From Applications to Policies: ICT-based Independent Living Services in the EU

MARCELINO CABRERA AND RUKİYE ÖZCIVELEK

INTRODUCTION

Information and Communication Technologies (ICT) play a critical role in fulfilling strategic objectives of ageing societies. Several European research programmes have been supporting a range of projects that promote independent living and quality of life in an ageing society using new ICT-based applications and services, with a view to enabling older people to live more independently. Notably, the European Action Plan ‘Ageing Well in the Information Society’ represents a big research programme targeted at improving the life of older people in general. Between now and 2013, the EU, Member States, and the private sector will invest more than €1 billion in research and innovation to promote ‘ageing well’: some €600 million in the Ambient Assisted Living (AAL) programme, an expected €400 million in the EU’s latest research framework programme and about €30 million this year in the EU’s ICT Policy Support Programme. The following countries participate in the AAL programme: Belgium, Denmark, Germany, Ireland, Greece, Spain, France, Italy, Cyprus, Luxembourg, Hungary, The Netherlands, Austria, Poland, Portugal, Romania, Slovenia, Finland, Sweden and the United Kingdom (the participating Member States) as well as Israel, Norway and Switzerland.

AAL and ‘Independent Living Services’ (ILS) are being used as corresponding concepts. ‘Assisted Living’ is usually defined as a system of housing and limited care that is designed for senior citizens who need some assistance with daily activities but do not require care in a nursing home. ‘Independent Living’, however, was originally coined in the context of people with disabilities. The term includes measures to enhance self-esteem, and self-determination, and the provision of socioeconomic resources that allows people to choose and maintain their individual lifestyles, while Ambient Assisted Living (AAL) aims to prolong the time people can live decently in their own homes by increasing their autonomy and self-confidence (Huch 2006). ILS do not only aim to prolong the time older people can lead more independent and participatory lives, are increasingly reflected in various policy areas. ICT-based ILS consist of different levels of applications, ranging from telecare applications to assistive technology services. Although a variety of ILS is available on the market today, there is no solid evidence as to the extent that demand and supply match. Existing data indicate that ILS technologies and systems are not widely used or distributed. ILS require in-depth assessment as they are inherently complex value chains which encompass many ICT-based applications and affect different policy areas. To date, few evaluations of policies in the ILS area have been carried out.

In this paper, we propose a framework for analysing and reviewing existing applications and relevant national policy areas in Europe. We also combine our research with the outcome of a high-level expert workshop. This work is based on the results of a research project commissioned by the Institute for Prospective Technologies of the Joint Research Centre (European Commission). We conclude with some observations on the challenges and the evolution of ILS.

Keywords: independent living, active ageing, ICT for ageing, ambient assisted living, social inclusion, ageing policies

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stay in their homes, but also to allow them to live and participate actively in society. The concept of ILS is therefore holistic in the sense that it encompasses socio-economic motives such as inclusion and wellness of older people.

There is increasing policy and funding interest in supporting independent living for older and disabled people. Correspondingly, there is a body of literature that describes a number of existing applications. There is, however, a lack of in-depth evaluation of policies that promote independent living services, and of the services themselves. According to a recent study (Koch 2005), most of the publications on this subject have the USA as their geographical scope, and refer mainly to home healthcare. This paper evaluates ILS applications together with policies through some illustrative applications. Obviously, the selection of applications described here is not exhaustive. A work package of the study this paper is based on was devoted to the inventory of ILS related policies, applications and contextual factors.6 We first set some necessary definitions and discuss determinants and barriers of independent living. After suggesting a model for the design of ILS, we discuss three application areas and explore related policies in these areas. The last section discusses challenges and gives recommendations and conclusions. The discussion in this article is based on the results of research conducted by JRC/IPTS on ‘The Future of Independent Living Services in the EU’,7 an international expert workshop8 and the analysis of recent scientific and policy literature.

INDEPENDENT LIVING SERVICES

The World Health Organization (WHO) defines independence as the ability to perform the activities of daily life with little or no help from others (living independently) (WHO 2002). ‘Independent living’ comes from a philosophy which states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities. The independent living philosophy promotes full participation by people with disabilities in society, and its main objective is to diminish the physical, economic and attitudinal obstacles that confront physically impaired people, with a view to integrating them into society. Leys and Rouck suggest that ‘the social model of disability’ should be applied to other groups such as older people, lower socio-economic groups, women, etc (Lays and Rouck 2006). An ‘independent living service’ is defined as any product, application or service that enables people, whose independence in daily life is challenged, to lead a more independent and participatory life.

