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Ethics, e-Inclusion and Ageing

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Abstract

Ethical questions about information and communications technologies (ICT) have been debated since World War II. Western democracies have had more than 50 years of experience in addressing and organising the ethical, social and legal aspects (ESLA) of scientific and technological developments. However, this expertise, tradition and experience are not enough to manage the most urgent ethical and social issues and contemporary challenges involving ICT. A systematic and institutional organisation of social values in the context of modern ICT tools is needed.

This paper focuses on four major areas: (i) developing a specific approach to ethical issues raised by ICT; (ii) describing in more detail the age-related digital divide in Europe; (iii) identifying technology trends and emerging challenges; and (iv) defining the legal framework for inclusion of senior citizens in the digital society. The paper then concludes with a summary of its key points on the basis of which it makes three proposals as a contribution to efforts aimed at overcoming the exclusion of senior citizens from today's Information Society.

KEYWORDS: information technology, ageing, e-inclusion, ethics

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1 INTRODUCTION

While bioethics and ICT ethics are not one and the same, the experience of shaping ESLA processes for biomedicine can help to develop an operational ESLA for ICT. One of the major lessons may be that ESLA is not the progressive accumulation of finalised insights and tools, but an ongoing process. Another major lesson is that the ESLA development is not the result of one single homogeneous and all-encompassing process, but requires the development and strengthening of specific niche-related processes with strong interaction among stakeholders.[1]

There is, undoubtedly, a growing convergence between biology and ICT tools, as exemplified by ICT implants that enhance brain function. With such implants, it is now possible to move artificial limbs through connections to the brain. Likewise, paraplegics can use them to control external devices such as a computer cursor. Through such devices, ICT continues to encroach upon the human body and upon the image we hold of ourselves as human beings.

This image is not limited to the body alone. When we think about our own identity, we include our personal history, what we do and what we did, how we organise our lives, and how we see the future. We include the type of work we do, and the way our achievements and actions are perceived by others. When we take account of these broader aspects of identity and current developments in the field of ICT, it becomes hard to see ICT as a merely neutral tool whose field of operation is in the solution of external problems. ICT has become a powerful tool that can change and shape human identity.

While there are many benefits to be reaped by the convenience and connectedness that ICT affords, there are many pitfalls to consider. At one extreme, some believe that current ICT developments will result in the final destruction of typical human features. This can perhaps most easily be conceptualised in light of neuro implants and prosthetic devices, which are discussed in section 3.1 below. The fear also exists that ICT does not enrich our human characteristics but rather replaces them by unnatural, technological characteristics, which are determined by scientists, industry and the market. It has been argued that ICT does not multiply or enrich relationships among humans, but that ICT reduces the rich complexity of human contact to purely technical connections with distant or virtual contacts. Furthermore, many assert that ICT does not multiply the impact of our work by allowing us to send the results

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[1] For example, the key researchers in Huntington's disease are in close contact with representatives of the HD league of patients, and are aware of the concerns of patients and their families. The patient organisations know the scientific leaders in their field and know the fundamental scientific context that scientists are developing.

around or publish them on the Internet, but that it takes the achievements of our creative work away from us. The end result, arguably, is that ICTs have the ability to strip human beings of everything that makes them human, of each and every element that constitutes their rich internal human identity. Seen in this way, the development of ICT is an assault on human dignity, on the humanness of human beings. Opponents of ICT underline that ICT *tampers* with human identity instead of enriching it, and that ICT should be prevented from doing so. Indeed, public policy must seriously evaluate the ethical aspects of ICT as they relate to the human being.

Near the end of the 20th century, public policy recognised ICT as a vital element in contemporary life. Proactive policy-makers promoted access to technologies as a priority of public policy. The e-inclusion initiative of the European Commission is a major contribution to this priority. Other policy initiatives include the promotion of adapted technologies for citizens with special needs (including senior citizens), and the promotion of ICT technology as an asset to strengthen the economy. Here, the growing number of older people constitutes a growth market for ICT products and services.

ESLA analysis requires the gradual development of a large variety of processes and networks of actors involved. While several pioneering initiatives are or have been operational, the real work still has to begin. In Western democracies, it is quite normal for ministries or departments in charge of health care to maintain a host of ethical committees and support ESLA work. Health care officials have structural communication lines with patients and captains of pharmaceutical industries. Public policy in charge of technology, ICT and its many uses recognises the need for such structural communication and, whenever possible, the need to talk to other stakeholders. At present, open and structural communication lines are not developed in the case of ICT and ethics. Clearly, this must change.

2 A CLOSER LOOK AT SENIOR CITIZENS

Placing senior citizens in a generic category based upon age does not provide an accurate image or assessment of the vast conditions and experiences found within this segment of the population. To understand more fully the challenge of including senior citizens in the Information Age, it is necessary to look at a variety of groups within the classically defined "elderly" population. To have a clearer understanding of the dynamics of such groupings, one can consider Internet use by those over 60 years of age within specific groups such as those based on gender, marital status, immigrant or native born, rural or urban and regional differences within the EU.

2.1 Gender

The life expectancy for women in the EU is generally three years more than that for men. Women make up 59 per cent of people aged 65+ and the proportion of women increases with age, e.g., 64 per cent of those aged 75+ are women, while 71 per cent of those aged 85+ are women. Among those over the age of 60, twice as many men as women use the Internet. Among those women who do access the Web, only 3 per cent consider themselves as having strong Internet skills.[2] The age-related digital divide, therefore, particularly affects elderly women, who live longer and often alone. Elderly women, especially those in the "older elderly" group, are at a higher risk of being excluded from the Information Society.

More elderly women might use computers and the Internet if they were part of their existing social activities. They could be offered free ICT training at local community centres and libraries. As elderly women are likely to live alone, ICT training should be presented as an opportunity for socialising; in this way, women would gain both valuable skills and social networks (Eurostat, 2008).

2.2 Marital status

Data from a labour force survey (2005) shows that 30 per cent of women and 13 per cent of men over 65 live alone. There are regional variations, of course; for example, in Spain, Portugal and Malta approximately 22 per cent of women over 65 live alone, compared to 37 per cent in the Czech Republic, Estonia, Hungary and Finland. Overall, the percentage of women living alone increases as they grow older. Thus, roughly 52 per cent of women aged 75 + live alone compared to only 21 per cent of men of the same age (Eurostat, 2008). These figures are obviously influenced by the fact that women in general live longer than men. The fact that more elderly women than men live alone and that elderly women use computers and the Internet less than men suggests that households with married couples are more likely to use a computer and the Internet.

However, there have been no significant studies undertaken that reveal differences in ICT use between married and single and widowed elderly people. This requires investigation. From the few studies that have been carried out, we know that, while 31 per cent of men and 19 per cent of women between the ages of 55 and 74 use the Internet, only 8 per cent of single households in the age group 60+ have broadband Internet access. This suggests a wider digital divide for the single senior citizen than for those who are married.

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[2] For the age group above 60, 18 per cent of men compared to 9 per cent of women use the Internet (Eurostat, 2008). For the age group 55-74, 31 per cent men and 19 per cent women use the Internet (European Commission, 2008).

2.3 Immigrants

In Europe (as in most parts of the world), immigrants are often among the most socially excluded and disadvantaged groups. Factors such as language barriers, low education levels, low rates of employment and employment in low skilled jobs reinforce their exclusion. Many people become acquainted with computers and the Internet via their jobs; however, many immigrants have not had this opportunity due to their type of employment (or unemployment).[3] Consequently, many immigrants enter retirement without ICT skills. This lack of skill is arguably most prevalent among those immigrants (usually women) who remain in the home rather than participating in the workforce.

While elderly immigrants are generally more digitally excluded than native citizens, addressing this exclusion is also more challenging. Language barriers and cultural customs call for greater sensitivity when interacting with these senior citizens. ICT training courses should be offered in multiple languages and take cultural differences into account. People may refrain from ICT training courses if they perceive insensitivity to their religion. For example, mixed gender ICT courses may effectively hinder some Muslim women from participating; women-only courses should, therefore, be available.

Such solutions require a greater level of awareness regarding individual needs which won't happen if we look at senior citizens as a single amorphous group. Inclusion of senior citizens in the Information Society is critical to their overall inclusion into European society. Without inclusion, we cannot form a cohesive Union based upon social solidarity and values.

