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Including Seniors in the Information Society

Emilio Mordini, Stacey Mannari

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**28 World Leading Expert Talks  
on Privacy, Ethics, Technology  
and Aging**

**With a Foreword by Viviane Reding**

*European Commissioner  
Information Society and Media*







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*European Commissioner Information Society and Media*



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## Foreword by Viviane Reding

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*European Commissioner for Information Society and Media*



With the Lisbon Strategy, the European Union set its course to becoming a competitive and dynamic knowledge-driven economy by 2010. In keeping with the core values of the European Union, such a society must be inclusive and accessible. As such, in 2006, the Riga Declaration built upon the Lisbon Strategy and outlined specific policy goals for e-Inclusion. With regard to older citizens, the Declaration seeks to address the needs of older workers and elderly people in general. In particular, there is a call for exploiting the full potential of the internal market of ICT services and products for the elderly, supporting innovative ICT solutions which can improve their employability, working conditions and work-life balance. Enhanced participation in society and the economy, self-expression through ICT access to goods and services, improved quality of life, autonomy and safety of the elderly should go hand in hand with the respect of their right to privacy.

Older citizens must be able to participate as valued, respected and contributing members of European society. Inclusion in the information society reflects a proactive human development approach that calls for more than the removal of barriers. It requires investments and action to bring about the conditions for inclusion. Between now and 2013, the Commission, the EU Member States and the private sector will together invest more than € 1 billion in research and innovation for ageing well, including € 600 million from the new Joint Research Program on Research Program on Ambient Assisted Living (AAL, a program to improve elderly people's lives with ICT), € 400 million from the EU's seventh Framework Programme for Research and Technological Development, and more than € 50 million so far in the EU's ICT Policy Support Programme. The main aims are to generate significant cost-savings in health and social care and create a strong industrial hub for ICT and ageing in Europe and make a better quality of life for elderly people (through e.g. smart home technologies for controlling heating, lighting, and even food stocks remotely, electronic alarm systems or e-health facilities). Europe is well placed to become a lead market for "ageing well" technologies, creating worldwide opportunities for European ICT companies.

Economic drivers are important but we also have a political and ethical obligation to ensure that all citizens, including the elderly, are digitally literate and have access to ICT. The “Ageing Well” initiative launched by the Commission<sup>1</sup> includes this dimension.

From a political perspective, participation is one of the five main principles affirmed by the Commission’s White Paper on European Governance<sup>2</sup>. Enabling people to fully participate in the information society, regardless of their individual or social circumstances such as disability or age, is also a right implied within the Charter of Fundamental Rights of the European Union. It rests within the right to engage in work, the freedom to conduct business, the freedom of information and expression, and – as far as older citizens are concerned – in *“the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”*<sup>3</sup>.

Participation and inclusion are indeed vital. The notion of Europe as a community of values is central to the EU Reform Treaty of Lisbon. The Reform Treaty inter alia clearly indicates a set of European Values, such as human dignity, freedom, democracy, human right protection, pluralism, non-discrimination, tolerance, justice, solidarity and gender equality. These values constitute the key frame for the policy design of the EU and the implementation of its policies, from research to security, from information society to culture.

I welcome this book generated by the SENIOR project, a project funded by the European Commission within the scope of the seventh Framework Programme, which presents interviews on Privacy, Ethics, Technology and Ageing with 28 world leading experts. These interviews are an example of a fruitful dialogue. They reflect the opinions and findings of people from academia, industry, policy making, civil society organizations, from a multitude of countries, disciplines, and cultural backgrounds, whose arguments are confronted and who are in an exchange designed to illuminate the multi faceted world of ICT and the elderly. They focus on the societal, ethical and privacy aspects of this area and open the conversation to citizens, leaders and societies. The European Commission, and the Directorate General for Information Society and Media, welcome participation in such dialogue and values its results.



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<sup>1</sup> COM/2007/0332 final of 14.6.2007 Communication from the Commission to the European Parliament, the Council, the Economic and Social Committee and the Committee of the Regions: Ageing well in the Information Society, An i2010 initiative, Action Plan on Information and Communication Technologies and Ageing.

<sup>2</sup> “The quality, relevance and effectiveness of EU policies depend on ensuring wide participation throughout the policy chain – from conception to implementation. Improved participation is likely to create more confidence in the end result and in the Institutions which deliver policies. Participation crucially depends on central governments following an inclusive approach when developing and implementing EU policies”.

<sup>3</sup> Charter of Fundamental Rights of the European Union Article 25.



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# Introduction

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*Stacey Mannari*

*Centre for Science, Society and Citizenship*

In modern society where information is traded on the NASDAQ and opinions are as common as colds, one thing remains undeniable. Worldwide, our societies are aging at a rapid rate never before seen in human history. According to Dr. Stephen Sapp, Professor of Religious Studies, gerontologist and Baby Boomer, “There’s controversy in some people’s minds about greenhouse gasses, about whether there is global warming, whether we can fix the problem or not. Well, we Baby Boomers exist. We’re going to get old. And we’re going to live a long time”<sup>1</sup>.

In fact, “It is estimated that by 2050, the number of people over sixty in Europe will have doubled to 40% of the total population or 60% of the working age population”<sup>2</sup>. By the same year, it is estimated that over 30% of Japanese society will be sixty-five or older<sup>3</sup> and that Germany will have lost 20% of its working age population<sup>4</sup>. The coming surge of elderly has such severe ramifications that it has been referred to as a “tsunami of elderly”<sup>5</sup>. With increased life expectancy rates, declining birth rates, and a fixed retirement age that hovers around the early sixties, our societies are faced with an onslaught of elderly, a shortage of care givers, and shrinking GDPs that limit our ability to provide care and services to our aging populations.

As a result, many are looking to ICT as a means to keep the elderly engaged in society, to enable them to live autonomously, and to resolve a wide range of medical issues. While the benefits of ICT can be extraordinary, they come with many social, ethical, and privacy considerations that must be taken into account. To better understand the issue, we consulted twenty-eight leading glob-

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<sup>1</sup> Stephen Sapp, “The Baby Boomers and the Transformation of our Later Years” p. 27.

<sup>2</sup> <http://news.bbc.co.uk/2/low/business/2248531.stm> accessed 23 Sept. 2008.

<sup>3</sup> Susan Orpett Long, “Aging in Japan” p. 18. Dr. Long is a Sociologist who specializes in Japanese society.

<sup>4</sup> Stephen Sapp, *ibid.* It must be noted that Dr. Sapp’s figure regarding the population in Germany also takes into account falling birth rates.

<sup>5</sup> Ase Keri Haugeto, “The Tsunami of Elderly: How Aging Citizens Will Change Our Societies” p. 123. Ms. Haugeto is currently leading the e-Health: Future Aging project within the Norwegian Board of Technology.

al experts from the fields of e-Health, gerontology, technology, sociology, biomedical ethics, robotics, care giving, governance, and the arts. They spoke to us about aging, accessibility, design, ICT in the workplace, caring for the elderly, e-Health, telemedicine, robotics, privacy, universal rights, and policy.

## What Do We Mean When We Say “Elderly”?

In Switzerland, when the Social Security system was put into place, beneficiaries began receiving pensions at the age of fifty-five with the expectation that they would live for a few more years<sup>6</sup>. In the United States, when Social Security went into effect, the average life expectancy was sixty-three. By comparison, a child born today can expect to see the 22<sup>nd</sup> Century<sup>7</sup>. As such, it would seem that “elderly” is a relative term. What was “old” in the past, will perhaps come to be “middle-aged” in the future. So, how do we define “elderly” today?

Most, if not all, of the people we spoke with agree that “elderly” today is not a blanket group, but is rather a group composed of sub-categories of people. There were a multitude of ways in which those we spoke with referenced the elderly. Some participants cited retirement as a marker of old age<sup>8</sup>. Others divide “elderly” into categories of active elderly<sup>9</sup>, frail elderly<sup>10</sup> or “young” elderly<sup>11</sup>. For software expert Yolanda Berbers, “age is something you have between your ears”<sup>12</sup> and for Adam Greenfield, ubiquitous computing expert, “...a person is elderly when one perceives himself or herself to be elderly”<sup>13</sup>. Such classifications beg the question, is “elderly” a social construct? According to Primatologist Dr. Augusto Vitale, “elderly” is a concept unique to human beings: “I wouldn’t expect a monkey to perceive another monkey as being an elder...while there are some subtle changes, there are no radical changes in behavior or cognitive functions that would tell you that a particular animal is old”<sup>14</sup>.

**“Elderly” today is not a blanket group, but is rather a group composed of sub-categories of people**

While the definition of “elderly” remains nebulous, what is clear is that the role of the elderly has changed in recent decades. In the past, “... elders possessed not only the sacred knowledge, but they were the repositories of very practical wisdom. They knew when and where to plant, where the animals hung

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<sup>6</sup> Sergio Bellucci, “Privacy, Affordability and Anti-Aging: Studies in ICT for the Elderly” p. 115. Dr. Bellucci is the Director of the Swiss Centre for Technology Assessment (TA-SWISS) at the Swiss Academies of Arts and Sciences

<sup>7</sup> Stephen Sapp, *ibid.*

<sup>8</sup> Susan Orpett Long, *ibid.*

<sup>9</sup> Stephen Sapp, *ibid.*

<sup>10</sup> Vincent Rialle, “The Benefits and Concerns of Smart Homes for the Aging” p. 67. Dr. Rialle is an expert in Biomedical ethics and Biomedical engineering.

<sup>11</sup> Anne-Sophie Parent, “The Elderly, ICT and the Need to Close the Digital Divide” p. 129. Ms. Parent is Director of AGE – the European Older People’s Platform.

<sup>12</sup> Yolanda Berbers, “Privacy, Ethics, Technology and Keeping People Included” p. 79.

<sup>13</sup> Adam Greenfield, “Assistive Technology, Privacy, Design and the Elderly” p. 93.

<sup>14</sup> Augusto Vitale, “Aging in Monkeys: How PRIMATES View Their Elders” p. 49.

out and when the birds came by, when the rains began or when the river rises or falls...what older people knew was essential to survival"<sup>15</sup>. In today's society, however, this sort of knowledge is no longer valued. We are living in the Information Age, where information is stored and accessed digitally and communication is instantaneous. As such, it is imperative that, as Neena Gill (responsible for passing the Ambient Assisted Living Program within the European Parliament) states, "...we find ways of making digital technologies available to those over sixty. [For] without such developments, we will be leaving a vast portion of our societies behind"<sup>16</sup>. Being on the other side of the digital divide has been compared to illiteracy: "Two hundred years ago, the issue was whether you were able to read and write; being able to read meant that your chances in life were enhanced and that you could do more things than those who were not literate. Now, we see the same thing with the digital divide. If you don't know how to use technologies, you are left out, excluded, from a huge sector of society and from many, many services"<sup>17</sup>. This sentiment was echoed by Jean-Claude Burgelman (Head of Information and Communication Technologies Unit) who claims that technology today, "is as important as the pen was in the 1960s"<sup>18</sup>. If technology has become so basic to our everyday life, excluding the elderly from participation in the Digital Society clearly raises ethical questions. However, to include them in today's technological world requires making technology accessible to them.

## Accessibility and Assistive Technology

A common belief associated with the elderly is that they are incapable of learning to use technology. However, according to Dr. Stephen Sapp, "...this perception is universally not true....In the absence of...some physical problem there is absolutely no evidence that older people can't learn or that their intelligence declines". However, it is true that as people age, their "systems begin to decline"<sup>19</sup>. They experience problems with manual dexterity, mobility and vision, to name a few<sup>20</sup>. As such, many older people need some form of assistive technology.

**In the absence of...some physical problem there is absolutely no evidence that older people can't learn or that their intelligence declines**

One particular concern regarding assistive technology, however, is stigmatization. As Dr. Marion Hersh, Senior Lecturer in the Department of Electronics and Electrical Engineering at the University of Glasgow, points out, assistive

<sup>15</sup> Stephen Sapp, *ibid*.

<sup>16</sup> Neena Gill, "ICT, the Elderly, and Emerging Global Markets" p. 39.

<sup>17</sup> Anne Sophie Parent, *ibid*.

<sup>18</sup> Jean-Claude Burgelman, "Economics and the Elderly: How ICT Can Help People Remain at Work" p. 61.

<sup>19</sup> Stephen Sapp, *ibid*.

<sup>20</sup> Dennis McCullough, "Slow Medicine: Getting to Know Our Elders" p. 149. Dr. McCullough is an M.D., a gerontologist.

technology must be non-obtrusive: "...technologies and devices have to be designed so that they are socially attractive....Most blind people [for example] don't want devices that make them look like robots, with a lot of clinking and clanking noises. Clearly that would be socially isolating..." However, according to Dr. Hersh, the elderly could benefit from things like announcements on busses and trains that clearly tell passengers the name of the next stop, announcements in elevators that announce what floor the elevator is on, assistive technology that provides access to websites, screen reader technology, or cell phones designed for the elderly<sup>21</sup>.

Several companies are making great strides in these areas. While Michael Takemura, Director of the Accessibility Program Office at Hewlett Packard, admits that no product will ever be 100% accessible, HP, none-the-less, employs a Global Accessibility team to ensure that everything from their large servers that run ATM machines to their printers and palm pilots are as accessible to as many people as possible<sup>22</sup>. In addition, HP works with third party vendors to make sure that their assistive technology is compatible with HP hardware.

Hewlett Packard has also teamed up with Microsoft to develop a PC that is specifically geared toward senior citizens. According to Robert Sinclair, Director of Accessibility for Microsoft's Accessibility Business Unit, "the project takes software that was originally designed for those with disabilities and reformats it into a system designed to create an easier way for seniors to access information"<sup>23</sup>. A unique feature of the PC is that it will eventually come with computer classes. Right now, Microsoft is looking at two ways in which to provide the elderly with this training. The first method involves sending a technician to the house to deliver and set up the computer and to provide several hours of tutorial. The other method involves giving seniors credits that can be exchanged for classes at a local community center<sup>24</sup>. The need to educate the elderly in the use of ICT was echoed throughout our interviews, as was the need to include them in the design of products geared for their use.

## Design

Participants raised several concerns about the design phase of new technology, the most basic of which is simplicity. Designers and engineers often have a different relationship with technology than the general public<sup>25</sup>. As such, they have a tendency to create technology that does not appeal to the average person. However, "The simpler designers can make a product, the more adaptable it will be to the broader market"<sup>26</sup>. The need for simplicity is reinforced by Adam Greenfield who claims that technology needs to be "as simple as chairs".

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<sup>21</sup> Marion Hersh, "Assistive Technology, Education, and the Elderly" p. 73.

<sup>22</sup> Michael Takemura, "Universal Accessibility, Design, and the Elderly at Work" p. 143.

<sup>23</sup> Robert Sinclair, "Assistive Technology and Senior Friendly Computing" p. 99.

<sup>24</sup> Robert Sinclair, *ibid.*

<sup>25</sup> Robert Sinclair, *ibid.*

<sup>26</sup> Robert Sinclair, *ibid.*

He says, “I know how to sit in a chair. I can see it at first inspection. I have to be pretty cognitively impaired before I can’t see what a chair is or figure out how to use it at first inspection...technology should be designed to that standard”<sup>27</sup>.

In addition to simplicity of design, there is concern that the design phase has too little funding and is not given enough time to adequately assess user needs. According to Ase Keri Haugeto, “The industry demands that designers be quick and [therefore] they don’t have enough time to thoroughly develop things. It takes time to understand people’s needs”. Greenfield seconds her opinion: “In [an] ideal world, there would be a mandatory discovery phase in the development of any proposed technology in which...you... send out trained ethnographers to do what’s called shadowing, to follow people in order to understand better their behavior and their needs”.

**Japan is the world’s first nation to experience such changing demographics and should therefore be watched carefully when looking at the changes taking place within Europe.**

The view that end users need to be taken into account from the beginning of the design phase is held by most participants. However, Dr. Berbers disagrees with Greenfield about the effectiveness of shadowing. She claims that while “people may think they have regular routines and habits...in reality they don’t”. When people change their routines and technology doesn’t change with them, they become very frustrated<sup>28</sup>.

Further concerns are centered around the necessity to fund projects designed to enter the market and designing products that aren’t repetitive. Regarding funding, it is important that research isn’t conducted simply for the sake of research. According to Michael Takemura, governments must be funding projects that will serve an end user<sup>29</sup>. Furthermore, designers and engineers shouldn’t be reinventing the wheel. If a product is already on the market and it works well, they shouldn’t be designing the same thing with advanced features that are essentially useless<sup>30</sup>. According to Dr. Lucy Suchman, Professor of Anthropology of Science and Technology in the Department of Sociology at Lancaster University, it is also important that the ethics behind design are taken into account and that projects are being funded because of their usefulness and not because designers want to realize their ideas<sup>31</sup>. Another important element to making technology accessible is universal design. According to participants, not only is it easier to design for the elderly and disabled from the beginning, it also makes for good business<sup>32</sup>. Clearly, if products are designed with the widest spectrum of users in mind, businesses will be able to sell more units.

<sup>27</sup> Adam Greenfield, *ibid*

<sup>28</sup> Yolanda Berbers, *ibid*.

<sup>29</sup> Michael Takemura, *ibid*.

<sup>30</sup> Adam Greenfield, *ibid*.

<sup>31</sup> Lucy Suchman, “Robotics Not Robots: Aiding the Elderly, Not Replacing Care” p. 55.

<sup>32</sup> Marion Hersh, *ibid*; and Michael Takemura, *ibid*.



## The Economics of ICT and the Elderly

In Japan, companies are catering to their “tsunami of elderly”. Japan is the world’s first nation to experience such changing demographics and should therefore be watched carefully when looking at the changes taking place within Europe. In Japan, companies are designing products with the elderly in mind, and are consequently tapping previously unexplored markets. A perfect example of this is seen through companies who are producing cell phones with large buttons designed for those elderly with dexterity problems<sup>33</sup>. According to Neena Gill, the global rise in the elderly population presents many opportunities to European businesses as well: “...we are encouraging businesses to think further and clearer; to recognize the needs and the potential of our aging societies”<sup>34</sup>.

**The EU has a general target where at least 12.5% of workers should get training ever year... we know very well that with older workers we are far from reaching this target.**

Not only are businesses looking at the elderly as potential markets, but they are also realizing the wealth of experience older citizens bring to the business world. According to Michael Takemura, many large and medium sized companies are presently facing a shortage of qualified employees and are therefore turning to older workers to fulfill their business needs. As such, HP has seen an increase in requests for assistive technology required to satisfy the needs of older employees<sup>35</sup>.

According to Jean-Claude Burgelman, “Keeping the elderly in the workforce is an economic, social and ethical obligation”. He states that, “It is an economic obligation because we need their knowledge and we cannot go on importing people from all over the world to work in our countries when we have people who have accumulated forty years of knowledge right here at home....It’s also a social obligation because you can’t just isolate people. And, it’s an ethical obligation. It’s not right that you should be thrown out [because of your age]...”<sup>36</sup> In fact, many elderly would like to continue to participate in the workforce, particularly if they could phase into retirement.

For many elderly, the abruptness of going from fulltime work to fulltime retirement is difficult. People would like to progressively retire<sup>37</sup>. This is certainly an area where ICT can be beneficial. According to Anne Sophie Parent, people “...would be happy to continue to work if they could do some telework and split their time between the office and home”<sup>38</sup>. According to Ms. Parent, not only can ICT help the elderly stay in their current positions, it can also open the door to second careers<sup>39</sup>. Despite the many benefits to the individual and to society, however, older people are frequently left out of ICT training programs. Ac-

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<sup>33</sup> Susan Orpett Long, *ibid.*

<sup>34</sup> Neena Gill, *ibid.*

<sup>35</sup> Michael Takemura, *ibid.*

<sup>36</sup> Jean-Claude Burgelman, *ibid.*

<sup>37</sup> Anne-Sophie Parent, *ibid.*

<sup>38</sup> Anne-Sophie Parent, *ibid.*

<sup>39</sup> Anne-Sophie Parent, *ibid.*

cording to Ms. Parent, “The EU has a general target where at least 12.5% of workers should get training ever year...we know very well that with older workers we are far from reaching this target”<sup>40</sup>. Given the rising number of elderly and the need for workers, this is clearly an area that could be improved upon.

## ICT and Carers

As ICT can help the elderly to remain in the workforce, it can also help carers continue in their own careers. Eighty percent of all care givers are family members<sup>41</sup>. However, as birth rates decline and more women than ever are in the workforce, the number of people available to help older relatives becomes increasingly few<sup>42</sup>. The demands upon careers is also quite taxing. 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”<sup>43</sup>. Monitoring systems that allow dependants to alert someone in an emergency permit carers to continue in their careers, knowing that they will be notified if they are needed at home<sup>44</sup>. In addition to enabling carers to participate in the work force, ICT also helps them in caring for dependents. Devices that monitor vital statistics can raise concerns before small problems become major issues<sup>45</sup>. ICT can also help carers stay informed about caring techniques and medical conditions, and it can help them establish and join support networks<sup>46</sup>. While many of the benefits of ICT are clear, there are numerous ethical and privacy concerns posed by such technology. This is particularly true of technology used for the monitoring of dependents and in areas of e-health and telemedicine.