The design of independent living services requires that the barriers to independence be determined. The main barriers to independence for older people are considered to be frail physical and/or mental health, housing conditions, lack of transportation facilities, community information and communication services, and low income levels (IPTS 2006). The most common physical and sensorial health barriers are: low mobility levels, 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 (IPTS 2006). Different surveys on the subject show that disability increases with age. For example, on average only 2.7% of people aged 25–34 are severely hampered, but this proportion reaches 13.9% for the age group 55–64 and further increases to almost 39.1% for people above the age of 85. The proportion of those moderately hampered increases more rapidly, from 8% in the age group 25–34 to 28.8% for people aged over 85 (OIF 2003).

It appears that independence in the older age groups is effectively enhanced by achieving healthy ageing. Therefore, determinants of health are also significant for independent living. Dahlgren and Whitehead’s (1991) model of health is accepted as a common model for the determinants of health. According to this model, interactions with friends, relatives and mutual support within a community can sustain people’s health. Wider influences on health include living and working conditions, access to essential goods and services, and the overall economic, cultural and environmental conditions prevalent in society as a whole. This model may also be used in the design of Independent Living Services. ICT-based products, applications and services provide new ways of interacting with friends, relatives and also lead to new ways of getting mutual support within a community. Several existing ICT-based products and services aim to improve living and working conditions. Among existing ILS applications, examples are described in the areas of employment, helping family carers, home health monitoring systems, telecare services, smart home services and information and networking platforms as discussed later.

Independence in the older age groups could be most effectively enhanced by achieving healthy ageing. This is made more likely by a supportive environment with sound economic, social and environmental conditions, including adequate and equitable income distribution through paid employment and social security provisions. Well-developed cohesive communities, high levels of accessibility 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, and hence independence.

Currently there are a number of day-to-day services and advanced applications of direct interest to older citizens and to people from other population segments. Technologies for working environments, for example, could help in extending working life in flexible and adapted ways. Domotics and robotics can support the smart management of homes and relieve many people...
from daily heavy tasks. New opportunities for people with mobility restrictions to participate in life can also be opened up through the access to services and content in the information society. The opportunities for developing new healthcare technologies are the key to realizing paradigmatic changes in healthcare.

**ILS APPLICATION AREAS AND POLICIES**

Policy fields include different arenas and concepts equivalent to the different application areas of ILS, like telecoms and information society, design for all, health, social, housing, employment, ageing policies and e-Inclusion policies. ICT-enabled independent living indeed requires coordination between many sectoral policies. For instance, housing is a policy that needs attention, as the home is the usual environment of older people. The most recurrent example of solutions for housing, which permit people to live more independently, are smart houses with domotic technologies.

Different ILS technologies and applications are illustrated in Figure 1 (Hüsing and Kubitschke 2006). As the arrow in this figure indicates, some of the applications already exist and some are still in development. The complexity of different technologies varies between mainstream everyday products and services, to ambient intelligence and newly-emerging materials. ILS cover assistive technologies, smart homes, workplace technologies, different online services, disease-specific healthcare technologies and telecare services. Functional problems, common among older people, can be alleviated by assistive technologies, as represented in the first column of the figure. This paper limits its focus to some illustrative health-related ILS applications and policies.

**ILS FOR FAMILY CARERS AND INFORMAL CARERS**

Health is the most important determinant of independence and informal family care is the predominant model of support for older people across Europe. This is due not only to economic constraints and community care policies but also to socio-cultural values regarding the role of the family. Thus family carers are becoming the key actors in the provision of care and their needs in fulfilling this role become essential in any vision of ILS. The core needs of family carers consist of information, education and support. Information and education centres teaching practical caring skills in daily life are therefore required. Family carers need knowledge about the illnesses of their relatives, common problems and treatment. They also need to be supported in their role (IPTS 2006).

There are already some examples of ILS solutions for family carers in different European countries. For example, Online Dementia Information (Emilia-Romagna Sociale 2008) is a regional website, in the Emilia-Romagna region of Italy, dedicated to dementia problems, where citizens can ask questions directly to a group of experts (geriatricians, neurologists, psychologists, therapists, nurses, lawyers). In the Netherlands, a virtual platform was created where people who need care are helped with the administration and organization of their own network of formal and/or informal carers. Carers are able to reschedule their tasks between...
themselves and exchange information between them and with the care receiver (Giesbert 2005).