2.4 Urban versus rural

Across Europe, there is a notable difference in the use of computers and Internet between urban and rural areas, with broadband penetration being significantly lower in rural areas. This clearly increases the issue of a digital divide for those senior citizens living in rural Europe, which in turn relates to furthering a sense of isolation experienced by many senior citizens in these areas. Many inhabitants of rural areas are already isolated by factors such as distance and poor modes of public transportation. As such, this is arguably the group which would benefit most from broadband coverage and Internet access, which would allow them to communicate with family and friends in far-away places and interact with peers via social networking groups. However, if broadband coverage is poor, this segment of the elderly population will not be able to participate in the Information

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[3] http://ec.europa.eu/enterprise/ict/policy/ict-skills/es-br.pdf

Society. As such, extending coverage to rural areas should be made a priority. In fact, the Commission has made it a priority. On 28 January 2009, in line with the European Council conclusions of December 2008, the Commission (2009) proposed to earmark €1 billion of extra spending for investment in broadband as part of its proposed European Economic Recovery Plan, with the goal of achieving 100 per cent high speed broadband Internet coverage for Europe by 2010.

While coverage is not typically a problem in urban areas, urban seniors run the risk of being isolated or alienated by too much ICT. If visits by care givers or family members are substituted with cell phone calls or e-mails, senior citizens can become isolated even in the most populated areas. In addition, social interaction in urban areas tends to be more anonymous, meaning that senior citizens could feel alone even when surrounded by people. Thus, it is imperative that a delicate balance is struck between closing the digital divide and closing seniors in a virtual prison.

2.5   Regional differences within Europe

Just as there are differences between rural and urban areas in relation to the use of computers, the Internet and access to broadband internet connection, so there are similar differences between different regions in Europe. We thus see notable differences between old and new Member States (NMS). For example, in the EU15 approximately 52 per cent of all households have Internet access at home, while only 33 per cent have access in the NMS12. However, these figures continue to increase; in particular, several new Member States (e.g. Czech Republic, Cyprus and Slovenia) have had a significant increase in the number of households with Internet access at home (Eurobarometer, 2008).

In relation to broadband access, a similar trend is clear: broadband access is less prevalent in new Member States where just under 25 per cent of households have access. As one might expect, the penetration of broadband technologies is significantly higher in urban and metropolitan areas than in rural areas (Eurobarometer).

Taking these regional differences in Europe into account, Europe's population of senior citizens is also at different levels in relation to their risk of exclusion. The age-related digital divide cannot be understood, nor combatted, in isolation. The entire population of new Member States is at greater risk of exclusion in the Information Society due to the basic unequal level of access to computers and the Internet. It is useful, however, to focus on age because across Europe the population is growing older. This makes it impossible for governments, policy-makers, ICT developers and the market generally to ignore the seriousness of the age-related digital divide, which is of particular concern in

new Member States. At the same time, senior citizens constitute a very heterogeneous group with different needs, attitudes and social backgrounds who face different barriers to e-inclusion. Although it is clear that, overall, senior citizens in Europe are at risk of exclusion, the degree of risk is interdependent on other factors, such as country of residence, immigrant status, rural/urban residency, gender and marital status, to name but a few. These differences present a variety of e-inclusion challenges to policy-makers and government leaders.

3 TECHNOLOGY TRENDS AND EMERGING CHALLENGES

Technology affects older people in at least two major senses. First, as mentioned in section 1 of this paper, technology may target senior citizens by aiming to improve and prolong their life. By increasing senior citizens' capacity to stay longer and more safely in work places, communities and homes, technology may improve older people's living conditions and – together with modern biomedicine – may help senior citizens to be healthy and vigorous until late age. Yet this raises a serious anthropological issue as most senior citizens die, and increasingly will die, after a period of protracted debility and feeble dementia stretching on average for some seven to 10 years (Andrew et al., 2008). In other words, the price to be paid for the assistive technology revolution seems to be a protracted period of considerable misery in the last years of life. In addition, thanks to medicine and technology's success in forestalling death, there is the risk that we have produced a culture in which death is even more unacceptable and more feared than ever. This is a perfect example of the ever-expanding character of human desire, in which we are now doing better but feeling worse (Nowotny, 2003). The corollary of this is that the failure to do everything possible to prolong active life is now regarded as morally culpable.

Second, technology concerns older people in a more general sense. As ICT is playing an important role in enabling older people to live independently for longer and in supporting their needs, it is important to ensure that general technology products are usable by this age group as well as to develop products specifically targeting the older population. The most immediate problem concerns accessibility in its broader sense, including physical accessibility, as senior citizens are often irritated with devices and technologies that are fiddly to use, and linguistic accessibility, as this is also due to the kind of language that is used to explain technologies, what they can do for people, and how much they cost. The older age groups feel particularly frustrated when it comes to understanding information they are given about technologies. Finally, economic accessibility is also an important issue, as many senior citizens feel that they

cannot take up the opportunities new technologies have to offer because the prices are still too high for them.

One can distinguish three main technology revolutions affecting senior citizens. They are the augmentation revolution, the biometric revolution and the wireless revolution.

3.1 Augmentation

New augmentation technologies will be used to restore and advance normal performance. These techniques will come via implants, brain interfaces, genetic selection and nerve-to-prosthesis applications, as mentioned in the Introduction. Technologies for endowing humans with physical or psychological skills which restore lost capabilities, or even enhance them beyond a level previously experienced, strengthening brain or motor capacities are becoming more prevalent, and more subject to scientific and ethical debate. Through bionic prostheses, bio-implants and bio-chips, technological artefacts can be already integrated into the human organism and this trend is expected to progress. In the next few years, nano implants in the brain might allow the development of treatment for neurodegenerative diseases but also of devices enhancing information storage and retrieval, and mood enhancers. The possibility to supplement, modify or replace biological components with technology components – also within the brain – and to network the brain with external machines and computer networks forms the current background for discussions among those who study technology trends (Wreye, 2004).

Drawing the line between necessary therapy and discretionary enhancement is genuinely difficult. Augmentation technologies will increasingly blur the border between alleviating the effect of disabilities and enhancing the human. Indeed, a pure technical fix of disability (age-related or not) is ethically problematic, because any disability is always the result of concurring physical, environmental and social conditions (EGE, 2005). For improving impaired human performance, it is necessary to define the intertwined concepts of normality, disease, disability and defect. Who decides what is a disability or disease or defect? Who establishes what is normal? This point is critical in ageing processes. Actually, we have not yet understood whether ageing per se is a physiological process. Some scholars (Strehler, 1977) have tried to identify ageing as a process which is universal, progressive, intrinsic and deleterious. There is no doubt that a degree of physiological deterioration will occur in all major organ systems with advancing age. Yet more recent studies (Kohn, 1982) have tended to cast doubt on the view that physiological deterioration is a characteristic of normal ageing. Anton et al. (2005) have argued that the lifespan, old age and death of an individual can never be physiologically normal and that senescence should be

always viewed as a disease. As a matter of fact, "the identities of many older people are defined in relation to issues of abnormality and normality. The 'cut-off' point where an old individual is or is not deemed to be 'frail' is in no sense clearly defined and variations in levels of assessment is of increasing concern for care managers. In a climate of resource constraints, distance from the norm has become valued amongst older people who do not conform to discourses of 'slow' and 'deterioration'" (Powell, 2004).

An analysis of achievable results and concretely feasible applications of augmentation technologies requires us to consider an ethical monitoring, to protect fundamental rights of persons against the potential risk of threats to the respect of human dignity, autonomy and personal identity. Such risks need to be assessed and compared with the opportunities for promotion of dignity and personal identity development, which are made possible by these devices through the restoration of lost functionalities and the chance of recovering effective interactions with the external environment (Lucivero and Tamburrini, 2008). Augmentation technology should not be conceptualised as a pure anti-ageing technology. Otherwise there would be the unavoidable risk of stigmatising those who fail – for many different reasons – to prevent ageing or rejuvenation. In other words, the human augmentation revolution may reinforce ageism by increasingly devaluing the status of those who, notwithstanding technology, become older.

The most challenging sector in the field of human augmentation is the area of brain-machine interfaces (BMIs). BMIs are adaptive systems made of artificial components, which interface with biological organisms and establish a new kind of human-machine integration.   BMIs are usually designed to restore lost motor and sensory functions and to overcome damages in the nervous pathway, directly connected to central nervous system, in order to bypass damaged neural areas and restore lost perceptual and motor functions. Examples of the types of systems emerging for widespread use in the near future include:

- stimulation devices for chronic pain therapy,
- limb prostheses for anatomical compensation of damaged neural pathways,
- implantable neuro-stimulation devices,
- cochlear and retinal implants.

