance for customization.
- Working towards a common ontology and language for independent living-related issues can provide the basis for developing quality standards and more comparable statistics, in order to benchmark performance and identify best practice.
- Devising and applying tools for more differentiated and comprehensive impact assessments of ILS are required to arrive at a fuller and fairer picture on the true costs and benefits of ILS services beyond mere cost-savings in the health sector.
- Devising and applying more systematic methods for ILS foresight analysis, including the identification of critical assumptions, contingency factors and policy levels, with regard to ILS can provide guidance for policy-makers and industry alike; and,

- More multi-disciplinary and co-ordinated research efforts are called for, in order to bring technology development for ILS in line with socio-economic realities of the health systems and user expectations and also to share failures, promising innovations and lessons learnt more systematically than is currently the case in the fragmented ILS R&D and implementation landscape.

6. CONCLUSION: SUMMARY OF POLICY MESSAGES

Ageing is a major challenge for European societies. Active ageing, with the help of ILS, presents a major opportunity to harness technological progress for individual autonomy and dignity, for social inclusion and for establishing an effective and efficient health system attuned to the challenges of the next decades. In order to make the best of this opportunity, it is of paramount importance that users and their needs be placed at the centre of Independent Living Services R&D, and its implementation. The workshop has helped to identify a number of research and policy challenges that need to be addressed in this respect:

- User involvement in the R&D chain needs to be strengthened. Too often R&D does not take into account the different needs of what is a very diverse and multifaceted group of users. Institutional mechanisms to systematically consult with and involve different user groups and their interest associations in the R&D process need to be strengthened and expanded.
- Current models of care provision need to take better account of user contexts. At the moment, care tends to be organized and separated into silos across traditional health care structures of intramural vs. extramural care or social vis-à-vis medical care. It thus misses the opportunity to harness new technologies in the service of shared and seamless care provision that coordinates all stakeholders in the care systems, allocates responsibilities to the most suitable level, avoids costly duplication of efforts and minimizes disruptions in the care recipient's daily life. A new culture and institutional structure for co-operation between stakeholders needs to be created. Integrated health information systems that bring together patient information from different providers will provide the backbone architecture for this new model of care, which will require incentives to co-operate and share information across organisations.
- Support for informal carers needs to be strengthened. Informal carers are the most important providers of care services in many contexts, but changing lifestyles, socio-economic conditions and demographic co-ordinates put enormous pressure on these informal support systems. Their role needs to be recognized more firmly in health policy-making and ways to support informal carers through ICT and to co-ordinate their work better with formal care needs to be systematically explored.
- Awareness of ILS and the opportunities they offer is limited among potential users, professional organisations and policy makers alike. Outreach strategies that familiarize all stakeholders with technological options already available and under development are required. Such efforts will help not only to match existing demand and supply better, but also to prepare the ground for more interaction between users, policy-makers and industry in the development of ILS and supporting policies that are more closely aligned with user needs. More efforts to raise awareness of ILS could convey a more realistic image of ILS and allay some fears and misunderstandings about its negative impacts. ILS cannot be a substitute for human care, but it can strengthen the latter. Moreover, ILS cannot be driven by cost-saving concerns only, since its potential lies in enhancing the quality of care for many, as well as in making care more effective. Helping to foster such a balanced notion of ILS will lay the foundations for pragmatic policies and realistic societal expectations.

- Policy-makers need to pay attention to affordability and inclusion issues, in order to spread the benefits of ILS widely, avoiding the risk that emerging ILS solutions are exclusively geared towards the needs of high-income users. Market forces alone are unlikely to ensure this widespread diffusion of ILS. Complementary policy interventions, however, can go some way towards opening ILS to wider user groups by helping to target R&D on priority needs and by diffusing excessive risks for business in this area.

- Fragmented research efforts need to be better co-ordinated and lessons learnt/ best practices need to be shared more systematically. ILS research is a multi-disciplinary affair, involving engineers, social scientists, economists, architects etc. Fostering a concerted dialogue between these experts is not easy. Agreeing on common definitions for key ILS concepts and on standards for measurement, service quality and technological interoperability can lay the foundations for easier communication flows and more systematic exchange of experiences.