An emerging application is social networks, matching families with care and service providers. For example, Care.com has launched their Family 2.0 site, which aims to match families with care and service providers in areas or industries such as childcare, tutoring, pet care and senior care (Family 2.0 2005). Another example is ‘CareSquare’ which is also a community website connecting parents and carers in a social network. It allows for peer-review, feedback, and real-time booking of care (CareSquare 2008). Both carers and families create their individual profile pages. Parents can network with each other, rate and review carers they have used, and read feedback left by others. Another example is ENURGI, a web-based healthcare services company that connects families and patients in need with local, clinical carers across the country. ENURGI allows patients, family members and carers to independently manage the care processes through online scheduling, messaging, referral and direct payment transactions (ENURGI 2008).

**ILS FOR HOME CARE SERVICES**

ICT-based home care service is a very broad term, and it may comprise anything from e-mail consultations, educational programmes for patients/family carers to advanced monitoring systems. Any ICT support at the point of need (home) might be regarded as ICT-based home care. Telecare, i.e. health and social care provided at a distance using ICT, generally to people in their own homes or the wider environment, is the widely used term for remote care of elderly and vulnerable people, providing the care and reassurance needed to allow them to remain living in their own homes. Use of sensors allows the management of risk and is part of a package which can support people with dementia, people at risk of falling or at risk of violence, thus preventing unnecessary hospital admission.

Telecare services are usually developed within the context of their role with other services. They aim to maintain the independence of older and other vulnerable people, allowing them to exert greater control over their lives and manage their own risks. Home health monitoring systems send data via the Internet or telephone lines to monitoring institutions that give feedback and may directly take the necessary measures. An example of this application is ExcelicareDirect, a pioneering project which uses Interactive Voice Response (IVR) technology. This was adopted by the Glasgow Royal Infirmary (AxSys 2008), to monitor rheumatology patients at home for medication compliance and side effects. Social alarms are the most widespread telecare applications in Europe and provide an emergency service. Penetration varies considerably between countries, however. They are most used in the UK, where they have reached large parts of the older adult population.

Smart housing is also included in the ILS application areas, as part of home care services. Smart Home Technology is a collective term for information and communication-technology in homes, where the components communicate through a local network. Smart homes aim to help frail people and people with all kinds of disabilities (physical, mental or sensory). Automation can include heating, security devices, entry/exit, control lighting control, on/off controls of various appliances and home entertainment. In the last two decades, a market for smart housing has emerged in many European countries, but the take up has been very small. For example, Norway has 10 years of experience with smart home technology as part of home care services (Laberg 2005). The Smart Homes Association started in 1993 to pioneer smart home technology projects in the Netherlands. In the 1990’s, there were some ten smart home projects in Finland (Roe 2006).

According to Essén (2006), in Sweden, large firms in the construction, electronics and automation industry are not explicitly or directly active in the development of new smart senior housing solutions. Many tried in the 90s and experienced market failures. The missing market breakthrough is often associated with the lack of coordination between the actors involved: IT and telecommunication suppliers, and manufacturers of white goods, other edificial appliances, entertainment electronics and security devices. The various different network techniques constitute a particular hindrance: for instance, Ethernet and WLAN for computers and consumer electronics, the European Installation Bus (EIB) for household appliances and edificial devices, and separate networks for alarm systems. Others have experimented with data exchange via power lines, Bluetooth or DECT (Digital Enhanced Cordless Telecommunications).

**ICT POLICIES FOR EMPOWERING FAMILY/INFORMAL CARERS**

There is a lack of good quality, comparable data on how ICTs are addressed in policies for empowering family and other informal carers. The SHARE survey (SHARE 2008) shows that patterns of support differ between countries, revealing a strong North/South European divide. A higher proportion of older people are involved in family support in the northern and continental countries, whereas in the southern countries help and support tends to be confined to a few individuals within the immediate family who are more intensely involved as either the givers or receivers of care. According to EUROFAMCARE (2008) project survey reports, family carers were rarely considered in the 23 countries as part of the paid labour force, with the main focus of interest
and data being on the potential and actual impact of family care on labour market participation. According to the SeniorWatch project, only two member states make specific reference to the use of ICTs in policy documents on empowering family carers. In the UK, a reference appears in the ‘National Strategy for Carers’ (1988), which recognizes 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 the strategy makes significant reference to the use of new technology as an important means of helping carers. In Belgium, a regulation that addresses the use of personal alarm systems for use in homecare has recently changed to allow for the use of more than one type of device (only one was covered before). It now allows for the use of a range of emergency alarm systems, such as video telephony, thus providing more choice to family carers.