As BMIs emerge, it is important to contemplate how they affect:

Personal identity and autonomy – In brain-machine interfaces, a technological device is connected to the brain, the main material substrate of human mental activity. How and to what extent does BMI interaction with the central nervous system modify mental activity? Which modifications are sustainable from an ethical point of view, with respect to the protection of dignity, personal identity,

autonomy and potential alteration of a human being's perception of his or her strength and limitations? Which changes in the control of one's actions are tolerable from an ethical point of view?

Alteration of self-perception and modification of subject-environment interaction – BMIs that are designed to overcome interruptions in the neural signal transmission bring about physical or psychological alterations to restore both perceptual transmission and motor transmission. The auditory brainstem implant is a prosthesis designed to restore hearing in people with injured auditory nerves through stimulation of the cochlear nucleus in the brainstem. Cortical visual implants send codified images, recorded by a tiny digital camera, to electrodes implanted in the visual cortex. These bionic systems for functional restoration may bring about alterations of perceptual capacities and may affect the human being's interaction with the external world.

Social identity and fairness – Auditory implant applications illustrate the impact of BMIs on senior citizens as members of a social community and the difficulties of re-adapting after a bionic operation. A reflection of these potential alterations of the identity of persons within a social environment is therefore needed.

Shared control: restrictions of individual autonomy – Where BMIs are used to restore motor functions, the human being and the robotic artificial system co-operate in the action, selection, and execution. How is action control shared between the human being and the machine, and is it still possible to claim that the human is still fully responsible for the execution of the action? Is the human being still autonomous?

3.2   Biometrics

The e-inclusion goal to assist senior citizens to retain their independence for as long as possible chiefly focuses on e-services. This type of policy carries with it the urgent need for reliable remote identification of elderly individuals. The recent explosion and deployment of biometric technologies have emerged from the realm of science fiction books and movies into the mainstream of daily activities such as travel, shopping, personal identification, banking, access to public services, voter identification and many others. With this growth, researchers continue to look for new methods of utilising many different characteristics of the human body to find the ultimate biometric identifier, which provides a high level of accuracy (i.e., uniqueness) and which is non-invasive, privacy-enhancing, inclusive and relatively easy and cheap to collect and validate. Current biometric methods for human identification now include fingerprints, ultrasound

fingerprinting, iris scans, hand geometry, facial recognition, ear shape, body shape, voice verification, computer keystroke dynamics and skin patterns. Emerging biometrics (second-generation biometrics) include DNA analysis, neural wave analysis, ECG analysis, skin luminescence, remote iris scan, advanced facial recognition, body odour and others. Multimodal systems, which match different identification technologies, are also progressing rapidly, as are multiple biometrics, which consist of different types of biometrics used in combination. Behavioural biometrics – which measure behavioural characteristics such as signature, voice, keystroke pattern and gait – are becoming more and more important.

A biometric system consists of some basic modules. The sensor module measures the biometric characteristic presented to the system. The aliveness detection module measures the person's physiological signs of life in order to avoid being cheated by artificial attributes. The quality checker performs a check on raw measurements and indicates whether the characteristic should be sensed again. The feature-generator module extracts the set of discriminatory features from the raw measurements and generates a digital representation of the biometric features, which is called the "live template". The matcher module compares the live template against one or more templates previously stored. The decision module takes the final decision about identity according to the system threshold for acceptable matching.[4] Biometrics are likely to affect the lives of more people more quickly than any other current technology and the possibility of social exclusion resulting from the use of biometric systems has not yet been fully explored (Wickins, 2007). As a matter of fact, biometric systems deal with people who fall within the range defined as ''normal'' by the individual system's commissioners, designers and administrators. It is very difficult to design a system that works well for the whole range of physical and behavioural characteristics expressed by humans, notably with elderly and disabled people. Senior citizens are sometimes less dexterous and slower to process through the

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[4] When only two set of templates are confronted (the live template and stored templates), we speak of authentication, which aims to verify an identity claim and answer the question "Are you who you say you are?". When the live template is compared against a set of templates stored in a database, with the aim of finding a matching set, we speak of (positive) identification. In positive identification, the person presented to the system does not explicitly claim an identity, and the question answered is "Who are you?". When the live template is compared against a limited number of stored set of templates, with the aim of checking whether a person is on a watch-list, we speak of negative identification or screening. The negative identification process intends to answer the question "Are you who you say you are not?" Both positive and negative identification require databases. In authentication mode, the template could be stored in portable media, retained by the user and submitted at the time of transaction in order to allow the system to compare it against the live template.

enrolment and verification steps. Sensory and motor impairments (e.g., poor eyesight, arthritic hands, poor memory) may also create particular problems. Observations from field trials and literature show that biometric systems are normally designed for the "average" (young) person. The senior citizen can be unjustly rejected by the system because her biometric features are not distinct enough (e.g., the fingerprints are worn) or she cannot be sufficiently protected against identity theft in case the system threshold for acceptable matching is set too low. If one considers that the new biometric services being established by governments are essentially compulsory for citizens (e.g., biometric passports, e-government, e-health, etc.) and that very large scale commercial services based on biometric authentication are in progress (also in order to obviate the need to remember lots of PINs and passwords, which can be an advantage for older persons), one can easily envisage impacts of the biometric revolution on senior citizens, such as the following:

Technological barriers. Despite some good research, there is still a lack of detailed understanding about how biometric data and biometric templates behave with ageing, especially specifically within an elderly population. Many human features change with age, and current biometric technologies have not been able to overcome some of these impacts to date. Accuracy of facial recognition technologies, which are the primary biometrics in use for travel and border security applications, does not hold up well over time. Fingerprint biometrics, which are inexpensive and fast to implement, and which are broadly deployed (e.g., in payment systems and logical access to computer systems), have very high failure rates for older persons, whose fingerprints have become worn over a lifetime, which is also true of many manual labourers, no matter their age (Modi and Elliott, 2006). In addition, where biometric applications are designed to rely upon a particular physical characteristic for identification, they will result in exclusion of those individuals who may, due to injury or disability, not possess such a characteristic (e.g., because of injuries to eyes, fingers, limbs, etc.). Usually, systems are designed to offer fallback alternatives, but these are often time-consuming to pursue and can create some perception of stigma at "failing" the system. A 2005 trial for biometric passports held in the UK found that individuals over the age of 60 had more difficulty in enrolling in biometrics than their younger counterparts (Atos, 2005, pp. 8-10). A suggested approach to remedy these issues is multimodality, which uses more than one personal trait or characteristic to identify a person. If one sample does not register, such as a scarred or faded fingerprint, another sample could be used, such as facial or signature recognition, which would lessen false rejection rates (Khan, 2006). In addition, researchers (Phua, et al., 2008) continue to look for different biometrics

which may be more reliable, unique and non-invasive, including such options as human tissue, evoked brain signals and heart sound.

Technology-based fear. Concerns over privacy issues as they relate to biometrics are not unique to senior citizens, but can be amplified by more generalised apprehension about technology borne out of a lack of knowledge, and ultimately cause individuals to wish to opt out of participation in some aspects of society. Identity theft is a significant concern to senior citizens, and biometrics aim to reduce the chance of this occurring (Hunter, 2006), but many users also fear that violent acts, such as cutting a finger off, may be committed in order to acquire information (Patrick, 2004, p. 2). There are, however, a number of ways to mitigate these concerns. Vitality tests that guarantee a living person is giving the information can be used to avoid the fear of harm while using biometrics. Over the past several years, vein-based (finger or palm) biometrics has advanced into the market, but remains a costly alternative to fingerprint or hand geometry, and may be slow to be adopted.

Health concerns and misuse of biometric data. Most of the privacy concerns associated with biometrics have focused upon the general issue that biometric data might be stolen and misused as easily as any other personally identifiable information, with the heightened problem that one cannot merely reset one's biometric traits. However, as the price of human genome sequencing rapidly and dramatically falls (*Next Big Future*, 2008), it is foreseeable that DNA tests, routinely used by law enforcement in investigations, will be used in everyday settings, in which case, new concerns about privacy are certain to emerge. In particular, once such technologies advance sufficiently, how much information can be obtained about an individual's current and future health and how can the information be used? How can such information be effectively protected? This is of particular concern to senior citizens who may find that they are diagnosed as having the potential for Alzheimer's, diabetes, cancer or some other chronic or life-threatening disease in the future. Such a diagnosis could negatively impact treatments, living arrangements and health insurance coverage. Clearly, such use would raise serious ethical concerns.

