

AGEING AND INVISIBILITY

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Ageing and Invisibility

Edited by
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and
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FOREWORD BY LAMBERT VAN NISTELROOIJ MEP

ICT and ageing: building the Silver Economy

Ageing and ICT

The direction of the demographic change societies all over the world are experiencing is clear: the population is ageing at a breathtaking pace. The number of people over 50 will increase by 35% in 2050, the number of people over 80 by 300%. This puts our social health- and social security systems under pressure.

ICT can assist the elderly in carrying out their daily work, keeping intact their social network, monitoring their health condition and improve their security. It can play an important role in enabling the elderly to stay at home longer and in good health while increasing their quality of living by supplying ways of keeping in touch with their loved ones. It can enable them to order their food and medicines online and participate in systems for monitoring and diagnosis.

These hardware and software applications should be integrated, easy to operate, economical and reliable. You can think of everything from consumer electronics, smart textiles, smart homes, telematics services to wellness and medical equipment.

In addition, products and services aimed at the ageing population can boost our economy. This is what I call the ‘Silver Economy’.

The Ambient Assisted Living initiative

In Parliament, I was the speaker for the European Peoples Party (EPP) on the EU Ambient Assisted Living (AAL) Programme.

The AAL Programme consists of four parts: research, development, legislation and co-operation (with industry). Between now and 2013, the EU, the Member States and the private sector are investing more than 1 billion euros in research and innovation for ageing well, stimulating employment, innovation, competitiveness and the quality of life of the elderly.

Local and regional ‘smart care’ initiatives

Next to (inter)national programmes like AAL, there is an increasing role for regional cooperation in this field as they know best about local wishes and possibilities. The province of Noord-Brabant, where I was a regional minister for 12 years, recently took the initiative to launch a €9 million programme named ‘Smart Care’. The programme is designed to provide tailor-made solutions in the region in the field of ICT solutions and services for the elderly. Such initiatives are important to scale up our research and development to the markets, all over Europe.

Ethical issues

The use of ICT involves serious ethical questions. It is encouraging to see that a recent SENIOR survey shows that 51% of surveyed IT companies in Europe have ethical

codes. Another 31% will adopt one in the near future. Social aspects of ICT for ageing societies are very important: the discussion should not only be about techniques and research. The solutions should be people-centred, and supported by the networks people use.

Thank you, SENIOR!

The SENIOR project shows how the ethical aspects can be integrated into the evolution of new technologies. The European Parliament and the new European Commission will soon start with the mid-term evaluation of the 7th Framework Programme for research. Your approach should be safeguarded and funded in the years to come.

Thank you for the excellent research work and the debate on the underlying values for our Silver Economy.

Lambert van Nistelrooij

Member of the European Parliament for the EPP group

Vice president of the Intergroup on Ageing and Intergenerational Solidarity

February 2010

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GENERAL INTRODUCTION

The book *Ageing and Invisibility* flows from the research work carried out during 24 months within the EU FP7 project SENIOR, which is the acronym for ‘Social ethical and privacy needs in ICT for older people’. SENIOR was asked to provide ‘a systematic assessment of the social, ethical, and privacy issues involved in ICT and Ageing, to understand what lessons should be learned from current technological trends, and to plan strategies for governing future trends.’¹ While new technologies hold great promise, they also pose risks to privacy and ethical principles. The SENIOR consortium undertook to investigating how new ICT can meet the needs of senior citizens without compromising privacy and ethics. The project was based on three main principles which determined its main phases – inclusion as goal, dialogue as instrument, and technology design as target. As an FP7 support action, SENIOR was part of the wider EU strategy established by the Lisbon Treaty aimed at eradicating poverty and social exclusion by 2010. The Riga Ministerial Declaration on e-inclusion of June 2006 identified six themes for social inclusion. One of these themes was e-Ageing, whose goal is to empower older people to fully participate in the economy and society.² The SENIOR contribution to policy implementation has been twofold. First, SENIOR described the ethical and privacy impacts of ICT for inclusion. This objective was achieved through a series of thematic expert meetings organised throughout the year 2008. Such meetings (i) defined ICT systemic solutions and technology trends, (ii) discussed relevant ethical and privacy issues and (iii) weighed the trade-offs between privacy, ethics and technological innovation. Second, the project identified ICT services and solutions that avoid exclusion and promote inclusion of senior citizens. During the year 2009, SENIOR collected a series of best practices showing how ethics and privacy principles can be incorporated in technology design. The inclusion target was pursued by setting out key actions, highlighting risks and grounding milestones.