## Monitoring, E-health and Telemedicine

Data that is collected by a device that monitors a patient on a regular basis can provide a wealth of information to the medical community<sup>47</sup>. However, informa-

<sup>40</sup> Anne-Sophie Parent, *ibid.*

<sup>41</sup> Stephen Sapp, *ibid.*

<sup>42</sup> Ase Keri Hauge, *ibid.*

<sup>43</sup> Madeleine Starr, “The Needs of Carers: Caring for Our Aging Loved Ones” p. 159.

<sup>44</sup> Madeleine Starr, *ibid.*

<sup>45</sup> Madeleine Starr, *ibid.* According to Ms. Starr, in a study conducted by Kent County Health in the U.K., “telehealth monitoring has reduced cardiac admissions by as much as 75% a year”. (p.133) Presumably, this marks a substantial savings to the health care system.

<sup>46</sup> Madeleine Starr, *ibid.*

<sup>47</sup> Hiroshi Shimada, “ICT, e-Health, and the Aging Crisis in Japan” p. 111. Mr. Shimada is a consultant for Fujitsu Limited in Japan.

tion collected through monitoring poses a variety of ethical questions and presents many challenges to maintaining an individual's right to privacy. Mr. Tavano, of Unisys Global Public Sector, provocatively argues that, "...privacy has been reduced to a bureaucratic measure". He claims that, "We are so use to having to sign away our privacy, or to signing something that acknowledges our right to privacy, that we don't even read what we are signing anymore"<sup>48</sup>. However, when we sign such documents, we knowingly enter into a contract whereby we agree to relinquish some of our privacy or we acknowledge our right to privacy. When ICT is used to collect data about our health, however, or to monitor our behavior, this line becomes blurred.

**Technology connects to your personal life; it collects data and qualifications about your personal life. In one way, it can become much more intimate than anything else.**

As Dr. Paul Timmers, Head of the ICT for Inclusion Unit, points out, "Technology connects to your personal life; it collects data and qualifications about your personal life. In one way, it can become much more intimate than anything else"<sup>49</sup>. Yet, in the areas of monitoring, telemedicine, and e-Health, many people are unaware of when devices are collecting this data and what becomes of it. According to Adam Greenfield, "Any piece of technology that collects information should make it clear that it's capable of doing that, what the intention of doing that is, on what channels it's collecting information and of what type, what sorts of networks it's connected to, who owns the networks, etc."<sup>50</sup>. In fact, the general consensus among participants is that people need to be made aware of when their privacy may be invaded. Exactly how to do this was up for debate. While Dr. Burgelman asserts the need for privacy enhancing technology as a solution<sup>51</sup>, Dr. Timmers and Dr. Adrie Dumay of TNO argue that current legislation designed to protect the individual's right to privacy cover such issues as data collection through the use of ICT devices<sup>52</sup>. This would also include, of course, data collected and disseminated under e-Health and telemedicine.

The areas of e-Health and telemedicine have raised particular ethical and privacy issues. One paramount concern is an erosion of the doctor-patient relationship. While Dr. Marion Hersh rightly claims that we cannot assume that this relationship is necessarily a positive one, the concern still exists that ICT will lessen the quality of patient care. To safeguard against this possibility, according to Dr. Dumay, the Netherlands has instituted a policy whereby "...only after the doctor has seen the patient in person can he or she begin to use ICT for interventions, communication, monitoring, giving out prescriptions, etc."<sup>53</sup>.

<sup>48</sup> Robert Tavano, "Privacy, ICT, and the Elderly" p. 83.

<sup>49</sup> Paul Timmers, "Including Elders in the Information Age" p. 105.

<sup>50</sup> Adam Greenfield, *ibid.*

<sup>51</sup> Jean-Claude Burgelman, *ibid.*

<sup>52</sup> Paul Timmers, *ibid.*

<sup>53</sup> Adrie Dumay, "Robotics, e-Health, and the Future of ICT" p. 45.

However, Dr. Dumay confesses that there hasn't been a vast uptake of telemedicine or e-Health in the Netherlands: "Here, doctors don't really like to use ICT to communicate with patients because they are fearful that they will be overloaded with questions that would normally be asked all at once in the office rather than continually over the Internet"<sup>54</sup>. This reflects the concern held by members of the medical community that

**Doctors don't really like to use ICT to communicate with patients because they are fearful that they will be overloads with questions that would normally be asked all at once in the office rather than continually over the Internet.**

ICT could open the door to continual requests for communication. In such a circumstance, doctors and nurses could easily become bombarded with trivial questions which could overload their already busy schedules. Such demands would negate the convenience and potential cost savings of such systems.

On the other hand, doctors also have to make sure that they don't rely so much on technology in diagnosis and treatment that the patient gets lost in the equation. In the opinion of Dr. Paul Schotsmans, Vice-Dean of the Faculty of Medicine of the Catholic University of Leuven, technology, in a certain sense, is dominating the medical field<sup>55</sup>. According to him, the high cost of technological devices requires that doctors and hospitals rely upon technology more than is necessary. He reveals that, "...in [his] own hospital...patients are being scheduled for procedures even at night when the machines can be used but there is no doctor available to interact with and reassure the patient". Clearly, "When the only information you get is from the technician, you have to say that this is not really what health care is all about"<sup>56</sup>. Indeed, there seems to be a general lack of communication within the medical community. According to Dr. Schotsmans, medical students are instructed in how to interact with patients in the first years of their studies, but what skills they acquire in this period are usually forgotten once they begin to work with technology<sup>57</sup>. If this is the case, clearly technology has the potential to interfere with the doctor-patient relationship and to alienate patients.

## Technology or the Human Touch?

As advanced as technology has become, there are some things that machines just can't do. According to Dr. McCullough, "Touch is one of the things that older people talk about missing. When people are quite frail or bedridden, touch becomes an extremely important way for people to communicate, and I don't think that our technologies are ever going to replace

**The rhetoric around elder care is full of the premise that there are going to be robot care givers**

<sup>54</sup> Adrie Dumay, *ibid*

<sup>55</sup> Paul Schotsmans, "ICT in the Medical Field, Finitude, and the Key to Happiness" p. 87.

<sup>56</sup> Paul Schotsmans, *ibid*.

<sup>57</sup> Paul Schotsmans, *ibid*.

that need”<sup>58</sup>. It appears that many people do, indeed, have a great fear that technology will replace human care givers. According to Dr. Lucy Suchman, “The rhetoric around elder care is full of the premise that there are going to be robot care givers”<sup>59</sup>.

While walking, talking, humanlike robots are the stuff of Science Fiction, we have seen that robot pets have made their way into the world of the elderly with mixed reviews<sup>60</sup>. According to Dr. Dumay, studies reveal that if a robot dog like the Aibo is placed in a group home setting, elderly residents will not only form an attachment to it, but the “dog” becomes a common focal point around which residents communicate with each other<sup>61</sup>. This finding seems to reflect a positive relationship between man and technology. However, Dr. Suchman questions the ethics of such devices: “My experience is that people are captivated by any kind of animation. If a machine performs anything like human behavior, people immediately project human attributes onto it and they assume that it will have a whole range of human capacities. But, what happens is that people run into the limits of these machines fairly quickly....Exploiting this fascination when you can’t really deliver upon expectations is very problematic, especially when you have people who are already vulnerable in terms of loneliness and depression”<sup>62</sup>. As Dr. Suchman points out, what happens when these robot “companions” fail to fulfill expectations, or when they break down? “Are we potentially putting people in a situation where they are much less happy than they were before?”<sup>63</sup>. This question seems to pervade discussions about e-inclusion and the elderly.

That being said, there are many benefits that seniors reap from ICT. The internet has allowed the elderly to remain in contact with far away friends and family members. Many seniors are using the web to network, plan travel, or research medical conditions.

Where grandparents use to receive an occasional photo of their grandchildren, Skype makes a Sunday call to Grandma an interactive experience<sup>64</sup>. Surveillance technology affords the elderly the possibility to remain in their own homes despite certain medical conditions. Telemedicine permits them to “visit” the doctor without leaving the comfort of their own homes, and robotics make it possible for them to receive assistance without having to depend upon care givers. However, while such advancements allow the elderly to maintain communication and to live as autonomously as possible for as long as possible, they also pose the risk of alienating and isolating them<sup>65</sup>.

Most, if not all, participants agree that despite their benefits, ICT cannot be

**By monitoring older people, are we neglecting other needs that they might have?**

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<sup>58</sup> Dennis McCullough, “Slow Medicine: Getting to Know Our Elders” p. 149.

<sup>59</sup> Lucy Suchman, *ibid.*

<sup>60</sup> Lucy Suchman, *ibid.*

<sup>61</sup> Adrie Dumay, *ibid.*

<sup>62</sup> Lucy Suchman, *ibid.*

<sup>63</sup> Lucy Suchman, *ibid.*

<sup>64</sup> Stephen Sapp, *ibid.*

<sup>65</sup> Stephen Sapp, *ibid.*; Adrie Dumay, *ibid.*

used as a substitute for human contact. According to Ms. Parent, if you implement systems such as monitoring systems or health smart homes to alleviate the need for professional care giving, "...you need to replace the nurse visit with the visit of a less skilled worker or volunteer who would still come once a day or once every two days and have a little chat with the person and spend a bit of time to check that everything is alright. We have had complaints from older people that they have not seen anyone for six weeks or two months in a row"<sup>66</sup>. This fear was echoed throughout most ethical discussions we engaged in.

From Dr. McCullough who asks if "...by monitoring older people, are we neglecting other needs they might have?"<sup>67</sup> to Adam Greenfield who wonders if being "...tended to by some kind of automated system...[isn't] a terrifying way to spend...[ones] final years on this planet"<sup>68</sup>, the general consensus among participants is that ICTs are fantastic solutions to certain problems, but that they should not replace human contact. This fear of substitution is not limited to the frail elderly, but is also extended to include programs and services that are moving exclusively to the Internet. If the elderly cannot afford a computer, or cannot access the Internet, they will be excluded from such services and programs. As Mr. Sinclair points out, this presents a huge problem when what we're talking about are government services and pension programs<sup>69</sup>. While moving services to the Internet risks excluding those who do not have Internet access or are not digitally literate, it also risks limiting human interaction and alienating the elderly from social contact. As Dr. Marion Hersh asserts, many elderly enjoy the personal interaction they receive when they frequent places like their local post office or bank<sup>70</sup>. If these services are moved to the Internet, people will lose this connectedness. Consequently, as Dr. Sapp suggests, it is very important that Internet services be on an opt-in, opt-out basis and that there is always an ulterior way to participate in services and programs<sup>71</sup>.

## Rights and Policy

While, again, most, if not all participants agreed that technology cannot replace human beings, there was not such a consensus on whether or not technology should be considered a universal right. When posed with the question, Dr. Berbers asked, "Is there a right to home ownership? [Is there] the right to have a mobile phone?"<sup>72</sup> However, according to Dr. Burgelman, "...ICTs are as fundamental for the future of our societies as the steam engine was for the Industrial Revolution or as elec-

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<sup>66</sup> Anne-Sophie Parent, *ibid.*

<sup>67</sup> Dennis McCullough, *ibid.*

<sup>68</sup> Adam Greenfield, *ibid.*

<sup>69</sup> Robert Sinclair, *ibid.*

<sup>70</sup> Marion Hersh, *ibid.*

<sup>71</sup> Stephen Sapp, *ibid.*

<sup>72</sup> Yolanda Berbers, *ibid.*

tricity was”<sup>73</sup>. If this is the case, then surely access to ICT must not be discriminatory. This is a real issue, particularly if the price of ICT automatically excludes segments of the population<sup>74</sup>.

Regarding policy and the right to access ICT, ethics Professor Rafael Capurro claims that, in part at least, this right is already covered by existing legislation. He states, “The freedom of information and communication is already stated in the Universal Declaration of Human Rights as well as in democratic constitutions”<sup>75</sup>. While he states that you cannot obligate nations to provide their citizens with Internet access, he asserts that there certainly needs to be societal and academic discussions on the right to communicate within the Information Age<sup>76</sup>.

In general, there is a wide range of policy areas that need to be addressed. In her interview, Ms. Gulacsi Gologan of CEN stressed the need to establish standards throughout the EU for elder care in general<sup>77</sup>. Ms. Gill asserted the need to establish a “minimum level of ICT knowledge in each member state...”<sup>78</sup>. Overall, participants emphasized the fact that it is important to educate seniors not only in the use of ICT, but also in how to protect themselves and their privacy when it comes to ICT. Regarding assistive technology, Mr. Takemura stressed that legislation must not limit the ability of designers and engineers to come up with creative solutions<sup>79</sup>.

From a design perspective, several participants emphasized the need to make including the end user in the design phase a part of funding requirements. Additionally, Dr. Rialle, expert in biomedical engineering and ethics, stressed the need to “...see the development of technology that is based upon professional advice...[as well as] policies that promote the teaching of technology”<sup>80</sup>. Regarding the most recent inclusion policy that came out in 2007, Dr. Timmers stressed what they call the four A’s: Availability, Accessibility, Affordability and Ability. Technology must be available. Technology must be accessible to everyone, including the disabled and the elderly. Technology must be Affordable; and people must know how to use it<sup>81</sup>.

<p><b>Are we offering ICT solutions to the elderly for their benefit or are we offering them for our own?</b></p>
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## In Conclusion

Discussions centered around ICT and inclusion of the elderly can reveal rather apocalyptic fears of seniors isolated in their homes and being looked after by

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<sup>73</sup> Jean-Claude Burgelman, *ibid.*

<sup>74</sup> Yolanda Berbers, *ibid.*

<sup>75</sup> Rafael Capurro, “The Elderly, ICT, and an Ethical Society” p. 41.

<sup>76</sup> Rafael Capurro, *ibid.*

<sup>77</sup> Andrea Gulacsi Gologan “The Need for Standards in Elder Care” p. 139.

<sup>78</sup> Neena Gill, *ibid.*

<sup>79</sup> Michael Takemura, “Universal Accessibility, Design, and the Elderly at Work” p. 143.

<sup>80</sup> Vincent Rialle, “The Benefits and Concerns of Smart Homes for the Aging” p. 67.

<sup>81</sup> Paul Timmers, *ibid.*

machines. As we have seen, while these fears are grounded in the very real possibility that ICT devices can and will isolate the elderly, the reality is that many of these devices have the potential to be very helpful in assisting the elderly to live autonomously and in a way that maintains a certain quality of life. However, it is important to make sure that these solutions are not forced upon those who do not wish to use them. Concern is raised by Mr. Greenfield's assertion that, "The people who generally push for the use of these technologies are not the people using them, but rather the middle-aged son or daughter of the user"<sup>82</sup>. Clearly, this raises ethical concerns. Are we offering ICT solutions to the elderly for their benefit or are we offering them for our own?

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<sup>82</sup> Adam Greenfield, *ibid.*





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# The Baby Boomers and the Transformation of Our Later Years

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*Interview with Stephen Sapp*



*Dr. Stephen Sapp, Professor and Chairperson of the Department of Religious Studies at the University of Miami, is an expert in the field of gerontology. He is past chair of the Governing Council of the Forum on Religion, Spirituality, and Aging, of the American Society on Aging, and is the founding president of the South Florida Chapter of the Alzheimer's Association. From 1990 to 2007, Dr. Sapp chaired the Bioethics Com-*

*mittee of Miami Children's Hospital. In addition, he is past chair of the University of Miami's Social and Behavioral Sciences Institutional Review Board and current chair of the Faculty Senate.*

*Dr. Sapp spoke with us about the ramifications of our aging population and what role ICT should play in coping with their demands:*

**Q: Looking at our view of aging, are we trying to prolong our prime for so long that we as individuals are missing out on certain passages or evolutions in life?**

The most common term for growing old gracefully is “successful aging”. “Positive aging” is another term that I actually like better. But the problem I have with all of these types of terms is that they are inherently ageist. If you look at what people mean by “successful aging” or “positive aging”, every element that makes up “successful aging” is really just a trait associated with youth, prolonged into the later years. For a long, long time it's been pointed out (talking about the U.S.) that we're a death-denying society. Geoffrey Gorer published a ground-breaking article called “The Pornography of Death” in which he argues that death has become the new pornography, the obscene thing that people didn't talk about and tried not to look at. I think that is now the case regarding age. We have become an age-denying society, one in which aging has been implicated in the stage before death. According to Stephen Post, there are three primary characteristics that give people value in America today: the first is ra-

tional, having a rationally working mind; the second is economic productivity (in this culture, you are not a person of value if you are not economically productive); the third is autonomy, or independence. Post says that Alzheimer's disease robs people of all three of these elements. I believe we can extend this far beyond just dementia to old age in general, given the popular perception.

**Q: Well, John Glenn went into space at seventy-six. Does this change how we define "elderly"?**

Like most categories that we use to define ourselves and others, "elderly" is an arbitrary construct. We see things as we are, not as they are. So, the definition of "elderly" is a social category that we have come up with. That immediately raises the question, "who does the defining?" Clearly, what was old, not even that long ago, isn't so today. When Social Security began in 1935, the life expectancy was sixty-three. So, what do you think the definition of "old" would have been then? A female child born today can expect to see the 22<sup>nd</sup> century. What becomes old now? I'm sixty-two. The way our society is structured, if I wanted to, I could retire this year. I think that's absurd. Why in the world would anybody want to retire at my age? In the United States today, if you turn sixty-five, you can expect to live for about twenty more years. Do the math. That is about one quarter of a person's total life span still ahead of him or her at the age of sixty-five. So, statistically speaking, at sixty-two, I've still got at least a fourth of my life still to go. Worldwide, of all the people in human history who have ever reached the age of sixty-five, somewhere between one-half and two-thirds are alive right now. So, it isn't just the U.S. population. It isn't just the German or the Italian or the French population. It isn't just China or Japan. The world as a whole is aging and living to be a lot older than in the past. Given that fact, I think we definitely have to redefine "elderly". But again, what do you mean by "define"? Are you talking about setting the age at which a person becomes elderly, or are you talking about the content of the term "elderly"?

**Q: So, would you say that we need to phase people out of certain jobs and find new roles for them elsewhere?**

I don't want to talk this way about people who are forty or fifty, that's too young. But, talking about the people of typical retirement age, sixty-five and older, there is so much that our countries, our societies, need done. In life, we need something to give us purpose and a sense of self worth. So, why don't we say, "let me find something for you to do, something where you'll really be contributing; there's something that needs doing that you can do". I think that there are roles for people who have been moved out of the socioeconomically productive roles. I think if governments sanction programs, or conceive of them, then it might make a difference. Programs that encourage older people to be active mentors to children or care givers or volunteers in society will certainly benefit them and it will be good for society as well. If we can encourage elders to mentor kids who would otherwise be hanging out on the streets or left in afterschool

programs or on their own, what's that going to mean to society down the road when that kid isn't out rampaging and doing bad things?

**Q: Can the use of ICTs help the elderly remain productive agents within society?**

The benefits to society are so tremendous if older workers remain in the workforce. As our populations continue to age, what has resulted so far (and there's no evidence that this is going to change) is a decline in the working age population at the same time that the number of elders who require government support is increasing. If you look at it in economic terms, a country's GDP is basically a product of the number of workers they have and the overall productivity. If the number of workers shrinks then the GDP has to shrink, unless there is a marked increase in productivity. So, I don't think it's realistic to think that with the demographics we have in the pipeline that we can possibly increase per capita productivity enough to make up for the anticipated shrinkage of the workforce. By 2050, Germany's working age population is expected to shrink by 20%, France's by 6%. On the surface, that would mean that Germany's productivity would have to increase by 20% by 2050 to make up for that 20% shrinkage. Couple that with the fact that non-working elders cost society more, in terms of benefits of various kinds, and you see that there is an incredible synergistic effect. So, there is a three-fold incentive to help older workers remain productive. One, they're continuing to contribute to the GDP by producing. Two, they're paying taxes to help support those people who are no longer contributing; and three, they are not adding to the number of those drawing on the system. There's just absolutely no question that keeping people in the workforce can only be of benefit to society. If ICTs can allow people to continue to contribute in some way to the work force, then I think that can be of great benefit to society and is certainly worth the investment in training people to use them.