3.3   The wireless revolution

The computing revolution was about information – digitising documents, photographs and records so that they could more easily be manipulated and stored. The wireless communications revolution is about making digital information about anything available anywhere at almost no cost. During the last 150 years, human communication has been transformed by the launch of wired

technologies and now by wireless technologies, as shown by the take-up of ubiquitous technologies, in which devices interact seamlessly. Some devices (sensors) only provide for sensing: movement, physical health, temperature, pictures, etc.; other devices (actuators) can take action, reacting to stimuli provided by the service, such as human interface devices, door openers and light switches. The key innovation in this revolution is that these devices communicate directly with each other through invisible wireless networks. Ubiquitous communication technologies, therefore, create a wireless technological network environment where access to control devices is a key issue for the user.

The technologies of ubiquitous communication are particularly relevant in the e-inclusion domain, especially in the context of Europe's ageing society. Wireless technology is the building block of most assistive technology for senior citizens, including home-based health and wellness measurement and monitoring, location technology, emergency calls and alarm systems, wearable computers and smart clothes. Wireless brings countless benefits. Devices and objects can be monitored or controlled at a distance. Huge amounts of data that were once impossible or too expensive to collect will become the backbone of entirely new services. Yet an essential ethical problem with the use of wireless technologies concerns the notion of autonomy; these technologies may threaten people's autonomy in the sense that they generate a new type of dependency, and create a huge amount of personal data beyond the person's control. Issues to be considered are the following:

Privacy and data protection. The streams of data from devices and sensors are different in kind from what most people are used to: the information is probabilistic rather than definitive, and the systems are vulnerable to being hacked into. Today's privacy rules presume a relationship between citizen and government or consumer and company. But the way in which information is generated and shared in wireless systems may involve so many parties that we have to change the way in which we look at privacy protection. Wireless communication may appear to be less intrusive because it is invisible and ever present, i.e., fully integrated in our daily lives, but questions remain: Who has access to the system and devices? Who has access to the personal data? How are data retrieved, interpreted and processed? How are data transmitted and to whom? How is the right to access determined and/or guaranteed? How is informed consent obtained?

Isolation and exclusion. A potential adverse impact of the deployment of wireless technology could be the impact on the senior citizen's social surrounding: as long as the senior citizen is "attended" to by a wireless system, the risk exists that his family and friends will feel less inclined to visit and spend time with him.

Legal status and justice. The legal status of wireless technologies at home poses the following questions: should they be considered as a universal communication service and as a medically necessary prosthesis and should they be included in the benefits provided under public insurance schemes? In other words, should such ambient assisted living systems be guaranteed to all senior citizens in need of such systems, or conditioned to their ability to pay for it? What will be the economic impact of these systems on social security schemes?

Autonomy and surveillance. Location and monitoring of people can be of vital importance for the security of some disabled and elderly users but these techniques are very intrusive. Devices can either prevent undesired wandering (e.g., automatically closing doors or gates to a house or community grounds to protect Alzheimer's patients) or remind others to take corrective action (e.g., at night time when someone inappropriately leaves the bed). Some systems can detect cases of incontinence via special moisture sensors on bed sheets.[5] Other systems allow caretakers to detect periods of restlessness in the night by using sensors in the beds.[6] Computer vision techniques can be used to determine asymmetries in gait patterns during visits to the doctor and consequently provide early warnings of the possible onset of a wide range of common neurological and musculo-skeletal disorders such as stroke, Parkinson's disease and arthritis.[7] Vision technology could also detect asymmetric tremors indicative of Parkinson's disease and can be used to track the effectiveness of medication regimes to control the disease. Yet it is clear that wireless technology systems and devices are bringing society to an autonomous human-machine interaction. This affects notions about autonomy, privacy and informed consent, as well as the possibility of opting out of the ICT society. If technologies are ubiquitous, they are forever present and access to control becomes a more pressing concern. Senior citizens who are less technologically savvy, suffering from dementia or who simply have difficulty understanding the new environment, risk losing their autonomy.

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[5] For instance, Vigil Integrated Care Management System TM. http://www.vigil-inc.com
[6] For instance, at Elite Care's Oatfield Estates Cluster in Milwaukie, Oregon. http://www.elite-care.com
[7] For instance, at the University of Rochester's Center for Future Health.
http://www.futurehealth.rochester.edu

4 THE LEGAL FRAMEWORK FOR THE E-INCLUSION OF SENIOR CITIZENS

4.1 The EU Charter

The first chapter of the 1996 EC Green Paper on "Living and Working in the Information Society: People First" affirmed that "The way we develop the Information Society, the most fundamental change of our time, must reflect the ideas and values upon which the European Union is shaped. These ideas and values should be transparent in order to gain and deserve the broad support of European citizens." The 2000 EU Charter of Fundamental Rights provides now a solid value framework to guide the development of the Information Society and notably the process of e-inclusion of senior citizens including those different groups of senior citizens mentioned in section 2 above. It contains explicit rights for senior citizens, in addition to the rights of human dignity, equality, privacy and data protection. The relevance of these rights enshrined in the EU Charter for senior citizens and for their inclusion in the digital age is evident. They can be summarised under three main headings:

- Dignity and liberty
- Discrimination and equality
- Data protection and privacy.

4.2 Dignity and liberty

Although human dignity is a fundamental right, there is a trend in the normative texts of international and constitutional laws, which include the EU Charter, to set the foundations of dignity on autonomy. Human dignity involves a complex notion of the individual. It includes recognition of a distinct personal identity, reflecting individual autonomy and responsibility. It also embraces recognition that the individual self is a part of larger collectives and that they, too, must be considered in the meaning of the inherent dignity of the person. There is an implication to be drawn from the recognition of human dignity as a source of human rights. Drawing upon the conception of human dignity and the intrinsic worth of every person, we can extend and strengthen human rights by formulating new rights or construing existing rights to apply to new situations. The conception of respect for dignity suggested above can also be applied to e-inclusion. Indeed, nothing so clearly violates the dignity of persons as social exclusion, forms of which were discussed in the first two sections of this paper. Put in positive terms, respect for the intrinsic worth of a person requires a recognition that the person is always entitled to participate in social and community life notwithstanding her age, disability and health.

Article 25 of the EU Charter, which recognises fundamental rights for senior citizens, puts forward the idea that senior citizens have a right "to lead a life of dignity and independence and to participate in social and cultural life". As pointed out by Stefano Rodotà (2008), Article 25 is not an isolated statement. It contains an explicit reference to the principle and right of human dignity which opens the EU Charter in Article 1, "Human dignity is inviolable. It must be respected and protected." Article 1 draws on the Preamble to the Charter[8] as well as on the 1948 Universal Declaration of Human Rights.[9] Its position in the Charter indicates the centrality of the person in the policies of the European Union and the function of human dignity as the real basis of fundamental rights.[10] Dignity must be interpreted as imposing not only a static attitude (respect), but mainly an active obligation to intervene to make dignity effective (to promote it). The implications of the positive, affirmative character of dignity extend to all fundamental rights enshrined in the Charter, which must be enjoyed by all to attain a dignified life. Mention can be made, for instance, of Article 3 "everyone has the right to respect for his or her physical and mental integrity", which commands a strong protection to health. Likewise, Article 35 requires Member States to afford a high level of human health protection.

Dignity implies a threshold below which nobody and no law can go. Even the use of fundamental rights by the individual needs to respect the notion of dignity: "It results that none of the rights laid down in this Charter may be used to harm the dignity of another person, and that the dignity of the human person is part of the substance of the rights laid down in this Charter. It must therefore be respected, even where a right is restricted" (Council of the EU, 2000b). Dignity offers clear guidance about the goals that EU policy-making needs to pursue. There is a clear obligation upon policy-makers to safeguard the individual against an erosion of the citizen's rights caused by market and other pressures.