During two years of activity, the team of SENIOR reached out to a great number of stakeholders including policy-makers, industry, academia, civil society organisations and regional and local authorities, among others. The SENIOR team investigated and reported on the relevant legal, social and ethical dimensions of ageing and ICT. This work was turned into deliverables, papers, articles in peer-reviewed journals and a book of interviews with experts from around the world.³ This is the second and last book produced by SENIOR. SENIOR’s last effort aims to provide researchers, civil society organisations, policy-makers and companies with a resource to know more about some ethical, social and legal aspects involved in the inclusion of older persons

¹ From the project’s Description of Work. SENIOR ran from January 2008 to December 2009. Partners are: Centre for Science, Society and Citizenship, Italy; European Business Associates Srl, Italy; Global Security Intelligence Limited, United Kingdom; Inclusion Alliance for Europe, Romania; IN-JET, Denmark; International Forum for Biophilosophy, Belgium; Trilateral Research & Consulting LLP, United Kingdom; Vrije Universiteit Brussel, Belgium. EU funding amounts to € 950.000. Website: <http://www.seniorproject.eu>.

² The Riga Ministerial Declaration on e-inclusion of June 2006 identified six themes which the European Commission uses to foster social inclusion: e-Accessibility (make ICT accessible to all), e-Ageing (empower older people to fully participate in the economy and society), e-Competences (equip citizens with the knowledge and skills for lifelong learning), Socio-Cultural e-Inclusion (enable minorities, migrants and marginalised young people), Geographical e-Inclusion (increase the social and economic well-being of people in economically disadvantaged areas with the help of ICT), and Inclusive e-Government (encouraging increased public participation in democracy). Further policy documents that constitute SENIOR background are COM (2005) 425/F of 13/09/2005; COM (2007) 332/F of 14/06/2007 and the COMMISSION STAFF WORKING PAPER [COM(2007)332] – Brussels, 14 June 2007 SEC (2007) 811

³ Available at www.seniorproject.eu

in the Information Society. Readers with an interest in ageing societies will find here an overview on the process of e-inclusion of older persons in the EU's Information Society. Highlights are put on the EU policy background for e-inclusion (chapter one); chapter two considers critically the active ageing spirit of e-inclusion; the legal framework for e-inclusion of senior citizens is described in chapter three; given their importance, the rights to privacy and data protection and the notion of consent are given space in chapters four and five. Chapter six explains why the convergence of technologies is significant in terms of support to the elderly, what are the risks and barriers to take-up of ICT amongst senior citizens. An important element in the e-inclusion strategies has been the identification and promotion of good practices. Chapter seven discusses the merits of good practices exercise. Chapter eight takes *congedo* and suggests a few recommendations.

As chapter one explains, the relation between e-inclusion and the broader socio-economic objectives of the Union interrogates a period of time that goes from the origins of the Information Society in 1993 to the present. Since its definition at the beginning of the nineties, the Union's social and economic policies – gathered today under the formula of the 'Lisbon process' – have pursued, along macroeconomic deflationary objectives (the Maastricht criteria), an expansion of the number of people who stay active, employed or independent in society. Since the year 2000, the EU's policies on the information society have been integrated into the broader European Union social and economic policies. Within this framework, e-inclusion is meant to assist – as far as this is possible, necessary or desirable – (active) ageing. Demographic ageing announces hard times for the welfare state as we know it; politics press on the Information Society to devise solutions which can help organise risks and opportunities, social needs and economic priorities, of an increasing ageing population. As the reader will see, both the 1993 White Paper as well as the Lisbon strategy (2000–2010, and, later, the Commission's EU 2020 policy) bring together economic growth goals, technological development and the social needs of an ageing population. Since Lisbon 2000, public policy engages different stakeholders within the internal market, including social partners, end-user organisations, governments, technology developers, service providers and so on. In the future EU 2020, to assure stronger governance the Lisbon method is expected to deliver Information Society indicators which may include ethical, privacy and social needs of 'e-ageing'.

Drawing from literary sources, chapter two elaborates a series of reflections that emerged during the debates, conferences, meetings and talks held during the SENIOR project (2008–2009). In particular, chapter two discusses active ageing and e-inclusion policies. It acknowledges that ageing actively and living independently are of great value to elderly persons; it also acknowledges that technologies can play an important role in this. However, this chapter also suggests that social policies such as those on active ageing can bring with them practices that oddly counter their goal, the well being or protection of the aged. The lives of elderly people, we argue, today as well as a hundred years ago, are affected by the attitude or mentality of a given society towards what is 'old'. Modern technological societies woo the idea of decelerating, arresting or postponing ageing. Such an idea finds fertile ground in the prevailing cultural, social and market-led representations of ageing, which involve a great deal of falsification and removal. The removal and falsification of ageing appear rather awkward though. Soon the old will outnumber the young: is such a society of the elderly building an image where being old means little good? We suggest that this apparent paradox be viewed in the context of demographic change and active ageing. Being old is fine on the condi-

tion that one is...not old. From an ethical point of view it is questionable whether the ostracism of ageing is 'good' or 'bad' for elderly people and/or for society as a whole. We limit ourselves to conclude that the rescuing of active ageing as the mainstream narrative on old age is problematic for a society which commends pluralism of lifestyles.