**Q: In the future, are we going to have a problem taking care of the elderly?**

It is estimated that up to 80% of elder care in the U.S. is provided by families. But we have a fertility rate that barely replaces people who die. In a number of countries within the EU, the fertility rate is well below the death rate. What we are going to have is an incredible confluence of three demographic trends. The first is the sheer number of aging Baby Boomers. There are 76 million of us in the United States alone who are getting ready to turn sixty-five between 2011 and 2029. Combine that with a much smaller number of offspring. Then compound that by, third, our increased longevity. Soon, you're going to see what I like to call a great-grandparent boom. The Baby Boomer generation has brothers and sisters to help take care of aging relatives. But we have fewer children than our parents did. Consequently, the burden on our children will be greater than what we are experiencing today. Fewer and fewer adult children will have more and more elderly parents and grandparents around who are going to tend to live much longer than in the past. So, yes, I think we will have problems taking care of our elderly.

**Q: What are some of the ways ICT can help the elderly take on new roles as they age?**

ICTs can help people stay connected as populations continue to be more mobile and families live farther apart. ICTs can also help elders in the workplace. The whole notion of working at home enables people to continue to be more involved. I'm thinking of certain companies or jobs or professions where, if a person doesn't want to come into the office every day but still has a real contribution to make, these technologies help him or her to do so. ICTs can also help elders participate more in society, either on line or in person. The more "connected" a person is, the more that person is going to want to participate.

**Q: Why is it important to close the digital divide and to include seniors in the Information Age?**

At some point, the mobility of older people is more likely to be impaired, maybe even to the point where they are housebound. So, certainly, ICTs can help them be connected. Also, as I've said, I think older people still have contributions to make. And the more involved in society people are, the more they can contribute, and, obviously, the more their quality of living will improve. I think that if we are going to close the digital divide and include elders, we're going to have to be sensitive to some of the issues of aging, like vision and diminishing manual dexterity. Regarding policy and the more practical side of these questions, I think manufacturers, maybe with government help, are going to have to modify the layout of the devices. I think one area that needs to be thought about is protecting older people from predators of various kinds. If older people get really connected to the internet, with all the scams that are out there, they will be really vulnerable and we need to give some thought to how we can protect them.

**Q: Can ICT inadvertently isolate the elderly?**

I think it's a double-edged sword. If we are talking about an active elder, someone who would normally be at the country club playing golf, or out playing cards, or at the garden club actively engaging in face-to-face, hands-on, social interaction of various kinds but instead is hooked on some new ICT toy, then I think ICT could certainly contribute to greater isolation. However, if a person would otherwise be housebound or already isolated to some extent, then I think that any technology that allows for contact and interaction could only enhance that person's life. Overall, I would vote in favor of ICT. I think in terms of families, it certainly is of benefit in keeping families connected. In the past, you used to get photos of grandchildren in the mail. Now, with things like Skype, you can use a video phone on your computer and interact with the grandkids from far away in "real time".

**Q: Is there some point at which access to communication and information services needs to be considered as a right?**

That point for me would be the point at which the lack of access excludes the person from participation in society. In other words, if this is something that

everybody else has, then by all means, I don't think you can exclude people just because of their age. But I do happen to value individual autonomy pretty highly, so I think access should be a right to the extent that someone wants it to be a right.

**Q: One of the potential barriers to educating the elderly in the use of ICT seems to be the belief that they are not capable of learning new information, that they have a drop in intelligence. Is this an accurate perception?**

It is absolutely not an accurate perception. Research has proven that this perception is universally not true. Older people do perhaps slow down in their cognitive process, they may take longer to learn new skills and tasks, but in the absence of organic problems (some physical problem) there is absolutely no evidence that older people can't learn or that their intelligence declines. One of the problems, and this sometimes gets misdiagnosed as Alzheimer's or dementia of some kind, is that if people aren't interested in something, they aren't going to learn it. One of the first things I read in the field of gerontology said, "All the improvements in hearing aids are worth nothing if nobody wants to talk to an older person". Well, all the ICTs in the world aren't worth anything if people aren't going to show older people they value them and the contributions they have to make. We have a problem with the perception and valuing of old people and aging. There's not a single point of attack that can resolve the problem. We have to change the way we think about aging in general. We have to change the way our cultures deal with getting older.

**Q: Why should we value our aging population?**

In the past, elders possessed not only the sacred knowledge, but they were also the repositories of very practical wisdom. They knew when and where to plant, where the animals hang out and when the birds come by, when the rains begin or when the river rises or falls. That's what the elders knew. Why? Because they experienced these things over and over again. So, what older people knew was essential to survival. Today's society, however, values tomorrow's knowledge, anticipating the future, being prepared for what we'll need to do. That knowledge is certainly not stored in old people's minds. So, by definition, there has been an ongoing acceleration of the devaluation of elders in terms of what you would call their tangible, objective, value to younger people and to society. But what I would want to argue, in response to why we should value our aging population, is that maybe knowledge, maybe wisdom, experience, whatever you want to call it, accumulated over many years of living, relating, and suffering, still has value. I would even argue that this knowledge has practical value in a lot of ways, as we struggle to get along with others and cope with the rapidly changing world. I find it between hilarious and infuriating when I hear a younger person say that older people are stuck in their ways and can't change or can't cope with change. Think about it. Can you imagine any comparable time period in history that has required more rapid adaptation to

changing conditions than the period lived through by today's seventy- to ninety-year-olds? Think about what happened in the 20th century. Some of these people went from riding around in horse and buggies to surfing the net; they fly in jet planes; they've lived through two World Wars. These people don't know how to adapt? Oh, come on! So, why should we value the elderly? I think there is a lot of wisdom; there is a lot of knowledge; there's a lot of mentoring that can take place. But really, I think if we have any interest in being a humane society, a civilized society, whatever that might be, we have to value individuals simply because they're human beings. We need to value them for who they are and not what they produce economically. Maybe, even, there's a little bit of a payback involved. These are the people who cared for us when we were dependant, when we couldn't cut it on our own. So, maybe for that reason alone we should value and care for them when they need it. One concept that I ran across in my research is called social capital. Capital is usually thought of as economic productivity. Well, there's also social capital. The highways we drive on, the schools we attended and our kids attended, the water purification plants and sewage plants, all of that is their legacy. Why do these things exist? Because today's older people worked and paid taxes and voted for bond issues, etc. So, even if they are not currently productive, economically, they certainly should have built up a considerable store of social capital and we ought to let them draw upon it.

**Q: How can we protect the rights of the elderly in the face of ICTs?**

I think we have to be careful with ICTs. I don't think the government should be spying on people, even under the guise of helping them. So, in any policy discussion or decisions, I would like to see that these technologies are made opt-in from the outset. If everything is on line and someone doesn't want to go on the internet, then there needs to remain at least a telephone option. Thought needs to be given to ensure that people aren't put in a position where the government or companies are collecting data about people that they have no business knowing. I think when we're talking about cutting-edge technology and older people, we need to remember that the time will come when a person can't manage most, or any, ADLs (Activities of Daily Living). This is where every country needs to really ramp up and start taking it much more seriously in terms of preparing for the vast number of us that are going to be reaching that stage. There's controversy in some people's minds about greenhouse gases, about whether there is global warming, whether we can fix the problem or not. Well, we Baby Boomers exist. The demographics are not going to change. Barring a worldwide natural disaster, a pandemic of some kind, we are in the pipeline. All those numbers I talked about earlier are real. We exist. We're going to get old. And we're going to live a long time. You can't say, "Oh, well, maybe that won't happen". It is happening and it is going to continue happening. If governments don't start taking the situation more seriously and addressing what we're going to do, it's going to make 4 dollar a gallon gas and long waits for health care in socialized countries look like the good old days when we had 25 cent gas and the doctor came to your house.

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# Aging in Japan

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## *Interview with Susan Orpett Long*



*Dr. Susan Orpett Long is professor of anthropology and founding coordinator of the East Asian studies program at John Carroll University. Her research in Japan has focused on issues of family and gender, medical care, and aging. She is the author of “Final Days: Japanese Culture and Choice at the End of Life” (University of Hawaii Press, 2005) and editor of “Caring for the Elderly in Japan and the US: Practices and Policies” (Routledge, 2000) and “Lives in Motion: Composing Circles of Self and Community in Japan” (Cornell East Asia Series, 1999). Since 2002 she has been a member of the Japanese American Study Group on Long Term Care and conducts research on ways the public care system impacts frail older people and their families.*

*Dr. Long spoke with us about the traditional role of Japanese elderly, changes taking place in Japanese culture, and elder care in Japan:*

### **Q: What is meant by Japan’s “hyper-aging”?**

That’s not a term that I’ve heard, but I would assume that it refers to the new Japanese demographics. Currently about 21% of the population is sixty-five and older. The fertility rate is 1.2 and life expectancy is eighty-two years, combined men and women. There are a lot of implications to that. The change has happened relatively quickly and it’s expected to continue to, what to me, are staggering numbers. Presently, the estimate is that by 2025 more than 30% of Japanese society will be sixty-five or older. That alone would seem to require some changes in attitudes and certainly changes in policy.

In such a society, people who are sixty-five or seventy are going to be young because there will be so many people who are even older. If you have 30% of your population that is sixty-five and older, that’s a whole different kind of society than what we think of now.



**Q: How is “elderly” defined in Japanese society?**

Officially, the Japanese government and most people use the international standard of sixty-five. In the past, that number was much lower. When I started studying Japan in the 1970’s, people thought of old age as beginning at sixty. In reality, the government uses one number, but how people think about it can vary from person to person. So, I think it’s really a pretty fluid definition. For example at one level, grandparenthood is a marker of old age, but many people who are in, say, their fifties and sixties don’t think of themselves as old.

Certainly retirement is another marker. However, I think more and more people are seeing health status as the more determining factor in defining age. So, with the exception of the far end where you’re totally bed ridden or have severe limitations, I think the definition of “old” is very fluid.

**Q: What is the traditional role of the elder in Japanese society?**

There were different kinds of roles that elderly people played; part of it was based on social class and on gender. Certainly, younger old people who were still active might have been people who had more power either at a societal or community level, or at least within the family. But, when an elderly person retired, their direct power diminished and they relied on their ability to exert influence instead.

Historically, if you look back to the Edo period or even the early 20<sup>th</sup> century, you will see that the elderly took on an informal religious role as the recipient of communication from their ancestors and as the ones to ask the ancestors for help in taking care of the family. So, in a sense they were seen as a link to the non-human world. Buddhist rituals and those involving ancestors continue to be viewed as a responsibility of older family members. Although contemporary Japanese people have a scientific world view, many people retain a sense of the importance in their daily lives of the spirits of departed relatives.

Historically, there were certainly expectations of women for continued household work and helping to care for any children who might still be in the household. Men and women would have continued working in the fields or family shops as long as they were able, and they would have continued to have active roles in the community.

Even though there was still the possibility of influence, the other side of the picture is that there was a lot of ambivalence about aging as people became less able to fulfill social roles. There is the myth in Japan of Obasuteyama, the mountain where family deserted elderly parents. Nobody knows if anyone ever really abandoned their elderly, but the image of such a place represents important ideas about aging, including the notion that those who cannot fulfill social roles are a burden on their families. Many elderly people today voice that they don’t want to become a burden. Even though people in the US and Europe have the idea that Japanese elders are important and respected in society, there’s always been another side of the picture, this fear of abandonment and the fear of not being able to function. In fact, today, there is little of what we would consider to be respect for the elderly. Professor Joseph

Tobin has suggested that this is a myth that's based more on our concerns than their behavior.

**Q: In Japan, how have cultural attitudes changed toward the elderly?**

As we have discussed, the sense of when you're old has changed. I think that the expectations placed upon family care givers has also changed, particularly regarding daughters-in-law. In the past, the co-residing daughter-in-law, the wife of the oldest son, had the responsibility of day-to-day care of their elderly in-laws. However, with the rise of the nuclear family, the increase of geographical distances among extended family, and the increase of women's participation in the workforce beyond family businesses, daughters-in-law are now less available to look after the elderly. Also, at the end of WWII, the inheritance law was changed requiring the inheritance to be evenly divided between all children. In the past, everything went to the first son, or to one single heir, giving the daughter-in-law an obligation to look after the elderly out of a sense of reciprocity. That doesn't exist now, and the changing demands of modern society mean that there are fewer and fewer people who are able to take care of the elderly. Plus, people are living so much longer that care that used to be about comforting people for a few weeks or months before they died is now often times long term care that requires a certain level of skill and education and could go on for years. Now, you're talking too about a seventy year-old woman taking care of her ninety year-old mother-in-law. So, all of these factors have changed people's willingness and ability to provide care.

**Q: What has been the typical retirement age in Japan and is that changing with the demographics you just mentioned?**

Back in the 1960's, the retirement age was fifty-five. It's gradually been moved up and now in most places it's sixty. The government is hoping to raise it further, but they're doing it slowly. Most people think an increase in the retirement age is going to have to happen.

**Q: Is retirement in Japan mandatory?**

It depends upon who you are. For the most part, back when the retirement age was about fifty-five, most people couldn't really afford to stop working. So, what retirement meant was an end to your fixed, stable employment and a shift to jobs either at the same company in a different kind of position (generally at lower pay), or jobs in subsidiary companies or, if you were a high level executive in a large company, you might go into work at a government ministry. Other people were able to take their lump sum retirement pay and open small businesses, or they would get a job working in a small, local company or store.

So, retirement didn't necessarily mean retirement. In the past, most retired people were still active in the labor force. I think that this is still the case today, only now we see people taking on these other jobs at sixty rather than fifty-five.

**Q: How is Japan reacting to what has been called its elderly “crisis?”**

The long term care system is certainly one of the key results of both citizen and governmental concern. People who were receiving long term care under medical insurance needed to be taken out of that system and put into another one for fear of overburdening the insurance system. So, that’s why the long term care system was developed.

Certainly people and the government have looked much more broadly at what the aging crisis means in society. They’ve had pension reform; they’ve had reform of the medical and welfare systems. They’ve had policy changes in housing. I think pretty much across the board, anyone dealing with economics is concerned about the work force, given the proportion of older workers and the very low birth rate. From what I’ve seen, Japanese public and private organizations have been very proactive in recognizing the trends and trying to stay ahead of the curve, unlike what I think is happening in the U.S.

**Q: How does care of the elderly differ in Japan from that found in Western cultures?**

I think that’s a difficult question to answer. If you look at the difference between elder care in western Europe and the United States, it’s huge. So, bringing Japan into the comparison, I’d say that Japan is, in many ways, more like Western Europe than like the United States. Like Europe, Japan has public systems for elder care, which we don’t really see here in the States.

In the early and mid 90s, Japan was looking internationally at different models for their eldercare system, and in the end they adopted a system based upon that developed in Germany. So, an insurance, premium based system was adopted.

The system went into effect in 2000. It is a mandatory system whereby every citizen pays into the system starting at age forty and they continue paying into it. That money is utilized to provide care either in people’s own homes or in institutions, regardless of income. The types of decisions made about care and the support for care are based entirely on the mental and physical condition of the patient. This is determined by an assessment system which involves a committee of professionals judging the application and providing an initial assessment either by someone in the local government welfare office or another individual who has care experience.

Then there’s also a medical form that the family physician fills out. All of this is brought together into a committee and then every case is reviewed and a determination is made. Then a patient is then placed into one of six levels of care, the first level being preventative and the last level being for people who need a huge amount of care.

Care providers can either be governmental providers, non-profit providers, or providers for profit. So, it’s a pretty open field as far as service provision. The decisions are made together by the elderly person, the families, and usually a care manager. Each elderly person has to have a care manager, which can be a family member, but is usually a professional care manager. The way the system

works is that, if you're at say level three, that represents a certain yen value. In conjunction with the care manager, people make decisions about how to use those resources.

So, if your value is say 40,000 yen a month, you and your care manager would decide whether to apply that value (there's no cash paid, but rather direct payment to service providers) toward some combination of daycare services, home helpers, respite care, and so on. There is a small co-pay that people pay for services and they continue to pay premiums, but the premium can be adjusted for low income individuals. The services received will be the same regardless of what your premium is.

**Q: What effects has the aging population had on Japanese society and their economy?**

Well, some Japanese companies are able to view the aging population as an opportunity. They see older consumers as a niche market that's very large and getting larger.

So, I think that Japanese companies are adjusting what they're doing and how they're marketing things, recognizing that there's this very large population of elderly people that they design for and sell their products to. For example, they're making simple cell phones with large buttons for the elderly. We always hear about youth culture in Japan, but increasingly there also seems to be a great deal of attention paid to the culture of the elderly population as well.

**Q: In what ways do the elderly contribute to society in Japan?**

Looking at economics, these are people who have had a strong ethic of saving. As a demographic group, they have accumulated a great amount of wealth. So, we see a trend toward looking at the elderly as consumers. Then there's a historical contribution that the elderly have made. This is a generation that has seen so much change, and Japan's post-World War II economic growth was largely on their backs. Some elderly remain active in their fields, other pursue non-vocational interests such as hobbies or volunteer activities. They often continue (for as long as they can) to contribute to the household income. Many "young" older people are involved in taking care of grandchildren. So, there are many things they do and many ways in which they contribute to society.

**Q: How do Japanese elderly tend to relate to ICT?**

I suspect that it is class related. Last year we completed a five year study that involved going into frail older peoples' homes and interviewing them about their lives and their experiences with the care system. I saw very little use of high-tech devices - mechanical devices, yes, but high-tech, no. However these were people who were very frail, in mainly working class families, and half were in rural areas. We did not see a complete range of households. But in the homes we visited, I really didn't observe many ICT- based products beyond such things as televisions and telephones.

I think Japanese companies are doing a lot to develop elderly user-friendly products, and I know there are university projects that are developing high-tech devices. Care providers are using a lot of computer technology, certainly the assessment process for long term care is computer based. I suspect that “young” older people with higher levels of education and income may be using computers more. So, it’s there, but the people we were interviewing were mostly in their eighties and nineties and I just don’t think that they were physically or mentally prepared to start learning how to use computers or high-tech devices. But maybe the people who are in their sixties now and using such technology won’t have this issue when they are eighty or ninety.

**Q: How are the Japanese using ICT in caring for the health of their elderly?**

They are using ICT in the long-term care system and in the health care system. Certainly in some of the institutional settings you find ICT. But, most people are in their homes and that’s where I haven’t seen much use of ICT in these working class families.

I don’t have the sense that they are afraid of technology; in a way there may be less resistance to new technology in Japan than in the U.S. But, the people we were interviewing were too frail to pick up new technology and probably couldn’t afford it. Keep in mind, though that we had such a small sample, and that someone else might find totally different results on the question of ICT and the elderly.

**Q: What can we learn from the ways in which the Japanese are tackling the demands and utilizing the resources of its aging society?**

To me, the outstanding thing is that they are looking ahead and they are planning and trying to do things before issues become crises. I also appreciate their more socialized approach to problems, a sense of national and community responsibility for creating this new society of mass longevity. These are things that I think are really important.

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## ICT, the Elderly, and Emerging Global Markets

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*Interview with Neena Gill*



*Ms. Neena Gill, the UK's first Asian female MEP, was first elected to the European Parliament in 1999 and was re-elected in June 2004 to represent the West Midlands Region. Prior to becoming a Member of the European Parliament, Neena was Chief Executive of ASRA and the Newlon Housing Group. Neena sits on the Urban Housing intergroup in the European Parliament and she is President of the European Parliament Delegation for Relations with India.*

*Ms. Gill spoke with us about the global rise of the elderly, emerging markets, and ICT:*

### **Q: What is your definition of “elderly”?**

We need to make a shift in the way in which we view age and the aging process and we need to begin to look at cases individually. People have different interests, different capabilities, different levels of fitness and of health. This is true at any age, including “the golden years”. We can no longer say that because someone is sixty they are ready for retirement. For some, this may be true, but there are many individuals who can (and choose to) work well into their eighties. Consequently, we can no longer say that retirement begins at sixty or at sixty-five. Therefore, we need to recognize the fact that we have a changing population. With this recognition, we can begin to look at the new ways in which the aging contribute to society and what might be inhibiting them from contributing further. Today, people are living longer than ever and continue to have a great deal to bestow upon society. If we look at the elderly as a blanket group without taking these variation and contributions into account, we will miss opportunities to enrich our nations. It is imperative that we find ways of making digital technologies available to all. Without such developments, we will be leaving a vast portion of our societies behind.

**Q: What are the risks of defining “elderly” by years?**

If we define “elderly” in terms of years, we risk creating legislature that can eventually be discriminating. If we define elderly as those over eighty, for example, we discriminate against those who might need assistance at sixty-five. Contrarily, if we define elderly as sixty-five, we might be limiting employment opportunities or other benefits to those over the age of sixty-five who are still in excellent health and can and want to continue working and contributing to society. Therefore, we must think carefully about the way we define aging.