4.3   Discrimination and equality

We are equal in having certain inalienable rights, which means that you cannot discriminate against a person because she is weaker or frailer than you. Substantial equality and fighting against discrimination are necessary conditions of respect for the intrinsic worth of the person. Article 13 of the Treaty of Lisbon explicitly states that "(1) Without prejudice to the other provisions of this Treaty

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[8] "The Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity... It places the individual at the heart of its activities."

[9] "All human beings are born free and equal in dignity and rights."

[10] Draft Charter of fundamental rights of the European Union, 4473/00, Brussels, 11 October 2000.

and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, *age* or sexual orientation" [*Italics added*].

The principles of equality and non-discrimination[11] are well established in EU law.[12] According to a consolidated jurisprudence[13], a difference in treatment constitutes discrimination either when it lacks "objective and reasonable" justification, or when there is no reasonable relationship or proportionality between the means employed and the aim to be realised.[14]

The cardinal provision in EU law on discrimination based on age is Article 6 ("Justification of differences of treatment on grounds of age") of the Employment Equality Directive (Council of the EU, 2000a), the legal basis of which is Article 13 of the treaty establishing the European Communities (TEC). According to the case law of the European Court of Justice (ECJ), the principle of non-discrimination on the grounds of age must be regarded as a general principle of Community law.[15]

Article 21 of the EU Charter proscribes discrimination based on certain forbidden grounds, including age. All fundamental rights are general in scope. The right to health, for instance, is a general right. Some groups, however, might require special attention in law. The reference to age in Article 21 and the ascription of Article 25 regarding rights for the elderly under the heading "equality" signals awareness that certain groups, such as senior citizens, are at risk of discrimination and are in need of special protection, for instance, in terms

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[11] Article 20 (Equality before the law) – Everyone is equal before the law.

[12] Non-discrimination can be regarded either as a principle which mediates between primary constitutional principles (to be applied in a non-discriminatory manner) or a right, in the sense that its breach constitutes a violation of the law, be it a convention, a treaty or a law.

[13] European Court of Human Rights, *Case relating to certain aspects of the laws on the use of languages in education in Belgium (Belgian Linguistic Case),* Judgment of 14 July 1968, 1 EHRR 252, para 10, ECJ, Case C-203/86 *Kingdom of Spain v. Council of the European Communities* [1988] ECR 4563, para 25, ECJ, Case C-279/93 *Finanzamt Koeln-altstadt v. Roland Schumacker* [1995] ECR I-225.

[14] In contrast, for instance, with the US, Europe detects discrimination whenever the *effect* of a measure or of a group of measures is discriminatory. The US approach looks at the *intent* to discriminate, thus reducing the scope of legitimate public intervention. The leading case is *Washington v. Davis,* 426 United States Reports 229, 1976, where the Supreme Court held that the equal protection clause contained in the Fourteenth Amendment does not prohibit governmental action that is foreseeably discriminatory against identifiable groups. Unless it can be shown that such action was undertaken with "discriminatory intent", it is not subject to constitutional challenge (Sedler, 1999).

[15] European Court of Justice, *Mangold v. Rudiger Helm*, C-144/04, para 75.

of affordability and accessibility of ICT products and services, or in terms of protection of personal data in the domain of e-health.

This broad legal backing for the value of equality, both in terms of rights and general principles of Community law, guarantees a uniform level of protection against age discrimination across the Member States. It also puts on public institutions a two-fold obligation, to remove legal provisions "intrinsically liable" to engender direct or indirect discrimination[16] and to promote affirmative actions aimed at avoiding conditions triggering discriminatory effects in our societies.

The rights to equality and to non-discrimination mandate EU policy-makers to pursue a policy of e-inclusion regarding senior citizens. It is commonly held that all second-generation rights (such as the right to a proper education and health care) are not enforceable, but a more precise understanding of human rights law shows that the right to non-discrimination is wholly enforceable and that making no process with regard to second-generation rights is equally prohibited. Article 25 demands that positive actions are taken to strengthen the independence of the elderly and their participation in social and cultural life.[17] Combined with Article 15 (the right of all citizens to engage in work), broad affirmative actions are allowed. Hence, equality and non-discrimination allow and oblige policy-making initiatives in the area of e-inclusion. Conversely, protection against age discrimination is tightly dependent on a strictly chronological approach to age, i.e., an age limit. Setting age limits responds to the need of welfare states to stream members of society into socio-economic categories in order to allocate scarce resources and organise appropriate interventions. It follows that the application of non-discrimination law is bound by such limits. The further legal implications of anti-discrimination provisions on e-inclusion, in particular on the e-inclusion of senior citizens, are not fully understood. Lessons can be drawn

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[16] Case C-237/94, *O'Flynn v. Adjudication Officer*, ECR I-2417, 1996, paras 20 and 21, where the ECJ found that "a provision of national law must be regarded as directly discriminatory if it is intrinsically liable to affect (the migrant worker[...]) and if there is a consequent risk that it will place the former at a particular disadvantage."

[17] Article 25 (The rights of the elderly) – The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life. Article 26 (Integration of persons with disabilities) – The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community. Article 15 (Freedom to choose an occupation and right to engage in work) – 1. Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation. 2. Every citizen of the Union has the freedom to seek employment, to work, to exercise the right of establishment and to provide services in any Member State.

from recent cases, such as the *Moniteur Belge*[18] and *Coleman* (EHRC, 2008) cases*,* both of which show the importance of the public sphere of e-inclusion.

The rights of family members could also benefit from information technology, for instance, to continue pursuing their own careers.[19] On the other hand, there are obvious ethical limits to the use of technologies as a substitute for human care-givers: "Technologies can be part of a program of caring, not be transformed slowly into the program as a whole."[20] To avoid this scenario, assistive technologies should thus operate in a context where the possibility for social contacts is an integral part of the notion of being independent. But this would require not only intervention at the design stage of a technology but, more importantly, in the public sphere, i.e., the community. The community should create conditions where informal care-givers are not forced to face a dramatic choice between the right to pursue their careers and the care of their family. Setting rules that allow a care-giver to take some time off from work without suffering prejudice, without being discriminated against would help, inter alia, promote the ethical use of assistive technologies.

4.4   Data protection and privacy

The Convention on the Rights of the Child is the only international convention that addresses the subject of identity as a fundamental right of every human being. Articles 7 and 8 of the Convention explicitly refer to the right to an identity. These articles deal with subjects including registration, name, nationality and the preservation of identity.[21] Only a few jurisdictions feature a constitutional right to an identity. (See, for example, Article 26 of the Portuguese constitution.) The right to an identity is, however, part of the common European ethos and it gives implicit foundation to privacy rights and data protection. John Locke's often

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[18] Belgian Constitutional Court (Cour d ' Arbitrage/ Arbitragehof), Arrêt n° 106/2004, 16 June 2004.

[19] According to Madeleine Starr of Carers UK, those providing heavy end care are "twice as likely than the general population to be in poor health themselves, as a result of caring…[they also experience] significant financial disadvantages; very frequently people have to give up work and therefore give up their income…this affects not only their working lives but it also affects their ability to put into the pension system…[thereby] creating a situation where carers themselves might go into poverty in their own retirement." SENIOR, *WP 1 Final Report*, Deliverable D.1.5, p. 97. http://seniorproject.eu

[20] SENIOR, *WP 1 Final Report*, Deliverable D.1.5, p. 9. http://seniorproject.eu

[21] Article 8, in particular, says: "1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference. 2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

quoted sentence, "though all the earth and all inferior creatures may be common to all men, yet every man has a 'property' in his own person", does not merely recognise the potential commercial value of every person's identity. It also – and foremost – acknowledges the dignity inherent in the concept of human identity. The individual's identity and private sphere do not allow intrusions by others without good reasons.

> In light of the large-scale use of information and communication technologies which underpin e-inclusion, critical weight must be given to the fundamental rights to privacy and data protection, enshrined, respectively, in Articles 7 and 8 of the EU Charter.[22]

The meaning of privacy as autonomy of the individual entails recognition not only of the right to be left alone (Warren and Brandeis, 1890) but also of "the claim of individuals to determine for themselves when, how, and to what extent information about them is communicated to others" (Westin, 1967). Hence, and according to an evolution in the last decades, well-fitting with the dual nature of the right to identity, privacy is not only concerned with the right to be left alone but also with the right to control one's own information and determine the manner of building up one's own private sphere (Rodotà, 1995, p. 122) and with "the right to choose one's life" (Rigaux, 1990; Gutwirth, 2002). Individuals, including senior citizens, constantly negotiate their relations with the outside world (Marx, 2001). Privacy and data protection grant them control rights when doing this.