The law which, in our view, is most relevant for the e-inclusion of older persons in the EU, is discussed in chapter three. At the level of European Union, the sources of law include human rights law, treaty provisions on equality and anti-discrimination directives and, as a part of the internal market, the Information Society. Human rights law is arguably the most important body of law for inclusion: the European Convention of Human Rights (1950), the Revised European Social Charter (1996) and the 2000 EU Charter of Fundamental Rights of the European Union are analysed and their relevance for older persons highlighted. In addition, international human rights law provides for an ample body of 'soft law' provisions, the so called international framework on ageing. In 2002, for instance, the UN Madrid summit invited states to mainstream soft law principles on ageing throughout their national policies. Concerning discrimination, the Treaty of Lisbon in article 9 recognises as one of the policies and activities of the Union 'adequate social protection, the fight against social exclusion, and a high level of education, training and protection of human health⁴.' In the European Union *acquis*, discrimination on grounds of age is forbidden in the context of employment. Old age discrimination, however, is increasingly treated as a horizontal public policy matter, for instance, in the area of services. A growing body of regulations is adopted in the Information Society. We follow the SWAMI⁵ method to enlist and illustrate some relevant areas such as interoperability, e-health, consumer protection, product safety which we deem important for ICT and the aged.

The fundamental right to private life and data protection are the object of a separate analysis in chapter four. Privacy needs in e-inclusion of elderly people, we suggest, include a protective dimension shielding the individual from undue external pressures, and an emancipatory dimension, more difficult to conceptualise, which relates to the individual need and interest in sharing life with others. Often, in concrete situations, older persons will have both interests and needs at the same time. In the Information Society, the protective function of privacy boils down to shielding older citizens from unnecessary or excessive categorisation including techniques such as spam, targeted advertisements, commercial profiling, in general when it is not clear why and for which purpose one person's preferences, tastes, etc. need to be opened up. The emancipatory function of privacy recognises the right to establish relations with others. Here the task of privacy protection is to ensure that sharing personal experiences or information takes place without the individual having to care, or to stay alert, or anxious about the fact that there is a '(data) arms race' going on behind his or her back. In this sense, the crucial function of privacy is to protect networks, such as situations of dependency, so sharing can remain a trusted interpersonal exercise.

Concerning data protection, the realisation of ubiquitous environments, in particular in the field of health care and surveillance, draws the attention to the tension between data protection and the requirements of the new ICT environment, which needs extensive data collection and profiling in order to make the user's environment act in-

⁴ Consolidated versions of the Treaty on European Union and the Treaty on the Functioning of the European Union Official Journal C 115 of 9 May 2008.

⁵ D. Wright et al., *Safeguards in a World of Ambient Intelligence*, Springer, Dordrecht, 2008.

telligently. From the European data protection regime, we identify three areas that ought to be given consideration, at least from an elderly perspective. They concern the definition and implementation of privacy by design settings and regulations; rules on the transparency and accountability of processors and controllers; and consent requirements.

The latter, consent requirements, is dealt with in a separate chapter, chapter five. Starting from an analysis of consent in human rights law, where consent is a key notion in the field of medical law, we discuss the data processing context, where consent is an increasingly formalised notion. We surmise that sociological changes in the IT society, unbalanced relations between users and client organisations, complexity of data processing and increasing situations of incapacity affecting consent in large sectors of the ageing population pose challenges to the notion of consent. The snag, from an elderly perspective, is to find solutions that, while not frustrating individual self-determination and liberty, assist, where appropriate, the individual declaration of consent so as to avoid putting excessive responsibility on him or her.

Chapter six includes a review of the state of the art of technology for inclusion of elderly people. After discussing inclusion in the context of the Internet and computer technologies, the chapter focuses on ambient technologies. The aim is to explain why the convergence of technologies is significant in terms of support of the elderly. Cases are discussed which involve applications for cognitive support, support for ADLs, communications, health and mobility. The final pages focus on the barriers inhibiting the development or adoption of these technologies and on the risks that might arise from failure of such technologies to take proper root.

An important element in the e-inclusion strategies has been the identification and promotion of good practices. Noting increased emphasis on good practices as a matter of e-inclusion strategy, chapter seven considers what good practices are, what their perceived value is and what are the criteria used for selecting them. The success in using good practices as a matter of strategy and policy is critically dependent on how they are selected and by whom and how well they are promoted or disseminated. The chapter includes four examples of good practices.

As the title of the book suggests, the benefits associated with the use of modern technologies will not come automatically. Information Society technologies do not stand apart and develop autonomously from social life; not inevitable, nor neutral, technologies are the product of the human project and the result of the work of networks of people, scientists, research leaders, companies, sponsors, politicians, investors, experts, committees, etc. which take decisions and make choices. Similarly, technological developments are given direction by narratives which emphasise contrasting views of ageing. The point the book makes is a warning: society should question itself about the use of technology to deal with ageing, whether this is ultimately ethically good, to what extent and within which limits. The risk we run is that ageing and the role of old age go in disguise and disappear from societal sight.

Finally, the authors would like to thank everyone who contributed to the SENIOR project. Special thanks go to participants to the numerous SENIOR meetings who graciously shared their insights with us and brought their experienced perspectives into the project. We gratefully acknowledge support of the European Commission services at the DG Information Society and Media, and in particular to the ICT for Inclusion unit, its head Mr. Paul Timmers and project officers Silvia Bojinova and Giorgio Zoia.

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