In Austria, for example, family carers are recognized in general policy. People who choose to look after their relatives are provided with a fiscal allowance for this purpose. Although there was no explicit reference to the use of ICTs in Austrian policy documents, there are some ICT-based initiatives including a web-based and free-phone information and advice service for family carers. In Spain, although there is no ICT-related policy to empower family carers, the potential that ICTs offer is very much recognized by the experts consulted in the report. They estimate that the use of ICTs in home-based family care will grow considerably, especially in the following areas: teleshopping, telemedicine, computerized mobile telephony, video telephony and some aspects of integral domotics. In Finland, the discussion surrounding ICTs and family carers has intensified. One initiative to result from this discussion is the ‘Satakunta Macro Pilot’ in which family carers are supported by a ‘coverage system’ which gives details of support and back-up carers held in a centralized information system.

So far, truly innovative ICT policies directed towards empowering family/informal carers do not seem to exist in Europe. However, the general tendency of giving more importance to informal care is there. The costs for formal care are increasing fast in many countries, and ICT could provide a solution by supporting informal carers. Though it can be expected that the use of ICTs to support informal care will increase in the future, this will be the result of spill-over effects from general ICT policies, rather than specially dedicated policies. ICT has very often been easily implemented in small-scale initiatives where direct personal advantages are tangible and immediate costs do not need to be large. So, ILS for family carers could be a promising area for implementation after all.

### POLICIES RELATED TO ILS AND ACCESSIBILITY

The EC (2005) published a Communication on eAccessibility in September 2005. It describes eAccessibility as overcoming the technical barriers and difficulties that people in general and those with disabilities experience when trying to participate on equal terms in the Information Society (IS). eAccessibility is seen as part of the broader e-Inclusion concept, which also addresses other types of barriers (financial, geographical or educational). Three categories of policy are analysed: anti-discrimination policy, design for all policy and other policy areas on assistive technology services.

#### Anti-discrimination policy for ICT based services

According to a study (Empirica 2007) which assesses the eAccessibility status and policy situation in Europe, people with disabilities in Europe continue to be confronted with many barriers to using everyday ICT products and services that are now essential elements of social and economic life.

The principle of functional equivalence in telecoms is crucial for people with sensory, speech and other impairments that affect communication options. This principle requires that basic communication functions, such as those provided by voice telephony to the majority of subscribers, are available to all. Adopting this principle means providing amplification, inductive coupling or tactile keypads to those who can make use of...
voice telephony, and equivalent services like text telephony and text telephone relay services for those who cannot. A practical example for ICT-related policies would be to make obligatory the inclusion of tactile indicators for people with visual impairments in all public telephones.

A recent study (2007), across Europe and other countries,\(^\text{11}\) considers the United Kingdom to be strong because its equality/anti-discrimination legislation obliges public agencies to use ICTs for internal and customer-facing purposes and also offers individuals the opportunity to seek redress in relation to both public and private service providers. The main legislation in this area in the UK is the Disability Discrimination Act of 1995 (which, in 2001, was the only anti-discrimination act in Europe, according to SeniorWatch national experts). The act outlines that telecommunication services should be universally available and should not discriminate against users because of their disability. A number of non-governmental regulatory agencies and pressure groups operate in the area of ICTs to ensure and improve services for disadvantaged groups. In Denmark, anti-discrimination legislation has been part of the Social Security Act for some time.

Though regulations for people with disabilities exist in several European countries (e.g. the Spanish law ‘Social Integration of the Disabled’ 1982; The Disability Concept of the Austrian Federal Government, 1992; The Fundamental Law of the Federal Republic of Germany, 1994), these policies do not refer to equivalence of access in ICTs or telecommunications. In other countries without explicit anti-discrimination legislation, the issue of equivalence of access to telecommunications is addressed in other more general integration policies or legislation. For example, in the Irish ‘Designation of Universal Service Provider’ document (1999), a fixed operator or person designated by the Director of Telecommunications Regulation is required to maintain affordable services for users in rural and high cost areas and also vulnerable groups of users, such as the elderly, and people with disabilities and special needs. In Italy, it is stated that the State is committed to ensuring full participation and integration of people with disability into society on an equal footing. In Spain, a programme entitled ‘The Programme of Global Accessibility’ was agreed between the Ministry of Employment and Social Affairs and the Fundación ONCE (The Spanish national organization of blind people).