The case law of the European Court of Human Rights regarding Article 8 ECHR show a progressive evolution in the understanding of what privacy is about, i.e., what privacy protects and promotes. In its case law, the Court has shown awareness of the mutually consecrative function of the private and public spheres. *Malone*[23] and *Klass*[24] extend privacy protection against unlawful interference by the state and by third parties in the private home and correspondence and, later, e-mail and the Internet. The protection of privacy has progressively moved beyond the "shadowy realm of the household" to embrace, in *Niemietz* and *Halford*[25], the workplace. In *Niemietz,* it was found that there was

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[22] Article 7 (Respect for private and family life) - Everyone has the right to respect for his or her private and family life, home and communications.

[23] ECtHR, *Malone v. the United Kingdom* judgment of 2 August 1984, Series A no. 82, p. 30, § 64.

[24] ECtHR, *Klass v. Germany* judgment of 6 September 1978, 2 EHRR 214, 1979-80.

[25] ECtHR, *Halford v. UK*, judgment of 25 June 1997, §44; *Niemietz v. Germany*, judgment of 16 December 1992, § 32. It is clear from these cases that telephone calls made from business premises as well as from the home may be covered by the notions of "private life" and "correspondence".

"no reason of principle why this understanding of the notion of 'private life' should be taken to exclude activities of a professional or business nature"[26]. As a result, sending private e-mails from the workplace is, unlike in the US, personal. With *Peck v. UK*[27], there are protections against disclosure of private data retained by a public institution. Similarly, in *Amann v. Switzerland,* the Court pointed out that the term "private life" must not be interpreted restrictively and that respect for private life comprises the right to establish and develop relationships with other human beings[28].

In the same case, the Court held that the storage of data relating to the private life of an individual amounts to an interference within the meaning of Article 8 ECHR, regardless of the subsequent use of the stored information.[29] For the Court, it was also irrelevant as to whether the information gathered on the applicant was sensitive or not, or whether the applicant had been inconvenienced in any way. It was sufficient to find that data relating to the private life of an individual was stored to conclude that, in the instant case, the creation and storage of the impugned card amounted to interference, within the meaning of Article 8, with the applicant's right to respect for his private life.[30] In itself, this does not mean that the act of storing data is prohibited. It only means that the second paragraph of Article 8 ECHR applies and that the interference needs to be based on a law, to serve legitimate interests and to respect the proportionality requirement ("necessary in a democratic society"). Crucial when assessing the existence of a right to privacy and the proportionality requirement is the idea of reasonable expectations of privacy.[31]

When there is no evidence to the contrary, citizens, including senior citizens, can develop expectations of privacy that, when reasonable, are legally protected. This notion of reasonable expectations has the potential of being a solid ethical and legal guideline for further developments with regard to e-inclusion.

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[26] ECtHR, *Niemietz v. Germany*, para. 29.2.

[27] ECtHR, *Peck v. UK*, judgment of 28 January 2003, §85.

[28] ECtHR, *Amann v. Switzerland*, judgment of 16 February 2000, § 65-67.

[29] ECtHR, *Amann v. Switzerland*, judgment of 16 February 2000, § 69.

[30] ECtHR, *Amann v. Switzerland*, judgment of 16 February 2000, § 70.

[31] ECtHR, *Halford v. UK*, judgment of 25 June 1997, §45: "There is no evidence of any warning having been given to Ms Halford, as a user of the internal telecommunications system operated at the Merseyside police headquarters, that calls made on that system would be liable to interception. She would, the Court considers, have had a reasonable expectation of privacy for such calls, which expectation was moreover reinforced by a number of factors. As Assistant Chief Constable, she had sole use of her office where there were two telephones, one of which was specifically designated for her private use. Furthermore, she had been given the assurance, in response to a memorandum, that she could use her office telephones for the purposes of her sex-discrimination case."

Without becoming merely subjective, it departs from the expectations of the persons most concerned with inclusion, in this case, senior citizens.

Positive obligations on the State are inherent in the right to effective respect for private life under Article 8 ECHR.[32] These obligations may involve the adoption of measures even in the sphere of relations between individuals. While the choice of the means to secure compliance with Article 8 in the sphere of protection against acts of individuals is in principle within the State's margin of appreciation, effective deterrence against grave acts, where fundamental values and essential aspects of private life are at stake, requires efficient criminal-law provisions. "Children and other vulnerable individuals, in particular, are entitled to effective protection."[33]

Privacy equally demands a right to be connected in the Information Society

Progressively, a strong tendency has emerged toward imposing on European states not only respect for privacy, but also the promotion of privacy in public: that is, the promotion of the realisation of private life in all places, such as hospitals, care homes, beaches, parks, etc., where the individual, through contacts with his peers, realises his personality, autonomy, informational self-determination (*Selbstbestimmung*[34]*)*. In this sense, the *Botta v. Italy*[35] case can be regarded as a landmark decision. Mr Botta, a physically disabled person, while on holiday at the seaside resort of Lido degli Estensi (Comacchio, Ferrara province) in August 1990, found that the bathing establishments were not equipped with facilities to allow people with disabilities to access the beach and the sea. Specifically, the resort lacked special access ramps, lavatories and washrooms in breach of Italian legislation. In March 1991, Mr Botta asked the mayor of

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[32] ECtHR, *M.C. v. Bulgaria,* judgment of 4 December 2003, Application no. 39272/98, § 150 with reference to *X and Y v. the Netherlands*, judgment of 26 March 1985, Series A no. 91, pp. 11-13, §§ 23-24 and 27, and *August v. the United Kingdom* (dec.), no. 36505/02, 21 January 2003.
[33] Ibid.
[34] In 1983, the German Constitutional Court formulated a *recht auf informationelle Selbstbestimmung* (right to informational self-determination). In that case, the court literally created, using Articles 1 and 2 of the Constitution (right to dignity and right to personal liberty), a right to informational privacy-self-determination with far-reaching consequences for the nascent Information Society. "The Bundesverfassungsgericht [the German Constitutional Court] 'invented' the new basic right of informational self-determination, which is the legal anchor for data protection in the German constitution. The decision is, to this date, the most important decision in the history of German data protection and the Bundesverfassungsgericht still frequently refers to it in new decisions. Understanding this decision and the right to informational self-determination is the very key to the German view on data protection" (Hornunga and Schnabela, 2009).
[35] ECtHR, *Botta v. Italy* (1998) 26 EHRR 241.

Comacchio to remedy these shortcomings. When he returned to Lido degli Estensi later in 1991, he found no changes. Whilst the claim itself was unsuccessful, the Court's decision reveals a far more sophisticated understanding of the realities which deprive so many disabled people of their ability to enjoy the same rights as Europe's non-disabled citizens. Most significantly, the Court ruled that Article 8 imposes positive obligations on the state to facilitate disabled people's access to essential economic and social activities. In *Botta*, therefore, the Court held that the notion of "private life" had to be expanded to "ensure the development, without outside interference, of the personality of each individual".[36]

In the *Kutzner v Germany* case[37], the Court stated that Article 8 ECHR creates obligations upon states to provide support to disabled parents in order to maintain their right to a family life. Other positive measures required by the ECHR included facilitating access by service users[38], or by their carers[39], to social service files.

Inclusion is not just warranted by the value of equality. Stepping outside and meeting others are essential to the development of the personality of the citizen and therefore warranted by the European understanding of privacy.

Data protection

European data protection rules affirm the principle of the free flow of personal data but attach to it eight conditions, or principles. These consist of various specific procedural safeguards to protect individuals' privacy and in promoting accountability by government and private record-holders (De Hert and Gutwirth, 2006, p. 77). In detail, they are the fairness obtaining and processing principle, which includes consent; purpose specification; non-disclosure of personal information unless compatible with the fair processing; data must be safe and secure, accurate and up-to-date; the processing must be proportional, not excessive; the retention period must not exceed the period of time necessary for the processing; the data subject has a right to access the data; an independent supervisory authority is established in each Member State and can hear complaints about compliance with data protection directives.

Individuals have thus been endowed with rights as data subjects: the right to fairness when giving information, to have a copy of their personal data (right to access); the right to correct data or to have data deleted; the right to opt out of direct marketing; the right not to be subjected to automatic decision-making and

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[36] Ibid.