**Q: Are you pleased with the recent EU legislature designed to improve the quality of life for older people through the use of ICT?**

In the European Parliament, the legislative resolution regarding the use of new ICTs designed for the elderly is viewed as the most important document we have produced on aging. We are very pleased that funding has been allotted for such essential research and development. With this project, industries will be able to develop products which will help our aging population not only in terms of independent living, but in all aspects of their lives. With this program, we hope businesses will develop highly innovative digital products such as smart devices designed to improve home security, user friendly interfaces for those with impaired vision or hearing, and mobile solutions for monitoring vital signs. Clearly this technology, while aimed at the elderly, will have beneficial effects for people of all ages.

**Q: What are some of the concerns you have regarding the EU legislature?**

While the personal and social benefits of ICTs for the elderly are enormous, the potential exists that these technologies will benefit some European nations and not all of them. We must recognize that there are vast differences that exist among the various EU member states regarding the use of ICT. These differences have the potential to create an imbalance in the opportunities and conditions of the elderly in various parts of the EU. Therefore, our objective is to establish a minimal level of ITC knowledge in each member state. With these ICTs, businesses across the EU will be able to tap into a previously unexploited financial market. The populations of Europe, the United States, China and Japan are getting progressively older as people are living longer. Consequently, we are encouraging businesses to think further and clearer; to recognize the needs and the potential of our aging societies. We cannot focus our attention solely upon young families. By 2020, 25% of Europe’s population will be over the age of sixty-five. This is a huge market that needs to be taken into account.

**Q: So, does this mean that the way that the EU approaches ICT and aging will benefit other countries as well?**

In the final analysis, while this program is being developed by the EU and is geared toward our citizens, this technology will eventually be adopted on a glob-

al scale. By identifying new technologies ourselves and by working in cooperation with other countries, we will be able to produce technology and products that will benefit people from every walk of life all around the world. This is the larger objective, to improve life as a whole.

**Q: What are the ethical aspects of bringing ICT to the elderly?**

In the European Union, we have certain values that instruct us to care for those in our society. This means that we are ethically obligated and morally instructed to take care of those who cannot take care of themselves. It is our humanitarian duty to look out for others. In the context of the elderly population, we are aiming to do just that with the current legislation regarding ICTs. Our societies would be unjust if we allowed only segments of the population to advance and live in comfort. This legislation is a reflection of the fact that ethics are taken seriously within the European Parliament. Regarding aging in particular, I think that most people are very responsive to the ethical treatment of the elderly and are concerned about making sure their needs are met. Fortunately, I do not find it particularly difficult to get legislation aimed at improving the lives of the elderly passed.





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# The Elderly, ICT and an Ethical Society

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*Interview with Rafael Capurro*



*Dr. Rafael Capurro is a Professor at Hochschule der Medien Stuttgart – University of Applied Sciences. He is a founder of the International Center for Informational Ethics (ICIE) and is Editor and Chief of the International Review of Information Ethics (IRIE). He is also a founding member of the World Technology Network (WTN) and is a member of the ICT&S (The Center for Advanced Studies and Research in Information and Communication Technologies and Society) International Advisory Board (IAB), University of Salzburg, Austria. He was also a member of the EU research project ETHICOBTS on ethics and robotics.*

*Dr. Capurro spoke with us about how society defines “elderly” and the ethical aspects of ICT as they relates to the older population:*

**Q: What is your definition of “elderly”?**

Basically, I think “elderly” is commonly associated with people who are retired, i.e., with people who are at least over sixty-five. However, as people are living longer and longer, the definition can be adjusted to mean people older than, say, eighty years. It is really quite difficult to say that someone is “elderly” when one retires because we have so many retirees today who are active in their lives and in society at large. I think that there is a tension between new technologies and old people to put it in very simple terms. In former times, old people used to be considered as ‘wiser’ and far more experienced than young people. Today’s technology (particularly ICT) changes this hierarchy and creates problems for old people to deal with new technology. But there are many examples of how old people become very quick acquainted with ICT.

**Q: Is there a way to define “elderly” that is not based upon age?**

If we are talking about ICTs and we say that seven year-olds are using ICTs, you could define them as “young users”. However, in a general context, “young”

is taken to mean a person who is fifteen, twenty, twenty-five years-old. In some contexts a ten year-old user might be considered young, in other contexts not. The same is true with old age. So, it really is relative, not only to the condition of the individual but to the context of the discussion and to the culture you belong to. In some countries elderly people might use less ICTs than “young users”. Elderly people who live in a small town or in a more isolated place might rely more on the internet as a mode of communication than someone in a large city might. But in both cases the cell phone, for instance, might be equally useful and used so that it makes no difference with regard to the definition of “elderly”. What is already well established is that ICT technology for “young” and “old” in one country might be completely different in another country.

**Q: How do you think that ethical concerns are affected by cultural and geographical differences?**

Well it depends on what you mean by ethics. If you mean the moral standards used within a society or within groups within a society, then of course they are affected by cultural and geographical differences. We have different moralities worldwide. With regard to the subject matter we are discussing now, you may have an ethical problem with exclusion of the elderly as well as of fair access to everybody. However, it is important to distinguish between the de facto moral codes within groups and the ethical reflection of these moral codes. The distinction between ethics and morality, i.e., of methodological reflection and its object, is a very important one, no less obvious in this case than, say, the distinction between economics and the economy. Technologies are inserted within cultural traditions, provoking different moral and ethical questions about how to shape a “good life”. There are different options people (within their cultures and moralities) can have with regard to their needs, their geographies, contingent histories (“bad” and “good” experiences), etc. One aspect I find particularly interesting is the creation of ICT free zones (or digital free zones) similar to car-free zones in our cities. Related to this question is also the addiction of (young) people to ICT and also the use of ICT for overcoming isolation in case of elderly people or disabled people.

Ethics, understood as “problematization of morality” (Michel Foucault), is a permanent reflection on moral (written or unwritten) codes of conduct. Different ethical observers of different moral codes can achieve different results that should then be compared and questioned in an intercultural dialogue. This is what is eventually meant (or should be meant) by “global ethics” as distinguished from “global morality”. Due to new technological and scientific developments, universal and local moral codes need to be understood and explained and criticized. I think that this is the task of “global ethics” as a free and open space of reflection. When dealing with the information and communication field, I call this reflection Intercultural Information Ethics (IIE). It is not reduced to the present digital technology, but should address comparisons with other epochs and media in order to see how different human societies have managed the relationship between truth, power, messages (who has the power to say what, to whom with what means etc.) and technology, the merging of

which creates different shapes of interactions within as well as between societies. Our capacity to transform ourselves has increased enormously through ICT and will continue to increase particularly in its combination with biology and nanotechnology. We are, as Theologian Karl Rahner once remarked, our own makers (*homo faber sui ipsius*). This is a main theme of our age. In the 21<sup>st</sup> century we are fascinated by communication and artificiality in contrast to, for instance, the 19th century and most of the 20th century where we were fascinated by nature and history.

**Q: What do you think about ICTs and the developing world?**

Internet cafes are important in developing countries because people generally cannot afford the costs for an individual connection at home. Africa has the highest growth in mobile use globally but only 1% internet penetration (in 2007) which means that there is 99% opportunity for growth (See: <http://appfrica.net/blog/archives/248>). Points of internet access can become social meeting points, especially for elderly people, as well as centers for increasing participatory democracy. This point should be explicitly addressed when discussing, for instance, the ethical questions of e-government in developing countries.

**Q: Do you think that access to ICT will become a universal right within the EU?**

The freedom of information and communication is already stated in the Universal Declaration of Human Rights as well as in democratic constitutions. But, in most cases when these rights were outlined, there were not the technical means of interactive global communication like we have now. This is the reason why there has been an important discussion about the right to communicate in the World Summit on the Information Society (WSIS). To communicate means, today, not only to get information from what is distributed by mass media (what is meant under “freedom of the press” and was addressed in ancient times under the label “freedom of speech”), but also to actively disseminate information to, potentially, everybody (what is addressed now under the label “freedom of access”).

If you go in a very practical way, then you have to look at what this means in a country, in a community and so on. We need, indeed, an academic and societal discussion on a universal right to communicate. Of course, you cannot impose on communities or political institutions an obligation to provide everyone with free access to the internet. It would be like saying that there should be a universal right to own a car as a logical consequence of the right to mobility (to be provided free of charge by the State!). But we can and should discuss, locally and globally, the question of internet censorship with regard to content as well as to freedom of distribution and access. This is not an absolute right although it should be a universal one. This is why we need a permanent ethical discussion concerning its limits and legitimization. Immanuel Kant provided very good reasons for this right in *What is Enlightenment?* as well as in *What does it mean to orient oneself in thinking?*

**Q: Do you think manufacturers are designing products for the elderly as a means of making a profit rather than from an altruistic point of departure?**

Well, they are supposed to do so! But your question addresses the issue of an elderly-friendly inclusive society with regard to ICTs. If you are looking at how the elderly can profit from the use of ICT (how you can improve their quality of life through ICT) and if your objective is to educate them in the use of ICT, then a society based on solidarity should provide them with help in elderly centers or hospitals, for instance.

**Q: Do medical ICTs like monitoring devices pose unique ethical concerns that other forms of medical monitoring or intervention do not?**

Yes, particularly as far as they become part of an online monitoring system outside of, for instance, the hospital setting, with limited (or no) possibility for autonomous decisions and with the danger of becoming prey to non-permitted interventions by third parties. Not necessarily. But there are risks concerning data protection that should not be underestimated.

**Q: What measures do you think need to be taken to ensure that information is used in an ethical way and that an individual's right to privacy is not violated?**

This is a very difficult question because moral (and legal) rules are not the same everywhere and the right to privacy is one of the most controversial issues in today's discussions within the field of information ethics. Individuals (and communities) should be extremely cautious with their e-health data, no less than with their, say, bank account or access to their PC or cell phones. This includes all technical means to restrict and control the access to such data.

**Q: What concerns do you have about ICTs as they relate to the elderly community?**

That elderly people might become the object of marketing activities that promise what they cannot fulfil and ask a lot of money for apparently cutting-edge health treatments using "the most advanced ICT technology" designed to "enhance" their lives.

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# Robotics, e-Health and the Future of ICT

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*Interview with Adrie C.M. Dumay*



*With over 20 years of research and management experience, Dr. Adrie C.M. Dumay is an expert in the field of technology in health-care. Presently, he is a research director for innovation in health care at the Netherlands Organization for Applied Scientific Research TNO and manages the TNO department Technology in Healthcare. In addition, he is a board member of various research councils and foundations to stimulate innovation in health care.*

*Dr. Dumay spoke with us about the field of robotics, e-Health, and the future of ICT:*

**Q: Regarding robotic innovations such as robotic dogs, can we truly connect to a machine in the same way in which we can connect to another living being?**

Studies have been carried out on how patients with Alzheimer's react to the robotic dog. I think the reaction depends very strongly on the stage of the disease. I don't think that people in the very beginning stages, or people without the disease, will really become attached to it. But, in Japan, people with Alzheimer's really connect with the robot. Again, in the early stage, I don't expect much of a connection, but with the progression of the disease, there are examples where people get really attached to them. There have also been studies done on the use of the robo dog in nursing homes. When the dog was introduced into the environment, people began talking to it, caring for it, even trying to feed it. They connected to it as though it were a real animal. Then they started talking to each other about the dog. So, the dog gave them a common subject to discuss and therefore stimulated social interaction. Clearly, this is a positive effect.

**Q: Have there been studies done with people living independently or are they always in a group setting?**

I've always seen studies that were conducted in a group environment. I don't know of any study where the dog was introduced in an individual's home. I

would expect quite a different reaction there, because I expect that what really stimulates people is the social cohesion, the social interaction that takes place around the dog. A good question to ask is, will it work in a European setting? All the studies I have seen have been conducted in Japan where they are quite knowledgeable about robotics. This is not the case in the U.S. or in Western Europe.

**Q: In using robotics, monitoring, smart homes and e-Health, do we run the risk of isolating our elders and turning them into virtual prisoners in their own homes?**

This is a risk, yes. But, when you take the needs of the elderly at home as the point of departure then you see the first need is for them to feel safe in their own homes. They often feel unsafe because they can no longer take care of their homes; they cannot oversee the whole house and what's happening in the outside environment. When ICTs are used to compensate for that, say through surveillance, it gives the elderly a sense of comfort, of safety, that enables them to focus on other things, like social interaction.

**Q: What measures can be taken to make sure that user rights, particularly the right to privacy, are not violated by ICTs?**

In the Netherlands, there are laws, rules and regulations to fully protect the privacy of people. There is a government organization that checks and controls invasion of privacy. These laws state that the reason for recording and storing data must be disclosed to the individual and that the individual must agree to have his or her information collected and stored. This is very strong criteria which is designed to guarantee that the individual's rights are not violated. If a device doesn't comply with these rules and regulations, then, as a provider, you have a serious problem.

**Q: What ethical issues are raised by medical ICTs, monitoring ICTs, and e-Health?**

The most dominant one is the one we just mentioned: will it isolate people or will it help them to better function in the home and in the world at large? So, ethically, ICT should not isolate people. Additionally, ICT should not violate aspects of privacy. I think those are the most mentioned ones. There are also gender related ethical issues and cultural and racial ethical issues that are raised by ICT. Also, immigrants, for example, have different needs than natives do, so ethically, we need to make sure that we take them into account as well. Regarding gender differences, it's very interesting that women often use the internet at night to search the web for child related issues, after their children have gone to bed. This is behavior that you typically don't find with men. This same pattern is also seen with Islamic immigrants where typically women might not be permitted to use the computer. We have found that they do so when the rest of the family is sleeping.

**Q: Are ICTs meant to replace human interaction or is there a way to integrate them into traditional methods of care and social interaction?**

There are definitely ways to integrate them, but you have to be careful about how you do this. You have to modify applications to make them adapt to social environments. An example of how ICT can be integrated with human interaction is seen through teleconferences between doctors and patients. A voice and video link between the two, facilitated with very simple controls, allows the doctor and patient to access electronic health records and discuss the patient's condition without the patient having to leave the comfort of his or her own home.

**Q: Are ICTs being used in the field of preventative medicine?**

Yes. We are seeing ICT, particularly the Internet, being used to gather information about particular diseases and disease prevention. People will surf the net when they know they are at risk for a particular disease. Also, when a physician prescribes a medication, patients will frequently access the Internet to research side effects or various details about the medicine.

**Q: How does the use of ICTs in the health sector effect the doctor-patient relationship?**

In the Netherlands, doctors can only communicate with their patients via the internet after they have seen them face-to-face. Only after the doctor has physically seen the patient in person can he or she begin to use ICTs for interventions, communication, monitoring, giving out prescriptions, etc. By requiring the doctor to physically see the patient, you ensure that the doctor is assessing the situation as accurately as possible. Then, any necessary follow-up can be taken care of through the use of ICT. In the Netherlands, a doctor won't be reimbursed for using the internet until he has satisfactorily proven that he has first seen the patient. Here, doctors don't really like to use ICT to communicate with patients because they are fearful that they will be overloaded with questions that would normally be addressed all at once in the office rather than continually raised over the Internet.

**Q: Do you think that as we use and promote the use of ICT, our societies are getting more and more informal?**

Definitely. Yes. You can see what Barak Obama is doing now in the U.S. He is using the Internet to mobilize potential voters. He is the first presidential candidate to do this. Through him, we can see that ICT definitely changes the rules of democracy. Recently, in the Netherlands, they began putting profiles of wanted criminals on the Internet. Ten years ago, to see such an image, you had to go the police station. So, ICT is definitely changing society and how we interact. I'm not familiar with the specific changes in interpersonal communication, but I assume we are changing in this area as well.



**Q: What are some of the benefits the elderly reap from ICTs?**

There are obvious ones, such as the ability to contact the outside world without needing to leave the privacy of your own home. Through the use of ICT, the elderly can communicate with whomever they want whenever they want from a safe environment. This applies to communication with physicians, shops, family, etc. This is clearly via the internet, but there are many other types of technology that are beneficial to the elderly. For example, we don't usually think of this one, but a hearing aid is a type of ICT that clearly has great benefit to the elderly. There are also ICTs that can benefit them in the home, technology that supports them in managing the household or keeps them safe, like ovens that turn off if left on too long. There are devices that help you get out of bed if you are physically impaired. There are devices such as talking type which help people who can't see very well use a computer and get around. There are numerous devices designed to help people with Alzheimer's. So, you see, ICT can help the elderly in many, many ways.

**Q: How do you take the end user (in this case seniors) into account when researching and developing a new product?**

That's a very good question and also a very difficult question. The typical development process begins with needs assessment, then you develop a prototype designed to address these needs. You then use this prototype to interact with the end users to further specify their needs and understand how the solution might work in their specific case. The problem is that if you use the elderly who, for example, are experiencing some form of dementia, it is very, very difficult to communicate with them. In this case, you have to look at a potential user group and introduce devices to individuals who might get the disease, but who do not currently have the disease. You can see, this means that we might not end up with solutions that provide maximum benefit.

**Q: In general, when testing new products such as monitoring devices or products that record biofeedback, how do you ensure the privacy of and obtain the consent of participants?**

In the research phase, there are clear protocols and regulations that we must adhere to. We must make sure that the participant knows and agrees with the objective of the study, that they know the risks and benefits of the study, that they know what information will be collected in the study and they must give clear, written consent that they know all of this and that they agree to take part in the study. Also the project itself must be approved by an ethical commission.

**Q: In your opinion, what needs to be done to make sure that ICT products are universally accessible and user friendly?**

Pricing policies are probably the strongest way to make sure that ICTs are universally accessible. If the price of these products and services is too high,

then clearly they won't be available to everyone. Also, we need to make sure that supporting services are available to train people in the use of ICT.

**Q: What, in your opinion, will the future of ICTs, the elderly and e-Health be?**

I think ICT has a very strong future in the world of the elderly and disabled persons when it is ubiquitous. So, when it is, let's say, under the hood of the machine, like the motor of your car. Nobody checks the motor anymore when they buy a car and the same should be the case with ICT. ICT is already available in a lot of devices, for example, sensor networks, decision making software, monitoring software, etc. As long as ICT is "under the hood", is invisible to the user, I think that ICT has a very strong future ahead of it.



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# Aging in Monkeys: How Primates View Their Elders

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*Interview with Augusto Vitale*



*Since 1991, Dr. Augusto Vitale has been working as a researcher in animal behaviour at the Italian National Institute of Health in Rome, within the Department of Cell Biology and Neuroscience. In this institution he is responsible for a colony of common marmosets (*Callithrix jacchus*). He has been President of the Italian Association of Primatology, and is currently General Secretary for the European Federation of Primatology. Dr. Vitale's main interests are the mechanisms and evolutionary consequences of social learning, and the different aspects involved in animal experimentation, ranging from scientific to ethical factors.*

*Dr. Vitale spoke with us about ageing and the “elderly” in the primate world:*

**Q: Can you describe your work for me?**

I work with primates. In particular, I work with the common marmoset (*Callithrix Jacchus*), a small monkey originally from the North of Brazil. I began my work studying social learning. In this area, we try to see the balance between individual learning and social learning within this particular species. We give them new information in terms of new behaviors to be learned or a new food to be eaten and we look at how they approach the new information. Within the past six or seven years, I've been really focused on ethical aspects of biomedical experimentation. Now, I am working on a new project, and am hoping to be able to study the bonds between researchers and their animals.

**Q: Have you seen any changes regarding ethics and biomedical research?**

Within the last fifteen or twenty years, both the scientific community and the general public are more and more aware of the rights of the animals. They have started to ask whether or not it is ok to use animals in biomedical experiments

and, if so, what is the best way to do it? Also, legislation has evolved; in fact, there will be new European legislation coming out by the end of the year that outlines new rules and ethical codes.

It's very important to look at costs and benefits in the field of biomedical experiments. We must weigh the benefits of the experiment with the cost to the animal. Some people would ask "Is it ok to cause one species to suffer for the benefit of another"?

It's a very interesting field because it brings together biologists, philosophers, social scientists; it's very multidisciplinary. I think that the only sensible way to look at the issues of biomedical experimentation is through a multidisciplinary approach and by looking at experiments on a case-by-case basis. It is not possible to give an absolute answer to the problem of the use of animals in biomedical experiments, every single case has to be looked at.

**Q: How long do primates typically live?**

It depends upon the type of primate. A macaque can live up to thirty years. An old chimpanzee will live to fifty. The problem is that we don't know very much about how long these animals live in the field where they face problems like predators and illness.

**Q: At what point is a primate considered "elderly" within their community?**

By the other monkeys? I don't know that there is this kind of perception. That's a bit of an anthropomorphic question. I wouldn't expect a monkey to perceive another monkey as being an elder. From my point of view, an old monkey is just a monkey who has a certain age. While there are some subtle changes, there are no radical changes in behavior or cognitive functions that would tell you that a particular animal is old. Age is more a continuous thing.