**Table 2. The main cluster of countries with ‘design-for-all’ policies**

<table>
<thead>
<tr>
<th>No specific policy but guidelines exist</th>
<th>No specific policy but covered in other policy areas (e.g., e-Government)</th>
<th>No specific policy but some concrete measures/initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finland, Netherlands</td>
<td>Austria, Denmark, France, Germany, Ireland, Italy, Luxembourg, Netherlands, Portugal</td>
<td>Belgium, Spain, UK</td>
</tr>
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*Source: SeniorWatch: D.5.1 Older People and Information Society Technology 2002*

Design-for-all Policies

The EC Communication on eAccessibility describes the ‘Design-For-All’ concept as a methodology to design products and services that are accessible to as broad a range of users as possible. The European Design for All e-Accessibility Network – EDeAN is a network of 160 organizations in the European Union member states. The goal of the network is to support all citizens’ access to the Information Society.

A practical example of design-for-all policy can be found in the USA where the regulations have forced government web pages to guarantee access to the blind, the deaf and other disabled people. Across Europe both the ‘design-for-all’ concept and the aim, although not explicitly labelled ‘design-for-all’, is increasingly visible in strategy statements and concrete measures.

Finland and The Netherlands were the forerunners in this area in Europe. Although there were no specific legislation or regulations concerning design-for-all in 2001 in Finland, government statements and some government-initiated research and development projects exist. For example, in the Finnish Consumer Policy Programme, 2000 to 2003 (the Advisory Council on Consumer Affairs, Ministry of Trade and Industry) special attention is given to the ageing of the Finnish population, in relation to, among other aspects, the Information Society. The programme states that IS services must be available to all population groups both technically and economically and that all population groups must be able to use essential services with reasonable conditions. It also states that IS services and products should be usable in different phases of a consumer’s life and require few modifications. The programme highlights ICT as an important facilitator for bringing everyday services to people with disabilities and advancing their independent living.

Norway has a Plan for Universal Design with the purpose to implement and use universal design in all relevant decision making in public administration. It is a government objective that the principle of universal design shall form the basis of development and
procurement activities. The Dutch government has no regulations towards Internet-for-all. However, the Dutch government has signed a declaration of intent in which it undertakes to make all public administration websites accessible according to W3C guidelines. The government promotes accessibility of public Internet services in a general way, not just to older people or people with impairments.

Other countries without specific policy or legislation appear to have addressed the design-for-all issue in other general policy areas. In Austria, France, Germany, Ireland, Italy, Luxembourg and Portugal, e-Government policy in particular appears to be the dominant driving force, with several initiatives aimed at implementing the sub-concept of Internet-for-all. In Italy, the Framework Law on Handicap, although not a design-for-all policy per se, commits the Government to undertaking initiatives to improve the accessibility of television and telephone services to people with sensory impairment and to facilitate the diffusion of ICT among people with disabilities. Furthermore, the ‘Stanca Act’ (2004) in Italy (www.pubbliaccesso.gov.it) aims to ensure that public procurement of ICT equipment adhere to accessibility guidelines, that workplaces and training measures for public servants be equipped accordingly, and that public funding be tied to an obligation on the part of the recipient to obey accessibility guidelines.

The situation in Belgium, Spain and the UK is different with initiatives happening in areas not directly related to e-Government policy. For example, in the UK, the PhoneAbility organization (independent focal point for telecommunications and the needs of disabled and elderly people) has attempted to introduce a basic set of ICT and design-for-all related requirements. In Belgium, the relatively small initiative Agetree, an interactive website, aims to contribute to the development of innovative products for older people by putting the knowledge generated by older people at the disposal of product developers and industry.

Other policies for assistive technology services

Provision schemes of assistive technology (AT) vary considerably across Europe. In Denmark, Finland, France, Germany and Italy, legislation is in place that explicitly deals with the AT issue, i.e. the Danish Social Assistance Act; the Finnish Social Welfare Act (1984) and Services and Assistance for Disabled Act (1988); the French Disability Act (1975); the German Ninth Book of the Social Code (SGB IX) (June 2001); and the Italian Health Reform Act (1978) and Social Services Reform Act (2000). In other countries, the service delivery process is quite complex and numerous pieces of legislation and several institutions are involved. In this section, an overview of the current AT services delivery processes will be summarized within the EU context. It presents the main clusters of countries with such processes and distinguishes between those with a clearly defined process and those without.