[37] ECtHR, *Kutzner v. Germany* (2002) EHRR 653.

[38] ECtHR, *Gaskin v. UK* [1989] 12 EHRR 36.

[39] *R (S) v. Plymouth City Council* [2002] 5 CCLR 251.

the right to complain to the data protection authority. Furthermore, European law applies a broad understanding of personal data. In Opinion 4/2007, the Article 29 Working Party confirmed the definition provided in Directive 95/46/EC as any information relating to an identified or identifiable natural person, the data subject. An identifiable person is "a person who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity". Processing of personal data enjoys a wide definition too as it "shall mean any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction" (Article 2, 95/46/EC).

In order for the processing to be lawful, the data subject must have given his or her consent unambiguously (Article 7, 95/46/EC). Personal data include those data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life. Consent is defined as "any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed".

Is the data protection framework enough to ensure, not only substantial justice, but also procedural justice in the data processing involved in technologies for senior citizens? While it appears that the use of ICT always involves some surrender of privacy, what raises concerns are the limits of the requirement of consent for vulnerable groups' sharing of their personal data. The personalisation of ICT services[40], the mushrooming of social networks where sensitive health data are happily transferred, might well compress individual privacy in favour of a collective understanding of the right to privacy which puts emphasis on the public interest in personal data to guide inclusion policies. Particularly worrisome are applications involving continuous monitoring at a distance and technologies such as those discussed in section 3 above.

In its Opinion on ICT implants (2005), the European Group on Ethics (EGE) in science and new technologies stressed that society should take care that such systems, where they are permitted, should not become systems of untenable restriction or even negation of basic rights, particularly when ICT implant systems become part of health systems in which data are permanently or occasionally transmitted to other parties. In addition, the opinion suggests that interventions in

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[40] "Personalising citizen services goes behind convenience. We can use them to confront the problems of inequality, an ageing population, greater competition and global security with ideas, innovation and opportunity", quoted by C.D. Raab, in Simone Fischer-Hübner et al., 2008, p. 13.

the body and in the environment should strictly conform to the principles of necessity and proportionality and not be allowed when there are viable alternatives; that interventions should be as non-invasive as possible; that all control devices could be removed without risk of dangers on the individual's life; that data collection and treatment should be strictly regulated, including non-sensitive data; that people must keep the power of accessing and controlling their personal information and take part in the decision-making process starting from them.

From the foregoing, we can say that the European data protection apparatus is generally well-equipped to guide the application of ICT for senior citizens. But we can also see that under certain circumstances, the data protection framework might be insufficient. When data protection law is insufficient, for instance, in cases of constant monitoring of the environment and of the body, the principle of human dignity and the spirit of the right to privacy as interpreted in *Botta*, as well as that of the right to equality and non-discrimination should impel the community to do something about it. In the final section of our paper, we draw some conclusions and make some proposals about what "the community" could do.

5 CONCLUSIONS AND THREE PROPOSALS

In this final section, we summarise the key findings of our paper and then conclude with three proposals which would, we believe, address some of the ethical challenges arising from the e-exclusion of senior citizens, especially some well-defined groups of senior citizens, which is to say that heretofore they have had not had access to ICTs. However, access to new technologies is not unalloyed. The technologies that bring benefits can also create new ethical challenges.

This paper has noted the fact that senior citizens are not a homogeneous group and highlighted the many differences in terms of their access to and use of ICTs based on gender, marital status, whether they are immigrants, where they live (urban vs rural, western vs eastern Europe). From an ethical point of view, it behooves European society and, especially, its political leaders to take steps to bridge the digital divides, to facilitate access to the Internet by disadvantaged groups such as those described in our paper. Universal access is not merely a matter of social equity, there are sound economic reasons why the e-excluded need to be included, which has prompted the European Commission and some Member States to undertake "broadband for all" initiatives. From this same optic, it is important to ensure that technology products are usable and accessible by senior citizens, understandable (as intuitive as possible) and affordable.

In theory, new technologies should help to overcome the digital divides and, while that may be true, some advanced new technologies, such as those mentioned in section 3, have raised fears that they are altering our humanness by unnatural, technological characteristics determined by scientists, industry and the market.

This paper has discussed three groups of new technologies affecting senior citizens. In the first group are devices such as neuro implants, brain interfaces, genetic selection and nerve-to-prostheses, which restore lost or diminished capabilities to senior citizens or which might even augment existing capabilities. Most challenging in the field of augmentation are brain-machine interfaces (BMIs). As BMIs emerge, it is important to contemplate how they affect personal identity and autonomy, self-perception and modification of subject-environment interaction, social identity and fairness. Drawing the line between necessary therapy and discretionary enhancement is genuinely difficult. An analysis of achievable results and concretely feasible applications of augmentation technologies requires us to consider an ethical monitoring, to protect the fundamental rights of persons against threats to the respect of human dignity, autonomy and personal identity.

A second group is biometrics. The e-inclusion goal to assist senior citizens in retaining their independence depends heavily on e-services, which requires reliable, remote identification of senior citizens. Although biometrics can enable this, they may impact senior citizens negatively, because they may create technological barriers, induce apprehensions about identity theft and how personal data, including DNA, might be used or who might have access to such data and how it might affect their treatments, living arrangements and health insurance.

The third group are characterised by some form of communication, including mobile phones, Blackberries, CCTV cameras, microphones and the like as well as networked sensors, actuators and other devices used in ambient intelligence. Wireless technology is the building block of most assistive technology for senior citizens, including home-based health and wellness measurement and monitoring, location technology, emergency calls and alarm systems, wearable computers and smart clothes. Wireless brings countless benefits. Yet wireless technologies prompt ethical concerns about autonomy, the generation of huge amounts of personal data beyond the person's control, the isolation and exclusion that may result if and when the new forms of communication become substitutes for real face-to-face interaction. These ICTs can be used to monitor or track the senior citizen, who may or may not be aware of his being surveilled, monitored or tracked.

While the new technologies can be used for good or ill, the EU Charter of Fundamental Rights provides a secure foundation for dignity. The principle and right to human dignity opens the EU Charter. Article 1 states: "Human dignity is

inviolable. It *must be* respected and protected." [*Italics added*] It doesn't say dignity *should* be respected or it *would be desirable* if it were respected. No. The statement is as powerful as it is short: it *must* be respected. Consequently, the principle of dignity means that no utilitarian consideration can ever justify the sacrifice of a single human being for whatever reason (be it ideology, religion, science, philosophy and so on). Dignity is an essential principle in e-inclusion.

The idea of dignity implies that there is a threshold below which nobody and no law can go. Even the use of fundamental rights by the individual needs to respect the notion of dignity: "none of the rights laid down in this Charter may be used to harm the dignity of another person" (Council of the EU, 2000b).

As we said in the preceding section, dignity implies a complex notion of the individual, with a distinct personal identity, reflecting individual autonomy and responsibility. It also implies recognition of human dignity as a source of human rights. Nothing so clearly violates the dignity of persons as social exclusion, manifestations of which were discussed in the first two sections of this paper.

Respect for dignity places a clear obligation upon policy-makers to safeguard the individual against an erosion of his or her rights caused by market and other pressures. Article 21 of the EU Charter proscribes discrimination based on certain forbidden grounds, including age, and Article 25 regarding rights for senior citizens under the heading "equality" signals awareness that certain groups, such as senior citizens, are at risk of discrimination and are in need of special protection, for instance, in terms of affordability and accessibility of ICT products and services, or in terms of protection of personal data in the domain of e-health.

Article 25 demands that positive actions are taken to strengthen the independence of senior citizens and their participation in social and cultural life. Combined with Article 15 (the right of all citizens to engage in work), broad affirmative actions are allowed, such as initiatives in the area of e-inclusion.

In its Opinion on ICT implants, as we noted in the previous section, the European Group on Ethics stressed that society should take care that such systems, where they are permitted, should not become systems of untenable restriction or even negation of basic rights, particularly when ICT implant systems become part of health systems in which data are permanently or occasionally transmitted to other parties. In addition, the opinion suggests that interventions in the body and in the environment should strictly conform to the principles of necessity and proportionality and not be allowed when there are viable alternatives.