**Q: So then, do you think that in human society we create old age?**

I think, in a certain sense, yes. We create old age when we categorize people because of their age and then give them a series of characteristics which we believe belong to old people. We believe, rightly or not, that people of a certain age have certain characteristics. It's not always clear that the kind of social categories we create are 100% in line with biological characteristics.

**Q: What biological differences do we see in primates as they age?**

If you look at chimpanzees, who are very close to us, you will notice that old chimpanzees have wrinkles; they have gray hair. Physically, as they age, their appearance reflects their age. If you look at macaques, their face, again, can be wrinkled, but it is harder to tell with them than with chimpanzees. There have been some studies done with older macaques where we see physical limitations of age. They don't move very much; we see that, as they age, they groom them-

selves less and less and are groomed by other members of the community more and more. Grooming for animals has a very social function and older animals in general tend to be groomed by younger members of the community. Older animals tend not to move as much anymore.

Studies have shown that older macaques have problems with memory, like humans do. Primatologists have observed that getting old is a matter of continuity and change; some changes are present (they tend to move less, they rest more, etc.) but there is also a continuity in that their temperaments, their personalities, don't change. An animal who was more shy in his youth, will continue to be shy in old age. An animal that was bold in his youth, will continue to be so in his old age.

**Q: Do you see a difference in how an older primate interacts within the community?**

It depends on what kind of primate. If you consider a primate like a macaque who lives in a matrilineal society, where females are the core of the group, an old female will retain her dominant status. So, the way she relates with others is basically to receive respect and favors, but this is because she is the dominant member of the society, not because of her age. For other types of monkeys this will be different, and for males, this will be different. Looking at baboons, for example, an older male who has been dominant is going to be challenged by the younger males, when he can no longer maintain his dominant position. Again, whether or not an older member of the community is treated any differently depends upon the type of primate, what kind of society they live in, and their gender.

**Q: Do the physical and cognitive changes exhibited in primates vary by gender or are they the same for both sexes?**

I don't think they change by gender because the biology and the neurobiology is the same for both males and females. I think that, again, depending upon which type of society they live in, the perception of the others regarding the aging individual could change.

So, the change is the same for both sexes, but the reaction to the individual on the part of society might change depending upon gender and the animal's role within the community. I think, though, that while the changes are the same, the males go through them perhaps a bit earlier than the females do.

**Q: Do older primates have a special role within the community?**

Not really. I would think that older individuals could theoretically have a role in that they have more knowledge. The older individuals know which plants to eat and how to use tools, for example. However, as the older individual knows how to deal with their environment because they have been there for a long time, the young members usually are the ones to discover new things; they are the ones to introduce novelty to the group. This is very important because you need both. If you are always adventurous with your environment, the risk is too

high. You need a part of the system that maintains the traditions and knows how to do things. But, you can't always do things the same way because if the environment changes, you need to adapt.

So, you need both functions, but with primates these roles aren't defined like they might be with the human species. There are very few examples of active teaching outside the human species.

**Q: So then primates don't categorize their members?**

I think to categorize is something we do as humans. I don't know that animals do something similar. I don't think they need categories. Animals need to reproduce, to defend themselves from predators and to eat. That's all they do. They don't need to listen to music. They don't need to go to church. They don't need to do sports. They just need to do these three things, which seem to be very little, but, the variety in which they do them is astonishing. That's what the fascination of behavior is, the variety of how animals go about solving these three little problems: to reproduce, to eat and to defend themselves from predators.

You might expect that you could categorize animals into age and gender categories, but really that's something we put on them, not something they put upon themselves. It's a very human thing to do, to categorize things. Animals live within a continuum. But, if we want to observe them, we need to categorize them, if we don't, we won't be able to do proper ethological science. But, the categories are something we place upon them.

**Q: Do you think we do a disservice to our society by categorizing people as "elderly"?**

Well, if this label, this category, blindly assigns certain behavior and characteristics, forgetting about individuality, then yes. Yes. If a category means automatically assigning certain behaviors, certain characteristics, forgetting about individuals, forgetting about cultural context, forgetting about environment, yes, we do a disservice because we are just faking reality. Reality is more complex than blanket categories.

**Q: Thinking about the elderly, can we relate primate behavior to that found within our own society?**

Every time you go from non-humans to humans you do so because you want to believe the continuum is there, but you have to be very careful because we have things that make us different from all the other animals. Although, we also find as we go along that many of the things that make us different are not there anymore. However, symbolic language separates us from the rest of the animal world. The way we construct complicated cultures is unique to us. So, keeping these differences in mind, you can jump from the animal world to that of the human. Thinking about seniors in our society, there are many cultural elements that inspire our behavior toward the elderly. You could probably relate the knowledge of older primates to the knowledge held by older humans. Al-

though, this knowledge is not always valued within human societies. Some societies have reverence for their elders and value them, while other societies cast them aside and put them in nursing homes or simply forget about them.

We can certainly look at the biology of aging. For sure, some primates are good examples of the aging process. Like I said, older macaques have difficulty remembering things. This is the exact same thing we see in older humans. So, you can look at the macaques to understand what happens as human reach old age. In this way, animals can be a model for studying the process of human aging. Social contexts, though, become more complicated. Social behavior is embedded in culture and human culture is much more complex than an animal's culture.

**Q: In your opinion, can a robotic animal ever be comparable to a real animal?**

I wouldn't think so, even though they are becoming more and more sophisticated. You can have very sophisticated robots that are able to read more and more of human behavior, but it wouldn't be able to substitute another biological entity. If we look at the relationship people have with dogs, we see a long evolutionary history. Dogs have learned to read human behavior in a fantastic way and they adjust their behavior to human behavior. You can have sophisticated robots that can react to a certain spectrum of human behavior, but it will always be a one way relationship where robots are trying to react to and affect human behavior. You can program a robot to do certain actions, you can even program it to do the actions randomly, but you will never get the same reaction as you would when a dog spontaneously approaches its owner and licks his hand or wags its tail.

**Q: Do you think a robot pet could ever be a sound alternative to a true pet?**

No. You can have a pet robot that can do things that will help you out, but it could never replace a living creature. It would be another thing, an object, that occupies space in your world. The thing that really interests me is what we think this thing will be. Will it be like a real pet, that someone will get attached to? People do get attached to robots, you know. Or, do we design them to be more like a machine, whereby you give your emotion to a real dog and the robot dog serves another function? The question is, "Do we need a person to be attached to a machine?" If the answer is yes, then you design the machine in a certain way, to maintain eye contact, for example. In my opinion, it would behoove us to have a certain level of separation.

**Q: Do you see any psychological risk in robotic pet therapy for the elderly?**

The basic question is, "How far can we go?" How far can we program a machine to react to the feelings of a person? If you have someone looking after you,



you have expectations of them. If you place those same expectations upon machines that fail to meet those expectations, I think you have a real problem. I think that the bonding that develops between an individual in need and the person or animal looking after them is crucial. This bonding has to do with expectation. "I expect this person or animal to react to me in a certain way". Can a machine ever be sophisticated enough to fulfill these expectations, to react as another living being would react? Personally, I don't have fear when a machine is technically doing things for you. I have fear when emotion and expectation gets in the way. What happens when these are not met? Then you could see psychological issues arise.

I have a parallel. Cammello is the oldest living capuchin monkey in captivity; he's about thirty-five or forty years-old and is a big dominant male. Once they did an experiment with him where they put him in front of mirrors; they wanted to see if he could recognize himself in the mirror. Capuchins don't; they believe there is another capuchin there looking back at them. Cammello came into the room and he saw the mirror and he saw another dominant male. He threatened the male to go away, but the male wouldn't go away; he would react in the same way as Cammello. So, Cammello retreated a bit and the "other" capuchin did the same thing. This "other" monkey was doing the same things and was not reacting the way Cammello wanted, or expected, him to react. After ten minutes of this, Cammello went into rocking, which is a clear sign of depression. The experiment was immediately stopped and the other capuchins went in and started to groom him because they know he was distressed. The world was not reacting in the way in which he expected it to and he did not know what to do with it. So, if you have another living being in front of you, you start to establish a relationship and this relationship is, in part, based upon knowing what you can expect from that other being. We can have very sophisticated machines that can react in an appropriate way, but how far can they go? Can a machine give you the spontaneity of an organic relationship? Can a machine react to you in the same way another living being can? Personally, I don't think we want a world that is completely run by technology. We want a co-existence, and we want that co-existence to work very well, especially those who are depending upon these devices for medical needs.

**Q: When thinking about the elderly, what do you think we can learn from primate communities?**

If I think about chimpanzees, respect. Chimpanzees are very close to us, and some of their older members are generally respected. They are groomed all the time; the younger members just pay homage to them. I think we can learn this from them, to respect our elders.

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# Robotics, Not Robots: Aiding the Elderly, Not Replacing Care

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*Interview with Lucy Suchman*



*Dr. Lucy Suchman is Professor of Anthropology of Science and Technology in the Department of Sociology at Lancaster University, and Co-Director of Lancaster's Centre for Science Studies. She received a Ph.D. in Social/Cultural Anthropology from the University of California at Berkeley, and spent twenty years as a researcher at Xerox's Palo Alto Research Center before taking up her present position. Her research has included critical ethnographic studies of everyday practices of technology design and use, as well as interdisciplinary and participatory interventions in new technology design.*

*Dr. Suchman spoke to us about the myth of humanlike robots and the ethics behind introducing robot pets into the world of the elderly:*

**Q: For lay people robots are science fictional entities, but in reality, what are robots today?**

I think in some ways the roboticists are the main perpetrators of the science fiction image. Robotics is really a part of the wider field of automation, which is about delegating some aspect of human activity to machines. This technology is all around us, it is in everyday forms of automation that by now we completely take for granted. The ultimate dream for people who are really interested in creating humanlike machines, or robots, is to create a machine that would replicate all aspects of human activity, that would essentially have all of the capacities of a human being. This is the figure, of course, that forms the science fiction fantasies.

My analysis of the current state of the art in robotics is that there has been remarkably little progress in this direction over the last twenty-five to fifty years. It's turned out to be an incredibly difficult problem and I think a lot of the assumptions people working in the field of robotics have about humans are actually leading them down the wrong path. I don't think we're even close to having fully human like machines.

I think there's a lot of work to be done demystifying this area. The rhetoric around elder care is full of the premise that there are going to be robot care givers. I think that conjures up in people's minds the idea that there are going to be robotic nurses and that human care givers are going to be replaced. This idea is a complete fantasy. Nobody has created a robot that can begin to come close to providing the level of care that a human care giver can provide.

I think that these false notions have been coupled with a fear that we don't have enough resources to take care of the growing population of elderly people. I think that this assumption really needs to be questioned as well. Much of this is being fueled by technology developers who want funding for projects that they are working on. They align with the policy makers around this idea that we're going to have a crisis and that we need these machines.

**Q: Are bionic robots (like, for instance, androids in the science fiction cult movie "Blade Runner") a real – although remote – possibility?**

I would say no. This is where, as I said, if you really look at what's going on in projects aimed at creating human like robots, you'll find that they are no further along than they were twenty-five years ago. They're constantly saying that they're about to get there, or they're going to get there in ten years or in twenty years, but there's really been remarkably little progress.

I think that's because there's such an underestimation of all the elements that actually make up human capabilities and relations between mind and body and reason and emotion and all of those things. They haven't been able to really make any inroads in these areas. So, I think those science fiction images of the perfect replica of a human being are very powerful fantasies, but they have no relation to the actual state of the art.

Now, they have made great strides in other areas of robotics. For instance, the Mars Rover is a robot. But, it's a little vehicle, and it's remotely controlled. There is a human who is actually directing the course of the Rover. They've made much less progress in developing robots that are self navigating. So, the progress that has been made has been in very specialized areas where you have machines that are dedicated to doing one specific task. That's very different from a robot that would be walking around and talking.

**Q: What do you think about the robot dog?**

There are several versions of these robot pets. There's the Aibo, which is the Sony dog that is no longer on the market, then Philips has the icat, and then there's Paro, which is a baby seal.

There's actually a great documentary that came out of the Netherlands that looks at experiments done with the icat and the Aibo, both in nursing homes and in private residences. The researchers gave these robot pets to older people and studied how they formed an attachment to them. What they discovered is that it is absolutely possible for people, particularly children and the elderly, to form attachments to these robots. These creatures are animated and we, as human beings, have an incredible ability to project personalities onto them. In

this documentary, you see that people began to schedule their time around these robots - like they were real pets! There's a poignant scene in the film where an elderly woman has to give the Aibo back and she is just devastated. When her daughter tells her she can get another Aibo, the woman said that this was the dog that she got to know and that another one wouldn't be the same. So, for her, this little robot had acquired a very distinctive personality. That's really powerful.

**Q: Is this a typical reaction that people have to robotics and robots?**

My experience has been that people are captivated by any kind of animation. If a machine performs anything like a human behavior, people immediately project human attributes onto it and they assume that it will have a whole range of human capabilities. But, what happens is that people run into the limits of these machines fairly quickly. So, there's an initial projection and then there's the practical experience of what the actual limitations are.

With devices like laptops or other common machines that we use on a regular basis, we become familiar with them and we know what they can do. These machines seem to work very well within our lives and the reason they do is that we have fit them into our lives. But, for the most part, I think that people's encounters with robots designed to be like humans or like animals is that it's not a lasting relationship.

**Q: So then, do robots reveal something about our innate humanness and our need for interaction, and if so, can they actually end up distressing people rather than helping them?**

I think that's a really good question and a really important concern. Look at the depth of feeling that the woman in the documentary developed for the Aibo dog. What's going to happen if the robot breaks? What happens when people come with these expectations, develop attachments and then run up against the limits of these machines? Are we potentially placing people in a situation where they are much less happy than they were before? We need to think about what the longer-term implications of these devices are.

There's something about animation, about liveliness, that is really compelling for us and I think that as people get older, that fascination becomes even more acute. I think that exploiting this fascination when you can't really deliver upon expectations is very problematic, especially when you have people who are already vulnerable in terms of loneliness and depression. We need to remember that these machines don't necessarily make people happy, they can also make people sad.

**Q: What are the ways in which current robots (or robotics) can assist the elderly?**

I think the real value that robotics could provide would be on a much more mundane level, and would be centered around the kinds of things we are cur-

rently doing to help disabled people. For instance, we have better and better mechanized wheelchairs or other machines for mobility, this falls under robotics. People could use all sorts of help in reaching things and doing things around the house, here robotics can help. I'm thinking about really mundane things, like they're look into making robots for lifting people and moving people.

I think the projects designed to make these machines humanlike is misguided; what we need are devices designed in collaboration with human caregivers, aimed specifically at aiding them in the lifting and moving process. So, this isn't necessarily state of the art design we're talking about, but rather it's about taking state of the art developments and applying them to practical tasks. I think, too, that the design phase of these things really should be done with elderly people, looking at what they need in their homes.

As we develop these devices, we also need to recognize that the care giving side needs to stay in the hands of human beings. I think a lot can be done by working side-by-side with care givers to see what kinds of technological support you could give them for the things that they do. So, I think it's about doing cooperative design projects with the elderly and their care givers to develop products that are really useful for them. Robot projects are really driven by people who are interested in developing robots.

**Q: So, what is the difference between robots and robotics?**

When you say robots, what comes to mind is an autonomous humanlike creature. I think this image of a robot has very little usefulness in relation to elder care. Robotics is a larger field that is much more about automation; it's about designing machines that do different elements of human activity.

**Q: The word "robot" means "worker", do older people need "workers" or carers?**

I think the distinction between worker and career is a good one. While there might be ways that machines can be integrated into care, care giving is profoundly important. It's very subtle and it requires the full compliment of human capacities, many of which we've only just begun to understand. The best care givers are people who are attuned to the needs of the people they are caring for. They do an incredible range of things for people and there's just absolutely no way a machine could replace them. This is not just a matter of time, it's not that eventually robots will be able to replace care givers. Robots can't come anywhere near approximating the complexity of functions that a care giver serves.

I think this whole question really brings us into the whole area of political economics of elder care and of work in general. It really raises questions about how we value workers. I think the idea that you can save money by replacing human labor with machines is highly questionable. I think the idea that there isn't enough money for human care givers is highly questionable. It's really a matter of where money is being invested and what kinds of political choices are being made. I think it's very, very important to redirect the whole discourse on

elder care away from this idea of robot care givers and toward the question of how we can create positive living situations and labor conditions.

**Q: Do you think there are any economic benefits associated with encouraging the elderly to use robotics?**

I, myself, haven't really done any kind of analysis of economic care, so I can't answer that authoritatively, but I have to say that I'm suspicious. I'm suspicious that there's a kind of assumption that we can save costs by introducing machines. I would really want to question what kinds of economic analysis are behind that assumption. If it's a matter of figuring out what you could do to enable someone to stay in the home, then there may be ways of investing in the technological infrastructure of their home that could be less costly than putting them in a residential care facility. But, for the most part, I think that these technologies are very expensive and they require huge amounts of maintenance. That's one thing that never gets talked about. It's as though people think that you're going to introduce these robotic systems and then they're just going to run on their own, but it doesn't work that way.

**Q: Do robotics present any particular privacy issues?**

Not robotics specifically, no. I think the privacy question has more to do with relations between family members, care givers, the medical community, etc. Family members can certainly invade each other's privacy. I think the question of who has the authority to make decisions is a really important one that needs to be looked at.

**Q: Are there specific ethical concerns raised by robotics?**

Well, again, looking at robotic pets, the argument that people who can't really take care of a living animal would benefit from the companionship of having a robot pet is something that we probably need to look at carefully. My primary inclination is to think that there should be other ways of bringing real animals into people's lives. I think the ethics of introducing a robot pet to people are really, really tricky. What kind of a commitment can you really make? If you give somebody a robot like the Aibo dog and they get attached to it, what are the ethical implications of that? What's the sustainability? What do you do in terms of maintaining these little machines; they need maintenance. There's another scene in the movie I was talking about where a researcher goes to a woman's home and the woman says, "oh, I'm so glad to see you, his tail fell off again". It raises the image of this elderly woman waiting for this researcher to come back because the tail has fallen off this dog and she can't fix it. So, how do we maintain these things that people are so attached to? What happens when they break down?

So, you really have to look at the ethical aspects of people's expectations. Another scene in the film centers around an icat that has been placed into a nursing home. The premise of the cat is that it is supposed to help you with practi-

cal things like remembering to take your medicine, but you can also talk to it and it talks back (of course with a very limited repertoire). Well, this one poor man, when the icat asked if there was anything it could do for him, went into a whole discussion about how they really want a swimming pool in the nursing home and he wanted to know if the cat could intervene on their behalf. So, clearly, people expect way more from these little machines than they are able to deliver.

That, to me, really raises the question about what's really going on here. Are we trying to help the elderly or are we really just dealing with designers who are looking for justification for their technology products? The main ways of justifying projects these days is to either cure cancer or make life better for older people, so are these designers just jumping on the band wagon? Clearly, this raises ethical questions.

**Q: What are some of the fatal flaws of robots?**

I think the basic problem in the humanlike robot area revolves around the assumptions that are made about humans, primarily that humans are largely brains and bodies. People make the assumption that the body is the vehicle that carries the brain, which underestimates the relationships between brains and minds and bodies. They also fail to recognize what makes up our individual capabilities, or what appears to make up our individual capabilities, which are actually based in our relationships, both interpersonal and with the world around us.

The current approaches to robotics have a really hard time dealing with the dynamics that make up human behavior. Instead, they're really focused on the individual as an autonomous entity, they don't see the profound way in which humans are intertwined together with their relationships. But, I think too, that if the area of humanlike robots shifted to what I'm talking about, the project wouldn't make much sense.

**Q: So, you don't think that robots could ever feel emotions?**

I would say no. I don't think emotions are separable from everything else. I don't think you can program emotions into a creature. Emotions are a part of all the things that have to do with being alive and being in relation with other things. I think, of course, you can get humanlike robots to mimic emotions, but, just as cartoons (which are also designed to mimic emotion) don't have real emotions, neither do robots.

**Q: Could interactions with robots complement or even substitute social interactions?**

I don't think that robots will ever be able to substitute social interactions, no. But, picking up on the word compliment, there is a project going on at the University of Siena in Italy, where researchers, directed by Patrizia Marti, are working with patients with Alzheimer's and developing different kinds of animated

objects that can be used by a therapist to work with the patients. That I think is a really interesting approach. There are also some very interesting projects going on with autistic children. There's a project going on at the University of Hertfordshire, in England, where they're using humanlike robots with these kids in ways that are really specifically designed to get them more engaged with the humans in their environments. [see <http://kaspar.feis.herts.ac.uk/>] So, I think that when things are very thoughtfully designed, and it's not about the idea of replacing, but is about the idea of introducing a new kind of object that creates a new dynamic, then there are actually some really interesting projects going on.