The majority of Member States have a clearly defined AT service delivery process. For example, Belgium has a clearly defined, though complex, one. Here, there are numerous pieces of legislation dealing with the delivery of services and AT to people with disabilities. Different systems of support are responsible for the provision of AT depending on the origin or cause of the disability. Belgium is divided into three communities and, in each, services are delivered through Public Centres of Social Welfare which are autonomous establishments decentralized to local level. In The Netherlands, several pieces of legislation also deal with the provision of services to disabled people. One piece of legislation specifically covers the provision of AT, giving all Dutch citizens the right to equipment and technical devices if these are medically prescribed. However, although the Dutch service delivery process is clearly defined, several institutions are involved depending on the type of AT required, i.e. whether a person requires an AT for work/education, transport/mobility, or for general care. From this analysis, a picture emerges across European AT service-delivery processes that is relatively analogous. Systems tend to have several players or sectors involved, depending on the type of AT required. Also AT delivery processes are predominantly based at regional or local level, as are the final decisions regarding eligibility.

However, in another cluster of EU countries (Austria, France, Portugal and Spain) there does not appear to be any clearly defined delivery process. For example, in Austria the process appears unclear and complex with services provided at the level of nine federal social security departments. Who qualifies for services is also decided on a federal basis. In France, the process is more rigorous and centralized with limited eligibility. AT is delivered at department level through the offices of the Sickness Insurance National Fund (Caisse Nationale d’Assurance Maladie des Travailleurs Salariés – CNAMTS), which is responsible for the lending, purchasing, and repair and reprocessing of AT. In Portugal, there are a variety of AT service delivery systems and a number of organizations are involved in the provision of AT, however the overall responsibility of AT services rests with the National Health Service.
As a conclusion, it could be said that policies related to the application of information and communication technologies in the health and care sector are slowly gaining ground. Assistive technology policies which are translated into actual laws have so far been limited to telecommunications and telephony and have not been adapted to new media to any great extent yet. Germany is an exception in this having introduced the ‘Law for Mainstreaming Handicapped People’ which pays special attention to barrier-free communication and requires public sector bodies to create an Internet presence suitable for disabled people. Apart from this, Design for All policies are increasingly visible in strategy statements and concrete measures. However, compared to the explicitness with which US regulations organize accessibility for disabled people to, for instance, government web pages and government ICT hard- and software, European measures are, generally speaking, quite modest.

In many European countries, assistive technology services are often delivered within a complex organization of partners and players, and different levels of government responsibility. Service providers, often public organizations, have problems getting the message across to their potential clients about which services they are entitled to and how to apply for them. In Spain, delivery of services is very fragmented among a carousel of organizations. A general trend is that delivery of services is more and more locally organized, close to older people’s daily lives.

CHALLENGES AND RECOMMENDATIONS

Independent living services constitute a complex value chain, which involves different ICT applications and policy areas. The various ICT application fields relevant for ILS vary considerably in terms of actors and service delivery chains involved and also in relation to market maturity.\(^1\)\(^3\) Independent living is becoming one of the emerging priorities at European level and in different national and regional health and welfare policies. One of the challenges is to coordinate different policies in a range of areas like healthcare, social, employment, housing and ageing. For example, the roles of housing corporations are changing. These corporations, national government agencies that fund new affordable housing and regulate housing associations, are becoming important actors in the provision of ICT-based ILS. One of the future priorities for developing ILS at European level is to co-ordinate and integrate a particular vision and approach to ILS issues, particularly for the older people (IPTS 2006b).

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Independent living is a concept and social field encompassing a broad spectrum of citizens and social groups (including people with disabilities, marginalized groups, etc.). Independent living for an ageing society should, in particular, focus on the different needs and perspectives of the people in this ‘category’. The development of ‘systems’ must be adapted to the broad spectrum of needs, demands and preferences of this group. It is imperative that older people are not seen as a uniform group, with specific shortcomings and impairments that have to be compensated. Current policies, programmes, and initiatives, too, often consider older people as one entity of 60+ or 65+ with particular (mostly negatively defined) characteristics. The development of ILS should be based on a more explicit strategy to identify the potential roles and expectations of different categories in society, and adapt the systems to these demands and needs. ICT holds many more possibilities for supporting independent living in a more positive way: communication, exploring old/new interests, lifelong learning and, through this, supporting a higher standard of living (avoiding isolation, depression, and social factors that force people into requiring care and support). As well as care-related ILS, welfare-related ILS needs further exploring and stimulating, especially for different segments in the older age group.