A regulatory response to the complexities of new technologies, senior citizens, e-inclusion and ethics is only one type of response. We propose that other, complementary responses have merit, among which are the following:

5.1   Development of corporate ethical codes on e-inclusion

As advancements in technology suggest, industry is a critical stakeholder in e-inclusion.   An important indicator of industry's participation in e-inclusion initiatives and policy is corporate statements of social responsibility and codes of ethics. At the European Council Summit in Lisbon in March 2000, the European Union set itself a new strategic goal for the next decade: to become the most competitive and dynamic knowledge-based economy in the world, capable of sustainable economic growth with more and better jobs and greater social cohesion. Underlining the important contribution of the private sector in achieving this goal, the European Council addressed businesses directly in "a special appeal to companies' corporate sense of social responsibility regarding best practices on lifelong learning, work organisation, equal opportunities, social inclusion and sustainable development." This was then reaffirmed by the 2001 Green Paper on Promoting a European framework for corporate social responsibility (European Commission, 2001). In a further document in 2002, the European Commission gave a description of corporate social responsibility (CSR):

- CSR is behaviour by businesses over and above legal requirements, voluntarily adopted because businesses deem it to be in their long-term interest;
- CSR is intrinsically linked to the concept of sustainable development: businesses need to integrate the economic, social and environmental impact in their operations;
- CSR is not an optional "add-on" to business core activities but about the way in which businesses are managed.

It also set out a number of principles:
- recognition of the voluntary nature of CSR;
- need for credibility and transparency of CSR practices;
- focus on activities where Community involvement adds value;
- a balanced and all-encompassing approach to CSR, including economic, social and environmental issues as well as consumer interests;
- attention to the needs and characteristics of small and medium-sized enterprises (SMEs);
- support and compatibility with existing international agreements and instruments (International Labour Organization standards and OECD guidelines for multinational enterprises*)*.

Among various instruments to implement these principles, the Commission (2002) has identified codes of conducts, defined as "innovative and

important instruments for the promotion of fundamental human, labour and environmental rights, and anti-corruption practices especially in countries where public authorities fail to enforce minimum standards... The biggest challenge related to codes is to ensure that they are effectively implemented, monitored and verified." Finally in the 2006 Communication on "Implementing the partnership for growth and jobs: Making Europe a pole of excellence on corporate social responsibility", the Commission stated that CSR can contribute in reaching "more integrated labour markets and higher levels of social inclusion". With this Communication, the Commission launched the European Alliance for CSR – an open partnership to make Europe a "pole of excellence" on CSR – whose priorities include "Better responding to diversity and the challenge of equal opportunities taking into account the demographic changes alongside the rapid aging of the European population".

However, corporate statements of social responsibility and codes of ethics are still rare in the ICT industry, and rarer still are those dealing with e-inclusion and ageing. Existing codes vary significantly from one corporation to another (if they exist at all) and are generally driven by needs such as:

- new markets and new market opportunities (which senior citizens can offer),
- improvements in trust and confidence in their products and services,
- reductions in their administrative burden (which e-government services could provide),
- reductions in regulatory hurdles and market barriers (say, harmonised legislation across the EU),
- a better understanding of senior citizens' ICT needs (which civil society organisations, the Commission, Member States and academia can provide),
- a better understanding of the most important determinants of ICT access and use and how ICT engagement develops over time, and
- ethical guidance.

Nevertheless, we propose that industry should step up its consideration of socially meaningful statements of corporate responsibility and codes of ethics with sufficient specificity to address some of the challenges mentioned in this paper, e.g., making products and services accessible to senior citizens, to take senior citizens into account in the design and use of biometrics and to secure their explicit informed consent in the development and deployment of wireless technologies, including embedded technologies used in ambient intelligence. Such codes of ethics should be informed by the European Charter of Fundamental Rights.

5.2 Collection of local and regional best practices

The development of CSRs and codes of ethics can benefit enormously from review of good practice case studies. In the area of e-inclusion, work has already begun on compiling good practices. For example, the i2010 e-Inclusion subgroup has compiled a useful and interesting collection of national strategies for e-inclusion, aimed at assessing the status and exchanging practices of e-inclusion policy approaches across the EU. The subgroup is updating the collection as the national plans themselves are updated (European Commission, 2007). The Commission also sponsors the European Journal of e-Practice, a digital publication which promotes the sharing of good practices in e-government, e-health and e-inclusion.

The UK released a cluster of e-inclusion reports in late October 2008, one of which provides results from the analysis of documents and contact with digital inclusion experts in 30 countries (Foley et al., 2008), while another (OPM, 2008) summarises insights and experiences gained from community and third sector organisations involved in opening up digital technologies to excluded communities. A critical success factor in these reports is the importance of engaging excluded communities. "For many excluded groups, support needs to be more pro-active and outreaching; it needs to come to the potential user, rather than wait for them to act."[41] Yet work has still to be done in order to compare local practices and to analyse regional diversities, in particular in the field of ageing.

We propose that the Commission, Member States and industry compile a set of good practice case studies and post them on the Internet (on the Commission's e-inclusion web portal as well as elsewhere on the Web).[42] Such good practice case studies could usefully be sorted or sortable in different ways, notably by theme and/or ethical issue, so that stakeholders could easily and quickly find cases of particular interest to them.

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[41] OPM, op. cit., p. 7.

[42] A somewhat similar recommendation emerged from an EC-sponsored workshop of e-inclusion experts convened in Bled, Slovenia in May 2008. The workshop report recommends the development and maintenance of "a good/bad practice case study library which illustrates the ethical dimension of ICT services and products used to promote social inclusion and improved quality of service to those in most need" (Rogerson, 2008).

5.3   Monitoring technology development in real time

Our third proposal relates to the monitoring of technology development. The pace of technological change has often challenged policy-makers. A new technology or application may reach the market before policy-makers are able to evaluate its ethical implications or impacts on privacy. Social networks such as Facebook and MySpace provide a good example. Each of these networks have well over 100 million users (more than 200 million in the case of Facebook), making them among the most popular sites on the World Wide Web, yet it's only in the past year or two that policy-makers have begun scrutinising their services. Social websites can be said to empower citizens in a way different from most online applications of just a few short years ago. The social Web phenomenon shows great promise in helping to overcome digital exclusion.

However, there remains a need for ethicists and privacy experts to monitor the emergence of such new technologies and applications and to debate ethical issues at an early stage, before they have garnered millions of users. Many technologies raise ethical issues, which may not be easily resolved by reference to some prescriptive guidelines. Indeed, the application of many technologies may raise context-dependent issues, hence, there is a need for ongoing review by ethics experts to identify solutions. In addition, some oversight may be needed to ensure that the application of technology is ethically defensible and/or is in line with the foreseen ethical solutions.

Monitoring the development of technologies can be done in various ways. One possible solution is via a web portal, like that launched by the Commission in June 2008 for exchanging broadband good practices. Another possibility is the establishment of an expert group tasked with preparing periodic working papers analysing the most important new technologies affecting the e-inclusion of senior citizens. The Commission has convened many such expert groups in the past. An example is the Digital Literacy Expert Group, established in November 2007, to provide the Commission with inputs for a Digital Literacy Policy Review[43] and to contribute to guidelines on digital literacy actions. Another example is the ThinkTrust project[44], supported under the Commission's Seventh Framework Programme, which reviews advanced new technologies with respect to their privacy, trust and security implications. The European Network and Information Security Agency (ENISA) also examines the impacts of new technologies and the risks arising.[45] Yet another possibility is for the Commission to convene a consultation as it did on RFIDs, which led to a Recommendation in which the

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[43] http://ec.europa.eu/information_society/eeurope/i2010/studies/index_en.htm#literacy.
[44] http://www.think-trust.eu/
[45] www.enisa.europa.eu

Commission said industry should undertake privacy impact assessments (PIAs) for significant new applications of RFID.[46] PIAs would be an important way to engage a wide range of stakeholders in arriving at some shared understanding of the best way to address challenges.

Several models exist for monitoring the development of technologies. We propose that the Commission consider one or more of them with the specific purpose of foreseeing and assessing the potential ethical implications of new technologies for senior citizens and e-inclusion. Over time, one or more of these models could be expected to build up the expertise and experience needed to address the most urgent ethical and social issues and contemporary challenges involving ICT. It would also be a systematic and institutional response to the challenges of emerging ICTs in the context of generally accepted social values, while recognising that social values, like technology, may change over time too.

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[46] http://ec.europa.eu/information_society/policy/rfid/documents/recommendationonrfid2009.pdf

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