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# Economics and the Elderly: How ICT Can Help People Remain at Work

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*Interview with Jean Claude Burgelman*



*Dr. Jean Claude Burgelman is a pioneering leader in the field of ICT. Until 2000 he was full professor of communication technology policy at the Free University of Brussels where he chaired the department of Communication Studies and created the research centre Studies on Media, Information and Telecommunications. He joined the European Commission in 1999 as a Visiting Scientist in the Joint Research Centre (the Institute of Prospective Technological Studies - IPTS), where he became Head of the ICT unit in 2005. In January 2008, he joined the Bureau of European Policy Advisers as*

*adviser for information society issues and innovation policy.*

*Dr. Burgelman spoke with us about the economic benefits of keeping seniors engaged in the workforce and the need to include them in the Information Age:*

**Q: What are some of the ethical fears that people have regarding ICT and the elderly?**

The main fear is the total take over by the machine. Of course, this is irrational, but it is to be taken seriously. If you want to develop technologies which help the elderly, you have to take their fears into account and build technologies that do not create these fears. In our ambient intelligence studies, we coined a solution called “technologies a la mode”, or technologies on demand. People must be able to choose which technology they would like to use and they must feel like they control that technology.

**Q: Do ICT devices infringe upon human rights and dignity?**

This is a general debate that is not limited to a discussion on the elderly. It is a debate about how to create trust and confidence with new technology. I don't think that special measures should be taken that target the elderly or children. It's just a general framework that should be applied to inspire trust and confidence.

**Q: Are there certain steps we can take to insure that these devices are not used in unethical ways?**

Well, there is a whole battery of measures and regulations and laws covering data protection, privacy enhancement and so on. I always advocate a three legged approach, regulation, technology and education. So, first, we need to apply the existing regulations.

Secondly, we should absolutely invest in privacy enhancing technologies. Lastly, we should make people aware of what happens when they go on line and if they get remote diagnosis and so on.

The debate is really comparable to protecting children from viewing pornography on the internet. If you have good regulations, good technology and educated children, the problem is minimal. I do not believe in regulation only, nor in education only. The mix is important.

**Q: How can we educate people in the use of these technologies?**

First of all, we should not regulate the education concerning ICTs, that's for sure. Realistically, the problem of ICT literacy is a generational one. Within the next twenty years the problem will solve itself, when the people who are elderly will be the people who are connected now. So, the gap will disappear by definition.

Secondly, there are many, many studies that show that once the elderly are convinced that technology is good for them, they use the technology. We should not under estimate the capacity of people to adapt. But, regarding what we should do to educate users, I think the best thing to do is to make the technology as intuitive as possible.

**Q: How can we alleviate people's fears?**

First of all, we should not over do it. With regard to health, people are willing to accept a lot of things. The best thing we can do is to develop technologies which put people at the center of the control mechanism.

Another important thing to do is to make these technologies transparent, and that includes all the data and traffic that goes along with remote censoring, monitoring, diagnosing, etc. We have to make sure that the traffic of this data is transparent and open to the user so that they can control it.

**Q: What role should government play in ICT policy making?**

I think government has an enormous task in terms of making sure that aging happens in the best possible way. On the one hand, we need to make aging as qualitative as possible and on the other hand, we need to make sure that we can afford our health care systems.

Technologies, ICT in particular, can help us to age more gracefully. If I can stay in touch with my grandchildren in Australia, via new technologies, then that adds quality to my life. If the price of Broadband connections are low enough, I can connect to the internet and keep in touch whenever I want.

The second element is using services like remote diagnostics, like social computing and so on, to try to empower patients more. This, in turn, will help to reduce health costs. Given the changing demographics, if we don't implement such solutions, we won't be able to afford the health care system any more.

If you take these areas as starting points, you will see that there are many things that government can do ranging from ensuring low prices for broadband to making sure that ICT for health gets off the ground, that hospitals implement these technologies, that doctors are convinced they can rely on the technology, etc. There are thousands of things governments can do, so there is not one single approach.

**Q: Can it be more cost effective to use an ICT aid in the home rather than employing a traditional care giver?**

Well, I do not think it's one or the other. First of all, it depends on the problem. If you have Alzheimer's, I don't think you will be able to do a lot with ICTs, as sophisticated as they can be. So, it depends upon the condition of the person in question.

Secondly, after twenty or thirty years of research, I think we all know that it is the mixture that is the magic solution. It is combining technology with the human approach that gives the best solution. I don't believe in the substitution of personal care. There are many studies that have found that the more social contact the elderly have, the better off they are.

You cannot substitute this contact with Skype. Skype is only helping you to increase your potential; it is not a substitution.

**Q: Can ICTs isolate the elderly?**

Yes. If they are applied incorrectly and they aren't thought through from the beginning from the user's point of view. If you only apply them as methods to improve efficiency, then yes, of course they will be isolating. On the other hand, if you conceive of ICTs as being quality enhancing devices (both work quality and life quality), then they won't be isolating.

What is so fantastic about Microsoft and Apple is that they made the alienating Unix computer world accessible to me and you. So, the same principle applies here. If you make products that require a PhD to operate, then they will alienating. If, on the other hand, you make intuitive technology, as we advocate in the European Commission, then they won't be alienating.

Personally, I think the future of Ambient Intelligence will be like driving a car. You don't need to know how the engine works to know how to drive a car.

**Q: Do ICTs help the elderly remain in the workforce?**

Not per se. Can they help? Yes. But, if the company doesn't adapt its policies then ICT will do nothing. If a company accepts that someone who is sixty-five years-old works from home with the help of ICT, then the company will certainly be able to exploit the knowledge that that person has been accumulation for

so many years. But if the company doesn't accept that policy, well, you can have all the ICT you want, but nothing will change.

So, again, it depends on organizational approach. I've always said that if we want to reap the benefits of ICT then we need to change our organizational structure. We have to accept that people are no longer at the office from 8 to 6.

**Q: Do you think we need to change our view of aging and of the elderly?**

For sure. We have to change it for two reasons. First of all because we have a lot of them and second of all because we will need them. Who is going to run the system if we put everyone on pensions at sixty? Now, that doesn't mean that we have to keep everyone working until seventy-five at the same pace that they worked at when they were thirty.

So, we have to find a way where work gradually becomes different, but that keeps people in the work force. Here, ICT can help to create an environment more suitable for your age while, at the same time, allowing you to be interested in what you do and to remain productive for the company. That's the thing to do. In this way, aging is not a problem, it is an opportunity.

There is so much intelligence going on pension that it's a scandal. We are letting such a valuable resource go untapped. We just put them out, so to speak. There is a lot of knowledge there that we should use, especially in light of the fact that all these people want to stay active. The less active they are, the more social problems and physical problems they have, so it's a vicious cycle.

**Q: If keeping seniors in the workforce in some capacity fulfills an ethical obligation to them, does it also fulfill an ethical obligation to the rest of society?**

Keeping the elderly in the workforce is an economic, social and ethical obligation. It is an economic obligation because we need their knowledge and we cannot go on importing people from all over the world to work in our countries when we have people who have accumulated forty years of knowledge right here at home. It's really a paradox that we throw these people overboard. It's also a social obligation because you can't just isolate people. And, it's an ethical obligation.

It's not right that you should be thrown out when you still have a contribution to make just because you might not be as productive as someone younger. In my world view, fulfilling these obligations to the older population then fulfills our obligations to the rest of society. Learning from our elders is essential; it guarantees the whole continuity of society. The young guy always wants to reinvent society and the older guy can tell him, "well, we have seen these things a few times before, so maybe we can help you". So, you see, valuing our elders is adding value to our own experiences.

It also fulfills a financial obligation to the younger generations. The longer the older generations remain in the workforce, the more we can decrease the burden on the younger people who have to pay for their pensions.

The system as it is now is absurd. It's absurd economically. It's absurd socially; and, it's absurd ethically. To a large degree, we create the problem ourselves.

We really should have a phasing out of older people from the workforce, it would be beneficial on social, both in ethical and economic terms.

**Q: What are the economic implications of ICTs and their use by seniors?**

ICTs reduce health care costs. They reduce the burden on the pension system. They increase the employment rate, and they increase the productivity of the knowledge capital. If you take knowledge capital as the accumulated knowledge of a society and if you keep it active, if you keep tapping into the knowledge of all members of society, then it benefits society as a whole.

Keeping the elderly active and employed is also good for consumption. The Silver Generation is also the Silver Spender. Almost half of the off-season tourism in Spain is by older people going and playing golf.

So, if seniors still have the resources to travel, then clearly their tourist dollars help fuel the economy. If they don't have money to spend, then the economy suffers.

**Q: Who should pay for special ICT devices such as talking screens or keyboards for those with less dexterity?**

A company, of course. I mean, why not? These are marginal costs. Of course, you can always enlist government support to give incentive to keep people active longer. Either way, people who remain in the workplace cost the system less. By making these small investments, companies keep the knowledge that an older person has accumulated. Then, if more help is needed from governments, why not? But it should begin with companies. How much does a keyboard cost compared to training some new? Smart companies want to keep their talent base.

Keeping the knowledge base does not mean that employees must maintain their same function. A senior employee doesn't want to travel around the world anymore, whereas the up and coming executive doesn't mind extensive travel. The older employee is content to remain in the office, or to work from home even. So, comparatively, the older employee would cost less, even if you gave him ten keyboards.

**Q: Do you think that ICTs should be considered a social right?**

ICT is a capability enhancing technology. It is as important as a pen was in the 1960's. It's a basic capability technology because you need it to be able to function and it's also a knowledge enhancing technology. By using ICTs you can develop your networks, your work, whatever you need to do. I think ICTs are as fundamental for the future of our societies as the steam engine was for the industrial revolution or as electricity was.

**Q: What are some the challenges the EC face in implementing universal access?**

Well, each year the challenges become less about the logistical aspects of making sure everyone is connected to Broadband or wireless services. Now, the

biggest challenge is price. If I am traveling with my cell phone to Spain and I want to consult a mobile service in Germany, I pay a fortune.

**Q: What are your hopes and concerns for ICTs as they relate to seniors?**

When we look at the future of ICT, and Ambient Intelligence in particular, we have to look at the Slow Food movement to get inspiration. The Slow Food movement is a reaction against the Fast Food industry. It's about trying to get quality in a globalized world. This quality refers not only to the quality of the food, but to the quality of the experience of eating. I think we should do the same with technology.

We should stop developing technology for the sake of developing technology. We should be inventing these products with a new way of living in mind, one that fits with our global challenges, our demographic challenges, and to ecological challenges. So, we should go from Slow Food to Slow ICT. ICTs can be very useful in helping seniors grow old more gracefully and in enhancing the quality of aging. In the EC, we try to advocate the improving capacity of ICTs. Let us develop technology that enhances the quality of life.

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## The Benefits and Concerns of Smart Homes for the Aging

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*Interview with Vincent Rialle*



*Dr. Vincent Rialle is an expert in Biomedical engineering and Bio-medical ethics. He has been a senior research scientist in computer science in medicine at the University of Grenoble, France, since 1980. He is also a hospital practitioner at the Grenoble University Hospital, where he is responsible for the “Alzheimer’s, Technology, and Sanitary and Social Interventional Methods” unit, devoted to the assessment of technology based healthcare innovation for cognitively disabled people. In addition, he has worked in sev-*

*eral areas of medical artificial intelligence, and his current research area is Health ‘smart’ homes and ‘ageing in’ place technologies.*

*Dr. Rialle spoke with us about medical smart homes and the benefits of ICT for the aging:*

**Q: What are some of the types of devices we might find in a smart home designed for the elderly?**

Smart homes that are designed for the elderly are generally designed for specific medical purposes, however smart homes can also be designed for citizens of all ages, with all kinds of special needs. So, while they can help the elderly to live autonomously, they can also help anyone with disabilities live a more autonomous life. In reality, there is no interest in designing smart homes only for elderly. Looking at the elderly in particular, what are being designed are devices that interact with the frail elderly or an at risk elderly person in order to manage care or to prevent emergencies.

**Q: What are the main components found in smart homes geared toward the elderly?**

In my point of view, the design involves two parts. The first part involves equipping the home with various technologies, mainly sensors, that are usually



wirelessly connected to a local computer. The sensors monitor such things as biosignals, activities, environmental conditions, falls, etc. In addition to sensors, smart homes can also be equipped with actuators such as motorized blinds, curtain and window openers, or electric door locks. Smart homes can also involve things like robotic assistance for walking, lifting, doing the housework or cooking. A smart home also includes an internet connection which allows the home user to access a range of information and consultations and an easy to use conferencing device for facilitating person-to-person communication. Something not usually included in a smart home, but something I think is important, is user friendly access to electronic health records and Internet resources for elders and caregivers.

The second component of a smart home extends beyond the actual home and is designed to enhance mobility outside the home, so this becomes then a Smart Environment. Mobility outside of the home is very important and so, we have to include technologies designed to facilitate a life within the community. It's very important for a person to go out, even if it's not very far. Likewise, mobile videoconferencing devices that allow the family caregiver to be connected to the patient while outside the home environment is also very beneficial. We have to remember, though, that all of these devices must be used in conjunction with professional gerontological practices and should be prescribed by professionals such as doctors or occupational therapists.

**Q: How does a health smart home differ from an average smart home?**

Health smart homes are designed to help maintain autonomy, independence and social inclusion of frail people (both elderly and disabled) and their caregivers. So, health smart homes include average Smart Homes and add to them devices for healthcare. Mainly, health smart homes provide a wide range of possibilities including injury prevention, remote healthcare follow-up, real-time detection of critical situations, etc. Some research has tried to provide devices in detecting changes in habits as a way of detecting changes in the patient's condition. One potential benefit of health smart homes is the amount of data they are able to provide to people doing epidemiological research on aging.

**Q: When looking at smart homes, what are the main market trends?**

The main trend I am seeing is the development of innovative whole person care based on ICTs; that is to say technologies designed to support any kind of service able to allow the elderly to remain at home rather than going into assisted living facilities (although these facilities remain indispensable for severe disabilities). The possibility to stay at home increases the patient's quality of life and decreases the number of hospital visits, which in turn lowers healthcare costs. In terms of the market in general, robotics and mobile devices are currently major areas of interest. One interesting trend I am seeing is that technology is currently being developed based upon user needs. It's important to keep in mind, though, that we need to be designing devices, not technology. You can have all the technology in the world, but if it isn't able to foster the development of personal care, what good is it?

**Q: How have the medical community and patients responded to smart homes and telemedical devices?**

Despite the scientific publicity and the commercial availability of certain technologies, the up take of the smart home concept has been very slow. Technologies are still rarely included in care plans. So, the medical community is still not very involved. Perhaps they have a tendency to hesitate to consider these technologies because they fear losing the relationship between physicians and patients. Whatever the reason, I have not yet seen a very good integration by the medical community.

On the other hand, most publications show that patients are very interested in these devices. They realize that these devices can help them to remain in their own homes and they find that to be very appealing. When I have done focus groups and large scale surveys, I have almost always had a positive reaction to the technology, both from patients and from caregivers.

**Q: How can ICTs in general help people with dementia or other cognitive problems?**

Cognitive impairment is a growing concern throughout the world. Many patients with cognitive impairments feel lost in space and time; they have trouble finding the right movements; they can't communicate effectively, etc. In these areas, technology can provide a wealth of aids. We have two or three different kinds of technology for dementia care. One area focuses on security and safety. This can include anything from smoke alarms to more sophisticated devices that send information to remote care centers. We also have communicative technology based on videoconferencing which helps family caregivers of cognitively impaired patients. We have also various software for supporting cognitive stimulation therapy. Then we have mobility enhancement of actions and the security outside the home. Patient tracking systems are now available. They are designed to avoid very dramatic circumstance such as wandering, which can lead to severe medical conditions and even death. So, patient tracking devices can be very important. I think almost every demented patient is susceptible to wandering. Some of them are at a higher risk than others; this is especially true when they live at home. We have to stress that tracking systems also augment the freedom of families because they reassure the family caregiver as well. These devices are very easy to use, so the caregiver will know where the patient is every time he disappears. However, we still have some imperfections in the technology. The satellite signals cannot always reach the device. If the satellite cannot locate the wearable device (often a watch), the patient cannot be localized. Even in these cases, though, the devices help because they will at least give you the last recorded position of the patient. These devices, however, raise the most ethical concern, particularly relating to privacy issues. It is also important to emphasize cognitive stimulation cannot be undertaken without the supervision of a professional specialized in dementia care. Many of these patients are experiencing a great deal of anxiety which can be augmented by inopportune use of cognitive stimulation software.

**Q: Do smart homes augment traditional, interpersonal care, or are they designed to replace traditional methods of caregiving?**

In my point of view, smart home technologies are meant to augment traditional care. They are not at all designed to replace traditional methods of caregiving. However, some people have tried to replace traditional caregiving with autonomous technology; in my point of view this raises a strong ethical problem, especially with people with dementia. However, if used properly, technology can be very helpful to both the patient and the caregiver. It's also important to realize that with the rapid increase of the elderly population, we will need technology to enhance traditional care since there might not be enough caregivers to go around. That being said, however, technology cannot completely replace the caregiver. Even from a design and implementation point of view, it is more difficult to replace traditional relations with robots and so on than to enhance them.

**Q: How are health smart homes developed?**

Health smart homes generally use a collaborative method of design that involves focus groups and looks at the end user, but so far the end user has rarely been a part of the design phase. I think that the right way to develop them is to include physicians, occupational therapists, social workers, and professional or voluntary caregivers in the design process. These are the people that are intimately aware of patients' needs and of what devices would best fulfill those needs.

**Q: What are the overall benefits of health smart homes?**

Many people want to stay in their homes and technology can allow them to do this, so this is the first benefit. The second benefit is the alleviation of the family caregiver's burden of care, especially for people with a disease like Alzheimer's. Caregivers are very stressed and tired, and if they can have devices that give them comfort or a break, it can be very helpful. Another benefit is the enhancement of professional caregiving. The professions related to ageing are laborious and have not been very well appreciated until now and so, if we can give them the tools they need to enhance their attractiveness and the efficiency and quality of life of the professionals, which in turn enhances the care and the quality of life of the patient, then we should do so. In my view, the point is to augment care and the role of the caregiver with technology that benefits everyone. Also, the home is a good place to develop prevention and therefore reduce the healthcare costs by reducing the need for healthcare down the road. With health smart homes, we clearly see financial benefits in terms of less hospital visits, a reduction in the number of falls and cardiac issues, etc.

**Q: How can we make sure that the elderly receive the benefits of these devices while at the same time respecting their privacy and ensuring their dignity?**

The only way to make sure that the elderly receive these benefits is to allow them to express their needs and feelings. This of course, creates individualized

solutions. Doctors and caregivers must listen to the patient's desires as well as to understands his needs, both of these are very important. Once everyone understands the needs and wishes of the patient, then a system of care can be developed that will deliver maximum benefit to everyone. It is also important that the patient can control these devices in some way, that he can turn them on and off. We have to allow people to use what they need and to recognize that not everyone will need or desire every option that a smart home can provide.

**Q: How do privacy issues differ with regard to telemedical systems than with standard medical care?**

I think that privacy issues do differ. With ICT, information travels from the home or from portable devices to remote care centers. It is no longer in a controlled environment, in one room or in one office, but is being transmitted over distances. We have to therefore design these networks in a very careful way to prevent the leak of that data and possible malevolent use.

**Q: Can smart homes inadvertently isolate the elderly, leading to depression and other social and psychological issues?**

We have not discovered such a phenomenon. Any such issue would be more linked to the bad use of smart homes and bad use of technology in general. A lot of elderly people living alone and with disease are depressed; this is true for caregivers as well. If smart homes do not enhance the human relationship, if they are used to replace the human relationship, they will of course lead to depression. But, this is the use of technology, not the technology itself. Technology must be an accessory of human relationships and exchanges. ICT must enhance humanity and not diminish it.

Some devices have an intrinsic ambiguous status. They provide remote follow-up, but they also mean the decrease of human encounters, so we have to be very careful about these technologies. They have to be very carefully designed and used. This must be a continuing social debate. Most scientific articles, though, currently reflect an increase in quality of life, this is the main trend.

**Q: What are some of the concerns that have been raised by smart home users?**

The use of these devices has not raised much enthusiasm. The primary issue is that people are afraid we will loose the human relationship if we use them. Another concern is the loss of privacy. People are also afraid of loosing caregivers to machines. A lot of people don't even want to hear about technology because they are sure that technology will mean a life without caregivers. We are really seeing a fear of becoming a society like the ones found in the novels 1984 (G. Orwell) or Brave New World (A. Huxley). We also have a negative view of aging and death and all of these negativities tend to push us away from the development of new solutions and technologies. In my point of view, caregivers are very stressed and have a lot of difficulties that technology can alleviate, but

we must always remember that technology does in fact pose the risk of replacing the caregiver in the long term and in certain situations.