At a European level, the complex and heterogeneous group of ‘ageing people’ lives in quite different contexts, depending on individual backgrounds, preferences, and expectations, and geographic and collective (cultural, social, economic, legal, political) factors. At the centre of this issue is the art of developing ILS which can be personalized enough to be experienced as customized services by the target group. At the same time, ILS should be developed in such a way that economic added value can be generated, enabling a healthy entrepreneurial atmosphere: costs should be proportional to the benefits that are gained by clients, entrepreneurs and society. According to Essén’s analysis, many of the projects have failed due to lack of funding. For this particular field, a better understanding and development of public-private alliances is needed.

ICT development in care and support settings focuses mainly on professional and formal forms of care provision. In an ILS perspective, one needs to consider informal carers, too. Developments in healthcare and social care provision – especially those induced by the need to control public and individual spending and by new visions about older peoples’ role in society – urge us to reflect on the structural integration of informal care in the formal models of welfare policy. The fact that millions of people who need care receive it through informal networks, is only now slowly being recognized by society. In some countries, the first steps have been taken towards formulating policies that pay attention to the special situation of informal carers, although, generally informal carers are still not sufficiently considered. Therefore, ILS policies should not limit their perspective to older individuals, but should include also the context of relatives, informal carers, and formal care (in its different forms). Formal and informal forms of
support and care are essential for living independently and can be supported by ICT.

There are several ILS applications on the market today and Europe is spending an important part of its research and development budget on ILS development projects. One of the problems of Europe today is that existing technologies and systems are not widely used and distributed. It has been estimated that there are currently more than 20,000 assistive technology products available in Europe. However, it is widely accepted that there are significant market and supply failures in Europe in this domain, although there is no reliable estimate of the numbers of people actually using these technologies. The market failure of smart housing is another example. The missing market breakthrough is often associated with the lack of coordination between the actors involved: IT and telecommunication suppliers, and manufacturers of white goods, other edificial appliances, entertainment electronics and security devices (see above on the various different network techniques for household appliances and edificial devices, and separate networks for alarm systems).

There could be many different reasons for this demand and supply mismatch, but it is becoming clear that the developers and producers should also consider many different social policy areas. The wide acceptance of many different technologies and applications was not foreseen, for example, mobile phones, and web2.0 technologies. For ICT-based ILS, the situation is different, there are different technologies and applications on the market, but there is not much evidence that all meet with demand. The solutions themselves can even become a problem for researchers and policy makers and much effort has been dedicated to ensuring these are actual solutions.

An exhaustive list of recommendations for policy making and the provision of assistance by governments can be found at the final report of the project that has inspired this article. Some crucial ones include:

The necessary involvement of different groups of users in ILS development projects, which should be far more encouraged, with particular attention paid to developing and implementing methodologies.

The ‘user’ should not be considered as the sole individual end-user of a service or technology. ILS is developing in a complex field of different kinds of users, having particular roles and relationships.

Informal, home and institutional care need to co-ordinate their activities adapted to the particular needs of different groups of older people: the care-seeker and his ‘context’ and such public-private partnerships of ILS providers should be able to co-operate easily in order to set up assistance at their level of needs.

More fundamental reflection and evaluation is needed about advantages and disadvantages of public-private cooperation in this particular field. In order to stimulate the industry, one needs clearer business models, adapted to the specific ‘market’ characteristics of the sector.

Uptake of ILS-related technologies that are already available today should be improved. A large number of pilot implementations and small-scale trials have clearly shown that ILS can help to improve the quality of life of older people, and this holds true for both lower-tech solutions, such as item locators, and more complex applications, such as remote care.

The identification and recognition of informal carers is an important element in the care chain for older people. It is therefore identifying, encouraging and cherishing the small-scale (ICT) initiatives adopted by individual or small groups of informal carers.

Strong actions are required to promote the potential of ICT-supported ILS among a wide audience, by involving small-scale user groups in the orientation phases of new building initiatives and let them join innovative project visits, and creating (discussion) fora for users of ICT-supported ILS pilot projects where they can share their experiences with other users.

More research and evaluation/assessment is necessary of ILS-related policies on the impact they have on older people and their context. Currently, too little is known about the effects of policy, and evaluations are too much focused on short-term effects. It is equally important to learn more about the effects in a larger context around the target group on the mid- and long-term.