7. AGENDA

Day 1 - Thursday, 24 Nov 2005

Avenue de Beaulieu 31 - 1160 Brussels (6th floor, room 30)

- 14:00 Arrival
14:05-14:15 Welcome and introduction, Gérard Comyn, Head of Unit "ICT for Health", DG INFSO/H/1
14:15-14:25 Keynote speech, Renate Heinisch, Member of European Economic and Social Committee

Session 1: Views on Older People Needs-I

- 14:25-14:40 Ageing and differences across the EU: The SHARE survey, Hendrik Jürges, MEA.
14:40-14:55 Views from the European's Older People Platform, Anne-Sophie Parent, AGE.
14:55-15:30 Discussion
15:30-16:00 Coffee Break

Session 2: Views on Older People Needs-II

- 16:00-16:15 Future societal trends and older technology users' needs, Heidrun Mollenkopf, DZFA (German Centre for Research on Ageing at the University of Heidelberg).
16:15-16:30 Past experiences and future prospects on older user needs, José Luis Monteagudo, Instituto Carlos III, Madrid.
16:30-16:45 Older user experience: Canadian perspectives, Dr. Louise Plouffe, WHO.
16:45-18:00 Discussion

Day 2 – Friday, 25 Nov 2005

Avenue de Beaulieu 33 - 1160 Brussels (ground floor, room 54)

- 09:00-09:10 Summary of first day discussions, EC organisers

Session 3: Independent Living Services and Special Health Needs

- 09:10-09:25 The evolving needs in family care, Lennart Magnusson, Boras University College, Sweden.
09:25-09:40 "Views from AAL 169 initiative – results from national user-supplier dialogues", Hartmut Strese, AAL 169 Initiative.
09:40-09:55 Alzheimer and user needs, Alain Franco, HAD, Département de Médecine Gériatrique et Communautaire CHU, Grenoble.
09:55-10:30 Discussion

Session 4: Independent Living Services and Health Needs

- 10:30-10:40 Introduction: Marcelino Cabrera, JRC IPTS.
10:40-10:55 Results from the Independent Living Service study, Josephine Dries, TNO.
10:55-11:05 The lifecourse perspective and technological needs for older age, Mark Leys, VUB.
11:05-11:30 Discussion
11:30-11:45 Coffee Break

Session 5: Technology and Older Users Health Needs

- 11:45-12:00 User perspectives in iWell and FinnWell experiences, Kalevi Virta, TEKES
12:00-12:15 Smart Home Technology: Technology supporting independent living, Toril Laberg, The Delta Centre, Oslo.
12:15-12:45 Discussion
12:45-13:00 Workshop Conclusion, Gérard Comyn, Head of Unit "ICT for Health", DG INFSO/H/1

8. GLOSSARY

Activities of daily living (ADLs): Self-care activities that a person must perform every day, such as bathing, dressing, eating, getting in and out of bed, and moving around.

Ambient Assisted Living (AAL): AAL is a concept which aims to prolong the time people can live decently in their own homes by increasing their autonomy and self-confidence. This may involve the discharge of monotonous everyday activities, or monitoring and caring for the elderly or the sick, in order to enhance their security and save resources.

Assistive Technology: Any device, or equipment that is used to maintain, increase, or improve the functional capabilities of individuals with disabilities.

Independent Living: Ability to perform the activities of daily life with little or no help from others. The notion of independent living is strongly connected to the idea of “community integration”, implying that people should not be institutionalised unless it is necessary.

Independent Living Services (ILS): ICT supported services to help people with disabilities and chronic diseases to be more independent. They also help communities to eliminate barriers to independence.

Informal care: Long-term care provided by spouses/partners, other members of the household and other relatives, friends and neighbours. Informal care is usually provided in the home and is typically unpaid.

Information and Communication Technologies (ICT): ICT is defined as a combination of manufacturing and service industries that capture, transmit and display data and information electronically.

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Abstract

The ICT for Health Unit of the Directorate General Information Society and Media (DG INFSO) and the Institute for Prospective Technological Studies (IPTS, DG Joint Research Centre) of the European Commission organized a joint workshop on "User Needs in ICT Research for Independent Living, with a Focus on Health Aspects". The objective of the workshop was to identify and discuss the main issues, from a user's perspective, regarding ICT for Independent Living with focus on health aspects in the ageing society. This report on the workshop aims to contribute to a clearer needs-oriented focus of the Ambient Assisted Living (AAL) initiative, a 5 year R&D project involving the European Commission, the Member States and European industry.

Understanding the needs of different users is crucial for the success of Independent Living Services (ILS), as it is in all ICT application areas. Older users are not a homogenous group and their needs vary significantly according to the socio-demographic and socio-economic characteristics of the group. This report focuses on the different target groups of Independent Living Services, active older people who prevent themselves from getting diseases through 'wellness' activities; older people with slight physical and/or mental handicaps, informal carers such as relatives of the older people. Understanding the needs of other ILS user groups such as professional carers and a broader group of professionals in the health system would also be required, but this has been excluded from this study in order to better focus on older users and informal carers.

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