**Q: What are some of the ethical problems posed by telemedical supervision at home?**

These technologies raise the risk of privacy disruption, exclusion, and loss of control on the part of the patient. It is very easy to do bad things with technology. So, the ethical problems are less to stress or pinpoint the vast variety of issues raised by technology, and more to take the time to conceive of the right use of these technologies in the first place. This is a long process because we have to talk with professionals who have to discover what is possible with technology and to clarify what they need. Clearly, this takes time. Unfortunately, what must be stressed is that the evolution of technology outruns these dialogues and the overall social debate. Technology goes so fast that our debates can't catch up with where technology is.

**Q: How costly are health smart homes and who covers these costs?**

The technological installation and maintenance is usually costly, but these technologies cannot be considered alone. It is the whole societal system which has to be considered. The goal is the development of devices designed to assist the patient, augment care, relieve the burden placed upon the family, and lower healthcare costs. So, the benefits of these devices can be profound. While the costs of smart homes are quite high, I don't think that's the reason we haven't seen a wide uptake of these systems. I think we haven't seen an adequate uptake because they haven't been implemented into caregiving practices, they haven't been grasped by professions focused on ageing. Clearly, as these systems become more in use as support of innovative care practice, their costs will go down.

As far as who pays for them, I think that depends upon the situation. I think that for very severe illnesses like dementia, if technology is helpful and helps avoid hospitalization, it should be covered by the healthcare and national solidarity system. But for technologies that enhance quality of living, I think these might be shared by the healthcare systems and by the users. We still need to find a good model for cost structures.

**Q: Are there government policies you would like to see enacted regarding either the development or the implementation of health smart homes, or of smart homes in general?**

I would like to see the development of technology that is based upon professional advice and I would like to see enacted policies that promote the teaching of technology. I would also like to see open discussions about technology that aren't based upon pre-conceived ideas. These are policies I would like to see enacted.

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# Assistive Technology, Education, and the Elderly

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*Interview with Marion Hersh*



*Dr. Marion Hersh is currently a Senior Lecturer in the Department of Electronics and Electrical Engineering, University of Glasgow. She runs the successful CVHI conference series “Assistive Technologies for People with Vision and Hearing Impairments” with European Commission support. In 2007 she was awarded a Leverhulme Research Fellowship to carry out research on “Mobility for Blind People: New Strategies & Solutions” in a number of different countries over an eighteen month period from April 2007. Dr Hersh also chairs the International Federation of Automatic Control (IFAC) Working*

*Group on Ethics and has organised invited sessions on ethics and technology at several IFAC World Congresses as well as at other IFAC events.*

*Dr. Hersh spoke with us about the design of assistive technology, the need to educate users, and the social implications of ICT:*

**Q: We often try to define the elderly and to place them into age based categories. Is this a legitimate exercise or should we rather look at the individual and whether or not he or she is experiencing some form of disability?**

It depends upon what you want to do. It is not really something I can answer yes or no to. People have different needs, and this is not just about whether or not people have impairments. They have different interests, different experiences and different cultural experiences that effect what they might want to do. I do not think that it is necessarily wrong to use age categories, but you need to be aware of the fact that people have different dimensions and they are not just defined by their age, impairments, disabilities or gender. There are all sorts of different ways in which people define themselves. There is also the issue of labelling, what terms people want to be identified with and what terms they use to identify themselves. For example, in America I think the term “senior” is fairly commonly used, whereas it is not used often in the UK.

**Q: Looking at the elderly in particular, what role should education play in promoting universal access to and the use of ICTs?**

I think first of all, that there is a difference between promoting universal access and promoting the use of ICTs. I think that there should be universal access, but that we should be very careful so that moves toward the use of ICTs do not mean that services and facilities are not available anymore in other ways. Replacing rather than complementing services and facilities provided in other ways by ICT will mean that people are excluded, whether because they do not like ICTs, they do not have personal access, or for other reasons. I think people should be empowered to make choices and to have information to enable them to choose whether they want to use ICTs, but that ICTs should not be in any way imposed on people.

Access to free education is important, particularly for older people and that it is important that this education is age appropriate and not either patronizing or too complicated. This education should also be available locally and during the day, for instance at local libraries and community centres.

I think that ICTs have the image of being something for young people. I think this will automatically change as the generations that are familiar with ICT get older, but there then may be other technologies which are seen as only for young people.

**Q: Can you describe the design process involved in creating assistive technologies? Does it differ from other fields of design?**

I think that end user involvement is very important for the development of all technology. In engineering in general, unfortunately, there is very little involvement of people who are not engineers, let alone people who are disabled or elderly, in the research, development and design of technologies and devices.

Obviously assistive technology is designed for disabled people or elderly people, and therefore, there are going to be additional issues, particularly communication issues. Some of these communication issues involve people who need large print or who use sign language or use a deafblind manual alphabet, or people who may not be able to speak clearly. There are all sorts of communication issues that then become access issues. So, access is not only about physical access, but is also about creating products in such a way as to make them accessible and it is about creating environments that people feel comfortable in.

Any technology has a design phase that is very important. I would say that “design for all” or “universal design” should be part of good practice. This obviously means that designers, engineers, architects and other design professionals need to be educated in “design for all”. It is much easier to design for disabled people from the start than to add components or other modifications later. I think that in the area of “design for all”, a lot more can be done than is being done at present.

With assistive technology in general, the cosmetic appearance is just as im-

portant as the function. Assistive technology which is either very attractive or resembles products, such as a mobile phone, that are in general use are important design goals.

**Q: Are there limits to what technology can do, a point at which technology is no longer a viable solution?**

Obviously, there are limits to everything except God. I think that there are issues about how you enable people to enjoy their old age - how you enable people to remain independent and active for as long as possible. This includes recognizing that being independent does not necessarily mean doing everything for yourself, but may mean making choices about how you do things. I think that assistive technology has different kinds of limitations. Many physically disabled people will prefer to have a personal assistant help them eat rather than to use a robotic arm, because using a personal assistant is quicker and they prefer to use their valuable time for paid employment or personal interests rather than self-care tasks. There are things which a person can do better and more efficiently than technology and things for which technology is better suited. However, what technology is better suited to and what people are better suited to may change as technology develops.

There are also issues of personal preferences i.e. what people prefer to use technology for and what they prefer to have personal assistance for. Therefore people need to have the information, support and financial and other resources to make and implement the best choices for them. Then there are the issues of availability of technology and whether existing technologies are being implemented or not. For instance, Japan was using tactile tiles in the 1970's, but many other countries have only begun using them in recent years. So, it is important to invest resources in making sure that existing technologies are being implemented and implemented effectively and that individuals have access to technologies that are best suited to their circumstances and preferences. High costs are often a significant barrier to the use of technology.

There are also, obviously, ethical issues with technology. Just because we can do something does not mean that we should. For instance, there are ethical issues relating to the use of technology with people with dementia. What sort of monitoring system is it ethical to install? To what extent is it ethical to put constraints on the liberty and freedom of movement of a person with dementia in the interests of their safety or of reducing the anxiety of their friends and relatives? This is a particular concern when professionals find it difficult to explain the system and obtain fully informed consent.

Nothing replaces a doctor giving a diagnosis personally (at least with the current state of development of technology) and there are ethical issues relating to whether it is desirable that technology should replace doctors. However, there are systems that monitor blood pressure and various other biometric signals and send data to medical professionals for analysis and diagnosis. This then raises the ethical issues of who has access to this data and under what circumstances, and ethical issues of consent to the use of this data, for instance for research purposes.



In addition to thinking about the limits of technology, we need to look at the uses of technology in a socially acceptable way. I suspect that few people would want to go around with a million sensors attached to their bodies.

**Q: What are some of the concrete ways in which the elderly benefit from assistive technology?**

In general, people who choose to use ICTs use them because of their benefits, such as better communication and the ability to do things that would otherwise be difficult or impossible. People who use a long cane may be able to benefit from the use of ICTs in the form of audio announcements on transport systems that announce the next stop, the number of an approaching bus or tram or the platform number at a station. Audio announcements in lifts of the floor number can be beneficial to elderly people with vision impairments. The low tech solution of making the numbers larger would also be useful. There are a whole range of ICTs that give access to computers. Elderly people are more likely to have vision impairments, so they might need a screen magnification device. Appropriately designed assistive technology which is easy to use gives access to people who might not otherwise have access to websites, computers, etc. Assistive technology goes from the very basic to the very high tech.

Most people have some degree of sight and/or hearing impairment, some degree of physical, and probably some degree of cognitive impairment as they get older. They do not see themselves as disabled, just as not hearing, or seeing as well as they used to. I think that often the degree of independence has much more to do with their attitude and the attitudes of people around them than with their degree of impairment. Independence and autonomy are a lot more about making choices than necessarily about doing everything yourself. The trouble is that once people become elderly, choices are taken away from them. So, assistive technology may give people the potential to make more choices. It is important to make sure that people are in a position to make choices about what assistive technology they want to use and that they have the appropriate training, support and follow-up services to ensure that they are getting the greatest benefits from any devices they choose to use. Another very important issue is the availability of assistive technology and that, in particular, there are not financial barriers to elderly and disabled people obtaining the technology they want to use.

**Q: How can we make sure that assistive technology does not isolate the elderly?**

This is a very wide question about which you could write a book. Obviously, assistive technology is not used in isolation. Elderly people live in a context. If someone is already isolated, ICT may help them make contact with other people and reduce this isolation and it may not. There are much wider social issues about why elderly and other people are isolated to begin with and preventing this isolation. There are also issues about having local facilities that elderly people can walk to like local shops, local libraries, post offices, etc. where people can go and interact with other people.

Again, technologies and devices have to be designed so that they are socially attractive. Unlike the suggestion in one of the older books on mobility devices, most blind people do not want devices that make them look like robots, with a lot of clicking and clacking noises. Clearly that would be socially isolating and most current assistive technology researchers are aware of this fact. Obviously, not everything can be made inconspicuous. For instance, it is not very easy to hide the fact that you use a wheelchair, but wheelchairs can be designed to look attractive and not to divert attention from the person using the chair. On the one hand ICT can make facilities accessible to people, on the other hand, there is also the possibility of isolation because ICTs can be used in your own home and do not require people to go out and access facilities. However, I do not think that it is assistive technology that isolates people, but rather the organization of society and a whole range of social problems, including discrimination, poverty and lack of access to resources that isolate people.

**Q: Do you think that assistive technologies and social ICTs should be considered as a right within the EU framework?**

Personally, I think all services should be paid for by taxation rather than by the end user. I would consider access to technology to be included in this. Similarly, I think that education throughout life, not just when you are young, but also when you are older, should be available. I see assistive technology in the same way. If we give disabled people the tools they need and remove the various barriers to employment, most disabled people will be able to work and will not be prevented from having good jobs. Consequently, they will pay taxes and contribute to the costs of assistive technology for themselves and others by paying taxes, as will non-disabled people who are in employment. I would actually say that people have a right to contribute to society. Everyone has the right to be a part of society and if you are not allowing some people to contribute, not only are you discriminating against them, but also society loses out. I would say that older people and disabled people are as much a part of society as everyone else.

**Q: Do assistive and ambient technologies have social implications for seniors?**

I think that all technology has social implications and that, unfortunately, with a lot of technology we do not think of the social and environmental implications. As more and more facilities are being moved online, we are losing local centres where people can at least interact with someone face-to-face. ICTs will also change the nature of some jobs. People may use ICTs in the workplace to communicate with the person in the next office rather than going to talk to them. Companies may use ICT to monitor their employees, lessening job satisfaction, putting pressure on employees to work faster, increasing stress and raising ethical questions about privacy. The use of ICTs has led to expectations of constant availability of workers, even when (theoretically) on holiday and a speeding up of work. Therefore, the use of ICTs in the workplace has had many

negative consequences, many of which could have been avoided by a different type of implementation of ICTs, with greater involvement and consultation with the workforce.

**Q: In an ideal world, what role should governments play in the design, promotion and education of ICTs as they relate to the elderly?**

As I have already indicated, I do not think that ICTs should be promoted, at least not if that means removing other alternatives. I think it is important that other alternatives are always available so that people who find it difficult or impossible to use ICTs will not be disadvantaged. For instance, if ticket windows are replaced rather than supplemented by automatic ticket machines, many visually impaired and elderly people will be disadvantaged, whereas having both options available benefits everyone. In terms of education, I think that education (on ICTs and using them) should be financed by the government, though possibly at the local level rather than at the national level. I believe in the social provision of services, so I believe that there should be free access to ICTs for everyone, in a wide range of public buildings which are easy to access and have extended opening hours. As ICTs become even more important, we should also be thinking about providing free internet access, particularly to elderly and disabled people, financed through taxation, in their own homes.

I personally would support an increase in income taxation in order to provide more services to people. However, overall, I think that ICTs have both advantages and disadvantages. I would support measure to facilitate access to anyone who wants to use them, but am not in favour of their active promotion. I would also strongly oppose any phasing out of existing non-ICT based facilities services as a result of the implementation of ICTs. In terms of design, I think there should be some sort of standard, with regards to both standardization and minimal design standards. Obviously it is very important that the user community, particularly older people and disabled people, are involved in drawing-up these standards. I also consider that government has a role in insuring that design standards are implemented. There is also a need for government to take a heavier hand and start imposing punitive sanctions on the heads of companies and other organisations that fail to comply with these standards.

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# Privacy, Ethics, Assistive Technology and Keeping People Included

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*Interview with Yolande Berbers*



*Prof. Dr. Yolande Berbers, Department of Computer Science, K.U. Leuven, NL, teaches advanced courses on software for real-time and embedded systems, and on computer architecture. Her research interests include software engineering for embedded software, ubiquitous computing, service architectures, middleware, real-time systems, component-oriented software development, distributed systems, environments for distributed and parallel applications, and mobile agents. She is currently coordinator of CoDAMoS (Context-Driven Adaptation of Mobile Services), an ambient intelligence project with three other Belgian universities (UGent, VUB and LUC) and eighteen industrial partners.*

*Dr. Berbers spoke with us about ethical and privacy aspects of Assistive Technology:*

**Q: Do you think that there has been a shift in the way we define “elderly”?**

There is certainly a changing notion of elderly because we have more people who are elderly. People are healthier later into life than ever before. When they started fifty years ago to think about having pensions, it was with the idea that people would die at an average age of fifty-nine or sixty-five or something. And, so offering them a pension was only for a couple of years. Now, of course, there is a difference because people live longer. To me, age in general is something that you have between your ears. It depends. Some people are old early and other people are old late. There are people who are quite old in age who can cope with themselves quite well and take care of themselves, even into their nineties. Then there are those who are in their seventies who are in quite bad shape. Being old in technology terms means you cannot cope with the technology that is there. It has a great deal to do with your background and how easily you can take up the technology, and has less to do with your real age. It also depends up-

on your environment, on the help you get in your environment, and on your level of education. It depends, too, upon how afraid you are of new technology. So, it depends on all kinds of things, but not so much on age.

**Q: What is the relation between the individual and technology?**

One of the topics I am working on is ambient intelligence. The idea is to produce technology that is easy to use and that actually helps you in your daily activities. But, the problem of technology is that developers try to anticipate what people want and they try to make things user friendly, it's not very clear yet how these goals can be achieved. It's much better than it used to be, but people's wants and needs are very diverse, and how they react to things is very different. This is especially difficult in the world of ambient intelligence. People may think they have regular routines and habits, but in reality they don't. Automation of daily activities becomes frustrating for the consumer when they deviate from expected behavior and technology does not deviate with them. Also, the idea that systems are directing daily activity is something that people don't like at all.

**Q: Do you think that assistive technology looks toward marketability as well as addressing customer needs?**

Companies have to make money. That's the structure that we are in. The company is not interested, as such, in promoting a better life for the elderly. They're only interested in selling as many products as possible. If a law is passed that will ensure certain standards that might propel sales of a product, then they will abide by it. But, they are certainly only interested in selling. That's normal. It's the way our economy is made.

Of course, in order to sell their products, these companies have to know what people will like, what products will help people, etc. So, they do look at the needs of people, in particular, they look at the needs of people who can pay for technology. If the technology is expensive, they will look at the needs of rich people and not of poor people, at least initially. Perhaps when they have sold quite a few units, the price will go down and the product will be available to everyone.

**Q: Do you think that access to technology will become a right?**

No, I don't think so. Is there the right of home ownership? The right to have a mobile phone? I think that technology will only become a right if it comes by force of law. For instance, the right to have a minimum amount of electricity exists nowadays; they cannot completely turn off your electricity.

**Q: What do think are the ethical challenges associated with technology?**

One of the big challenges in technology is how much are you going to decide for other people. How much power are they losing and how much are you taking over? Regarding ambient technology, it's very easy to bring people to a point where they become so lazy they don't think anymore. To me, that's one of the challenges, how do you keep people still actively thinking?

Another ethical issue arises when we talk about information gathering. What do you do with that information? In the medical sector, are there quite a few rules and laws in place about who can see the various elements of a patient's file. But, that's primarily focused on things that happen in hospitals. People could certainly misuse the personal data collected by technological products. So, maybe these laws and regulations should be broadened to include these new types of technologies. A further ethical challenge regards accessibility. Is this a product for everyone? Is it ethically right to promote technology that is nice, but that is so expensive that only the rich can afford it? Until now, we have always accepted that if you want a nice car like a Ferrari, but you cannot afford it, well, too bad for you. When it's about health, it's a different story. In Belgium, we still have a very good health care system. When you need to have surgery, you go to the hospital and, even though you might have to pay for some of the operation yourself, you're taken care of. In the United States, however, you see a big difference between the rich and the poor. Regarding new technology, I don't think it will be considered as the health care system, as all inclusive. I think it will be more like with cars, if you like it and you can afford it, fine. If you like it can you can't afford it, well, too bad for you.

**Q: Regarding medical technology, when someone has a device that is literally under their skin, does that device somehow alter the person's humanity?**

No. I don't think so. I have glasses on my eyes, other people have pacemakers that control their heart rate. Do people think we are no longer human? No. These devices are designed to be of help. We have all kinds of help.

**Q: Do you think that privacy is a concern with assistive or ambient technologies?**

If you have some sort of device, or implant, that records data, that monitors some of your functions and sends information wirelessly to some source, people become afraid of privacy issues. But, if you are in the hospital and they take your temperature and write it down, it's really the same thing, and no one thinks about it. If monitoring your whereabouts is something that will benefit your health, then yes, that's fine with me.

**Q: Do you think that technology has the potential to become dangerous?**

What is it dangerous? If you look at how many people die in car accidents, cars are very dangerous. Technology has always been dangerous. A hammer can be dangerous. To me, there is no limit, or line; it depends upon how technology is being used. If the benefits are high enough, any potential dangers will be overlooked.

**Q: What do you think will be the future of robotic agents in the home?**

I'm sure they will be able to do a lot. I think the easiest examples are things like cleaning your house or keeping your agenda. But, robotics can also fulfill

a social function, helping to resolve feelings of loneliness for example. Technologically, however, it will be awhile before we see these solutions.

Furthermore, I think these solutions will be very expensive and something that only the wealthy will be able to afford. Although, really, it depends upon how you calculate the expense. For governments who have socialized health care systems and have to pay for elder care, it might be cheaper to provide robotic or assistive technology in the home than to place someone in a group home or other assisted living situation.

**Q: Do you think that technological assistance can substitute human assistance?**

In a certain sense, yes, to a degree, I certainly do. I don't need a nurse to take my temperature if my temperature can be automatically taken. Nurses also have a social function, but you can do the social function differently. You can have people who only do the social function and you can have all the technology done automatically. Most nurses in hospitals have so many patients to take care of that their social function is rather limited anyway. A lot of these functions can be done automatically. Similarly, the computer has two sides. You can say that it is an anti-social thing because you sit there behind your screen and you're not socially connected. But, the computer really helps you to keep socially connected. For example, older people use the computer to stay connected to friends and relatives. Some people are against technology because they say that it's socially not interesting, but this is not true. It has different sides to it.

**Q: What barriers do you think assistive technology will face in the future?**

Technologically, it's very difficult to say what the barriers are. We are doing things today that were considered science fiction twenty years ago. An important barrier that assistive technology will face is that of trust. People have to trust these technologies and they have to accept them. We will have to build this trust by showing examples. An interesting way this gets done is through television and film. Elderly people watch television quite a few hours a day and when they see supposedly "normal" people using technology, they are more apt to use the technology themselves. For companies, it's important that new products are being used and introduced in this way.

**Q: Do you think technology can become an agent of discrimination?**

Not everyone uses technology in the same manner. Because of economic and social factors, not everybody has access to technology. People who are not intelligent enough to understand how technology works will not use technological devices, or they will not use it in the right way. Older people have to learn how to use technology, so their use of these devices will depend upon their exposure to technology in general and their educational level. So, yes, technology will discriminate. Just as education is discriminating, so too is technology.