Rather than installing ‘traditional’ integrative platforms for enforcement of multidisciplinary ‘joined’ policy development, a real effort should be made towards integrating social mechanisms and channel user needs in ILS-related policies. Through these channels user parties should be able to join the development of and debate on ILS and the use of ICT for them.

As explained, independent living for an ageing society should, in particular, focus on the different needs and perspectives, but there is a broad spectrum of needs, demands and preferences of older people, who are not to be seen as a homogeneous group. It is this variety of needs, demands and preferences that makes independent living a complex field. This paper has given a comprehensive overview of a number of facets of the independent living notion and the policies and actions that support it. However the overall independent living space is broader and more complex than has been reported herein. In particular, as we age and become less able to perform as we did in our youth, all of us will wish to enjoy independent living support irrespective of whether we suffer a specific disability. Clearly we all can benefit from ICT as we ‘age well’. It is also clear the totality of independent living requires deeper and more comprehensive data collection and socio-economic analysis.

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Notes

2. The Future of Independent Living Services in the EU, 2006, IPTS, JRC, EC.
3. The Action Plan aims to: overcome technical and regulatory barriers to market development, through market assessments and by facilitating the exchange of best practice between Member States; raise awareness, and build consensus via stakeholder cooperation in 2007 and establish a best practice Internet portal; accelerate take-up through, for example, a set of pilot projects and a European award scheme for smart homes and independent living applications; and boost research and innovation by immediately supporting a joint public-private research programme dedicated to ‘ambient assisted living’. It aims to foster the emergence of innovative, ICT-based products, services and systems for Europe’s ageing population. See: http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/launch/index_en.htm
4. The programme AAL is prepared as a so-called Article 169 initiative – referring to the respective article of the European treaty. This article allows the EC to participate in the AAL programme which, however, remains a member state driven initiative in the first place. See more at: http://www.aal-europe.eu
5. ‘Ambient Assisted Living’, is defined as enablers of technology, and ICT-enabled services for integrated social, medical and emergency services, including personal emergency and location-based services.
7. JRC IPTS has conducted a research project on ‘The Future of Independent Living Services in the EU’ (http://fiste.jrc.es/pages/health.htm) in a European Consortium, made up of TNO, Empirica and Vrije Universiteit Brussel. It is one of the first studies in this area. EU defined ILS as a new research area in the FP7 work programme.
9. The Ministerial Conference ‘ICT for an inclusive society’, Riga, 2006 (http://ec.europa.eu/information_society/events/ict_riga_2006/doc/declaration_riga.pdf), set the basis for consequent policy actions by prioritizing the needs of older workers and elderly people. These priorities should consist of exploiting the full potential of the internal market of ICT services and products for the elderly; improving the employability, working conditions and work-life balance of older workers; enhancing active participation in the society and economy and self-expression; and realizing increased quality of life, autonomy and safety, while respecting privacy and ethical requirements, stressing that this can be done through independent living initiatives, the promotion of assistive technologies, and ICT-enabled services for integrated social and healthcare, including personal emergency and location-based services.
10. There exist many pilot experiences in the field of smart housing. Examples are FutureLife (Hünenberg), Tele-haus (Munich), InHaus (Duisburg), SmartHOME (Munich), Smart Home (Berlin), Easy Living (Tobit Software), Homelab (Eindhoven), e2-home (Stockholm).
11. For an inventory on policies of relevance for eAccessibility that has been collated by the MeAC study see: http://ec.europa.eu/information_society/activities/einclusion/docs/meac_study/meac_policy_inventory_06_11_07.pdf
12. ‘Assistive Technology’ means different things to different people. However, Assistive Technology Devices are items frequently used by people with functional deficits as alternative ways to perform actions, tasks and activities (within their home). Simple assistive technology could entail electronic prompts and memory aids (both in smart homes as well as in mobile devices). New assistive technology may also include personal devices for communication, mobility, transportation, (voice-controlled), manipulation, self-organization, sensory support; direct bodily communication/connection; special peripherals and human-computer interfaces; adaptive interfaces. Functions include control of visitor access, door opening and closing for the wheelchair-mobile user, personal alarm functions, control of furniture and beds, control of the ambient environment and operation of home entertainment and communications equipment.

References

Family 2.0 (2005) ‘Talking Tech on Family 2.0 (a niche of Web 2.0)’, available at: http://family2point0.wordpress.com/category/family-20-organize/