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# Privacy, ICT, and the Elderly

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*Interview with Roberto Tavano*



*Mr. Roberto Tavano is a partner with Unisys Global Public Sector based in Italy. He is responsible for developing and leading the practice in Italy while coordinating and executing the rollout of Unisys Business Blueprinting-enabled programs and solutions throughout Continental Europe, the United Kingdom and Nordic countries. Roberto joins Unisys from Cap Gemini Ernst & Young Italia SpA. In addition to serving as vice president of the public administration and e-government practice, Roberto also provided services as vice president, e-business & supply chain, southern Europe, and was responsible for regional strategic decisions regarding platforms, investments and technology.*

*Mr. Tavano spoke with us about the issue of privacy as it relates to ICT and the elderly:*

**Q: What are your thoughts on privacy in general?**

I believe that it is a very relevant concept, oftentimes ill-defined and used. Privacy is a fundamental concept, broadly understood, but it is also something very personal as it implies that the individual has full control of him/herself. Being in full control of the individual, it descends that privacy is tightly connected to one's liberty and personal identity.

In spite of this, we often see privacy been reduced to a bureaucratic measure. We are so used to either having to sign away our privacy with waivers or to signing something that acknowledges our rights to privacy that we no longer bother to read what we are signing. When you reduce control of one's privacy to such bureaucratic, light-hearted "ticking-the-box", you end up lowering the attention paid to the actual issue. In the end, most privacy laws are more geared on a future forensic use rather than being an actual means of controlling misuse of, or abuse, of one's own personal data.

In a dynamic framework, privacy should be considered in the context of an



exchange, where each one of the exchanging parties takes the liberty to lower their own defensive barriers and activate their own communication channels as much as they are willing or need to. It has always been like that in human relationships, within societies, businesses, etc.

**Q: Has technology modified the line that divides public and private spheres?**

Yes and no. Technology is only a means of communication, the quality of the communication is not different or superior. It's always in my hand. It's always me who decides the extent to which I reveal myself, the extent to which I allow someone to enter into my private sphere. It's not necessary that I go on MySpace and even reveal who I am. I can use a pseudonym, an avatar, or thousands of other ways, if I'm sophisticated enough, to protect my privacy and my identity. However, this implies that I'm technologically savvy. Consequently, those who are digitally illiterate are more vulnerable and open to predators.

**Q: How can we protect our identities in the complex web of technology?**

Again, we choose what we disclose. Whether I go to the supermarket and I pay with iris recognition or fingerprint ID, or whether I do an internet transaction or I choose to go to the bank, it's always me, the individual, that validates the transaction. I must balance privacy and convenience. Therefore, my privacy is not violated because I have chosen to reveal information about myself. When I go to the doctor, I might decide to disclose more, to allow more access to my privacy. But, it is still me who, on a voluntary basis, is giving this information (no one made me do it). In either case, my identity stays with me.

**Q: Then, looking at assistive technologies, are you saying that the elderly agree to give up their privacy in exchange for some benefit?**

Assistive technologies come as suites of products, applications and gadgets that help to support, transmit and connect long distance entities. These connections can help to simplify relations and to cut costs. Technological assistance often implies remote assistance. However, in a medical context, it's not replacing the doctor, but merely placing the patient in an environment in which he can be monitored and observed. In this way, should something happen, actual doctors are able to intervene. So, from a privacy point of view, the problem with assistive technologies is not technology itself. If there is a problem, it's in how technology can be used. When I choose to have a sensor installed in my home, it is my personal choice to communicate to someone through that sensor. Therefore, it cannot be an infringement on, or a threat to, my privacy. No one forced me to use the technology it was my choice, my decision. On the other hand, though, no one has the right to abuse or misuse my data – it's too easy to imagine what sort of uses could be possible in such a scenario.

**Q: But, if institutions, hospitals, and police place these sensors in communal environments, how does that affect my right to choose what I disclose?**

This is the problem. The majority of technologies are asexual, apolitical and agnostic. Take, for example, video cameras on the streets. The goal is to capture people that drive through red lights. It is a positive goal and also has an important social meaning. It's a win-win situation.

However, some people feel uncomfortable about the cameras because they abstractly feel their liberty is being put at risk. I believe the true question is: can those behind the cameras abuse their role? Can the images be used improperly? Theoretically, yes. But really, it's always a matter of balancing risks (of abuse or exploitation) with benefits (safer roads).

When talking about devices designed to assist the elderly, it is the context that really matters, and we need to take into account the individual's right to pursue happiness, living as one wishes. To achieve this, we sometimes must be ready to give up some of our privacy. Ultimately, the responsibility of one's privacy stays with the individual.

**Q: Then how do education and disclosure come into play?**

There must be a consensus on the process. People must be aware of what is going on in order to be able to make decisions. Today, when you sign a general authorization form, allowing some use of your biographic data, most of the time you don't truly know what the process is. Nobody knows what it means, this is why it is considered bureaucratic and generic. It can be applied to thousands of situations.

Looking then at how technology is used, the user interface is one of the issues that I most often hit upon in my work. A tool that is constantly used must present an easy and intuitive user interface. We are talking here about accessibility. Assistive technologies should be proposed with ever more intuitive, immediately accessible user interfaces. Any solution should be designed in such a way that its use becomes immediately automatic, natural. To me it's important that a problem is not only considered from a privacy point of view, but that it's also seen from the designer's point of view. Lawmakers should take care of privacy, designers should take care of accessibility, and marketing should take care of selling the product.

**Q: Is it ethical to use data collected about what people desire to create market trends?**

I do not see anything negative in collecting data about what people like, with the final aim of fulfilling some specific market request. There is nothing negative if the fulfillment is not linked or limited to a specific person, if it's anonymous. It's a two-way street, where market and marketers stimulate each other. As a consumer, I always retain my freedom to buy into a value proposition or not.

**Q: Can we address privacy issues in the design phase?**

Technology develops because people have ideas, or because there are problems and people invent solutions. Research must always advance independently from any other consideration because the thirst for knowledge has always existed within human beings. While it is difficult to balance context and control, we cannot set limits in the R&D phase.

Moreover, who would set these limits? Legislators? Most of the time they do not even understand technology, although they think they do. Often, they are slow in understanding the impact technology has today; what about future impacts and developments? Who has the right to forbid development, to limit progress?

**Q: Who has control, us or technology?**

Both. The moment in which the bank gives me an ATM card, it is the card itself that matters, so to speak, not so much myself. In fact, anyone can withdraw money with my card, if they know the PIN code. As a user, I am informed, I know the process and accept it. I balance risk and convenience and decide whether or not I will hold an ATM card in my pocket. But, how many elderly people use ATM cards, though? I have never seen a study on the subject, but asking some random questions gave me the impression that many among them become sort of lazy, and do not want to learn new methods. They are pushed back by interfaces they don't immediately understand.

**Q: Do you think that access to technology should be considered a right?**

Everyone should have the right to access technology. Looking at the elderly, not only do they have the right to access technology, but there is an economic incentive to encourage them to do so. From an economic point of view, if putting someone in a hospital or an institution costs, say, X € a-day and keeping that person at home costs one-fifth of that sum, it's obvious that it's better for people to remain at home. So, quantitatively, it makes sense to keep people at home, but it also makes sense qualitatively. People generally prefer to remain in their own homes where they are happier and they have less psychological stress.

One potential problem is that assistive technologies can be quite expensive. However, these costs are bound to decrease dramatically as more users come along. Nowadays, we do have these technological tools, and I believe we soon will come to a point in time when these technologies become a common component of everyday life. What we must do next is to show the way, demonstrating how these technologies can be useful and non-invasive. For the elderly, some sort of facilitation and education will be needed to help them access new assistive technologies and enjoy their fundamental right.

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# ICT in the Medical Field, Finitude, and the Key to Happiness

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*Interview with Paul Schotsmans*



*Dr. Paul Schotsmans is an expert in the area of Biomedical Ethics and Law. He has a licentiate Degree in Educational Sciences and a Doctoral Degree in Theology. He has served as research assistant at the Department of Moral Theology of the Catholic University of Leuven and as Professor of Medical Ethics in the Faculty of Medicine of the same university where he became Ordinarius Professor in 1995. Dr. Schotsmans was appointed Director of the new Centre for Biomedical Ethics and Law in 1986, and in 1996 he was elected president of the Department of Public Health of the Faculty of Medicine. In 2005 he became vice-dean of the Faculty of Medicine of the Catholic University of Leuven.*

*Dr. Schotsmans spoke with us about aging and the use of ICT in the medical field:*

**Q: Do you think that elders have a different private/public sphere in comparison to younger people?**

I would say that they have a different contribution to make. I am personally in favor of an “activation” of the elderly, understanding, of course, that we have several groups of elderly. This activation would include things like giving the elderly charge of the children while their parents are at work or school; it could also include giving the elderly charge over helping recently released prisoners adjust to life in society again. So, maybe one of the positive challenges facing the elderly is activation rather than rest. They need to orientate themselves to other spheres such as culture, music, dance, and so on, where they are promoters of a societal network. That is my belief.

**Q: In the past older age had its own specific value, do you think this is still true?**

Well, I think it becomes more and more true due to the fact the we have a larger group of senior people. This group is composed of several generations,

those between sixty and seventy-five, those above seventy-five and then those above ninety. We are seeking value and meaning at each of these new stages of old age and it becomes a real challenge for Western societies to give a new meaning to the contribution of seniors in the society. This is certainly true for the group between sixty and seventy-five or eighty.

In my opinion, we are searching for meaningful ageing, or full flowering life. A full flowering life focuses on the question of where we come to at the end of our lives. I think this is a new challenge for us all.

**Q: From the moral philosopher's point of view does it make any sense to state that an age has more or less "value"?**

In my personal view, it's a very delicate question. You can give age a value in a positive sense. We can think of virtues like wisdom and experience that we see in seniors. They also provide continuity to society, which is a positive element. On the other hand, age can become a limiting notion and can create many ethical problems. At the moment, there is a big debate going on in Holland surrounding an institution that decided not to reanimate people above seventy years-old. This has created a lot of reaction. Personally, I would argue that you cannot say in general that seventy years is some sort of limit for medical treatment or other services. You should always look at the biography of the person before making any kind of decision. So, there is a positive side and a negative side, in my opinion, in the moral debate about age.

**Q: In promoting youth, do you think that we lose some of our humanity, our life experience?**

Yes. That is my opinion. Experience is growing through the years. In my opinion, the desire to preserve youth is creating a soft idea of youth and a soft idea of happiness. If you go to what you can call regenerative medicine, to the era of plastic surgery and drugs which are designed to preserve youth, you will find an empty happiness. For me, the progression to old age has its own rhythm. It is also linked to the development of virtue, to experience. All of this would be lost if we could produce eternal youth, or if we were to prolong youth to the moment of death.

**Q: So, you think there is something unethical about trying to extend youth until the moment of death?**

The point will always begin with what you mean or understand by "meaningful life". Not only in human genetics, but also with organ transplants, we see that more and more elderly are coming on the waiting list and are receiving new organs. So, again, we see the extension of life possibilities. We see this also in stem cell research where quite a lot of research is being done, much of it on behalf of those with Alzheimer's. In my opinion, however, human happiness is linked to finiteness, to what the French call so beautifully the finitude. So, we should be very careful with these kinds of experiments.

There is a real ethical and philosophical debate that surrounds how we consider quality of life (that is the more ethical term) or happiness (which is the more general or cultural term). We need to understand what could be the value, the meaning, of living with limited possibilities. I think the secrecy of human happiness lies here, in living with our limitations. I know that some sort of scientific investments are giving us pictures of the perfect life until a very old age, but I don't think that this is really valuable for the future development of our societies. I would invest much more into other priorities within the health care sector.

**Q: What are some of the ethical concerns surrounding ICT and the elderly?**

At the moment, I see two challenges. First of all, what we have seen until now is that the elderly were not picking up ICTs, or they were picking them up very slowly. With this, there was a sort of exclusion going on. It is not like with someone in the workforce who is immediately impregnated with all the new developments in technology. It's taken about ten years to see the uptake of ICTs by the elderly. But, now when I look at various societies in Western Europe, I see that they have invested an enormous amount of time in the training of the elderly to keep up with ICT developments. The Belgian government, for example, invested quite a lot of money so that every family could have a computer and internet connection in their own houses. It was amazing to see how, essentially, the elderly were picking it up. The uptake, in fact, is going rather quickly, much more so than I think was anticipated. Personally, I think this is a good thing; it helps the elderly to actively participate in new forms of communication that are being exploited by the rest of society.

I will give you a concrete example. I know quite a lot of elderly who have studied how to work with picture technology. The elderly are much more adept at working on pictures than younger generations because the elderly have time that the younger generations don't. There is a particular family I know where, for the husband's sixty-fifth birthday, the wife, who is sixty-three, prepared in a sort of picture story, the whole continuity of the family tradition. The impact it had on the younger generations was amazing. They suddenly became aware of where they came from, of what the main goals were within the family. Normally, this information has been transmitted by words, but now it is received in a very communicative way. So, this is a good way to use ICT, as a means of integrating the family and the family history.

**Q: Do ambient technologies, smart homes and other ICTs pose ethical problems?**

There are ethical problems, of course. Of course there is the general problem of privacy. But, in a certain sense, I think that technology always has possibilities and limitations. I personally always think that it is the role of human beings in general, and in this case the elderly in particular, to see how they can integrate the ambivalent ethical structure of all kinds of technology. Everything we

do is ambivalent. Our decisions have positive goals and negative side effects. I think we need to integrate our choices and decisions to produce ethical outcomes.

**Q: Do you see anything morally relevant in the fact that ICTs are somehow “humanizing” the world of things?**

I personally don't think that all this new technology is really enhancing the quality of life. These are very pleasant tools and instruments but they do not really change the basic challenge of the meaning of life. In a certain sense, devices like face recognition or lights that turn on when you enter a room are steps forward, but for me, these devices are not addressing the basic value of the meaning of life. These devices, I think, are maybe a little bit too cold. They aren't warm enough for society.

**Q: Do you think that in using all of these technological advancements, we've created a world for ourselves in which life no longer has meaning?**

The danger is there. The danger is there that we are not really living in a certain sense. I think this is made very clear by the number of people who are returning back to a simpler life. For example, many people are choosing to go on vacation in places where there is no comfort at all. Personally, I am always struck by the television programs where they show the remodeling of homes.

You see that everything is so technological, so cold, that I am certain these people must have a warmer place where they really live, a room or something they don't show you on the program. Of course it is impressive to see the technology, but we must think about the real way of life. Technology is too perfect. There is really a need to integrate technology into humanity. Technology must not dominate humanity.

**Q: Looking at the medical field, do you think we are searching for technical solutions to problems that should be solved in the doctor-patient relationship?**

For me, that is certainly the case. One of the fields where we see this happening the most is in the field of health care where everything is left to technological devices. We speak always about patient's rights and recognition of patient's rights, but what I see, also in my own hospital where we have 2,000 beds and where technology is progressing, is that the technology is dominating in a certain sense. For example, patients are being scheduled for procedures even at night when the machines can be used but there is no doctor available to interact with and reassure the patient. Some of my colleagues will say that if this technological system helps then it helps. Of course, medically this is correct. But, I think it is crucial that the doctor-patient relationship is protected.

When the only information you get is from the technician, you have to say that this is not really what health care is about. There should be an integration between technology and human guidance.

**Q: Do you see this balance as being easily facilitated?**

I am convinced that this is really a big challenge for health care in the future. The technology is so expensive that it must be used enough to be paid for. Consequently, doctors frequently forget about the overall well being of the patient. So, the world of health care becomes more and more a world of technology. We should always keep in mind that patients are human beings who are coming to doctors with the expectation of receiving a diagnosis and who need to have some communication. This is the reason why we have been investing in some communication training for our physicians because we saw that they were no longer able to communicate. They were ordering technological interventions and that was it. The patient was not informed about why certain interventions were being used nor were they informed about the results of the interventions. So, all medical faculties of the Low Countries have agreed to create communication training programs for young physicians.

**Q: Do you think there are measures the EC can take to ensure that doctors effectively communicate with patients?**

Well, I think the instrument they have is the Office to assure the Quality of Programs. They need to conduct hospital audits on a regular basis and the audits need to include communication skills. Just as research projects have ethical standards, I think that the same can be done regarding communication. The EC can withhold funding from medical projects that don't maintain standards of communication with patients. In the Low Countries now we have quality audits every few years and they usually include an investigation into what they call the humanization of medicine. This is one of the five crucial points that they look for. The result has been a tremendous progress on the human side of the medical training. We expect that our young students will become some sort of technological geniuses, but this needs to be balanced with humanization as well.

**Q: How prepared are doctors to rely upon ICT?**

In the basic years, students study basic science. Once they start their resident years, and their specialization, they learn how to work with new techniques. At this stage, we need to make sure that the interest for the patient is not lost. I see that this is done in the basic training, in the first six years or so, but that it is largely lost once they go into the specialization years. At this point it is only technology that they are learning about and the number of physicians who have good communication skills and are able to communicate with their patients is rapidly declining.

So, I think we still have quite a lot of work to do in this area. I have spent more than 24 years teaching medical ethics and I have seen several students who were very humane in their encounters with patients before they entered the specialization phase, later become robots.



**Q: How do you handle the issue of consent as it relates to ICTs?**

I think in certain cases, like patients with Alzheimer's, we must work within the basic frameworks set out at the international and EU levels. Within the EU, several countries have developed a framework for patient's rights. Within these guidelines are procedures about who we can contact when a patient can no longer give consent. So, there are legally developed, very specific rules that have been developed about the process of asking for consent.

**Q: Do ICTs change the way we look at ethical questions as they relate to health care?**

Fundamentally not, in my opinion. I think that all of what we do, what we make, what we create, has positive and negative aspects. The most important thing is that we teach health care providers how to balance things in such a way that ensures that human dimensions are taken into account. So, we must teach them how they can work with technology in such a way that they are aware that they are the ones working with technology and that they have to integrate technology with the patient.

Technology dramatically changes the site of hospitals. One of the ways it changes the hospital is that now patients may stay only one or two days, while before they had to stay fourteen days. But, the way in which we use even very advanced technology should be the same way in which we use a technology as simple as a mobile telephone. We need to integrate technology into our lives. I think this is the basic attitude that we should learn. This is what I would call ethical integration. I have to say, I'm not so afraid of technology, on the contrary, I applaud when technology is progressing. The most important thing, though, is to look at how we use the technology.

**Q: Does there come a point at which it becomes unethical to use ICTs?**

No. In my opinion not. But, I have to explain that a little bit more. It's very rare that I would say that something is inherently unethical. Clearly, rape or murder are unethical. Of course, technology can be used in an unethical way. For example, the internet can be used to spread hate mail. To prevent abuses, we need to develop a base attitude about how to work with technology. But, technology in and of itself cannot be unethical. Technology has, again, positive and negative aspects. The point is, how do we use technology in a positive way?

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# Assistive Technology, Privacy, Design and the Elderly

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*Interview with Adam Greenfield*



*Adam Greenfield is an expert in ubiquitous computing. An internationally-recognized writer, user experience consultant and critical futurist, he has worked for clients ranging from global companies like Toyota, Caggemini, and Sony to local nonprofits. Before starting his current practice, “Studies and Observations”, Mr. Greenfield was lead information architect for the*

*Tokyo office of well-known Web consultancy Razorfish; prior to that, he worked as senior information architect for marchFIRST, also in Tokyo. A co-founder of professional journal “Boxes & Arrows”, Adam has spoken frequently on issues of design, culture, technology and user experience before a wide variety of audiences.*

*Mr. Greenfield spoke with us about the need for simplistic design that takes into account the needs of the elderly:*

**Q: How do you define “elderly”?**

I think a person is elderly when one perceives himself or herself to be elderly. I mean that in a really concrete sense. When a person no longer perceives oneself to be at the focal point of the culture and cultural activity, when advertising and popular culture is no longer directed at him or her as an audience, when the modalities and practical affordances of everyday life are no longer appropriate to one’s physiological state of being and possibly to one’s cognitive state of being, and when, in general, one no longer feels oneself to be an active player in cultural production or the maintenance of society. I think that point is going to be different for each person.

**Q: Can we treat the elderly as one group or do we need to take something more than age into account?**

We can’t address every single case, every single conceivable circumstance, but I think you can certainly look at the center mass of the target audience and

thorough, good, rigorous, ethnographic practice and contextual design, make interventions and designs that will suffice for them. In the United States, we use the euphemism, a “special needs population”, or a “special needs audience”. What I think that papers over is that every “special needs audience” is different.

I think we have to do specific ethnographic inquiries for people who are physically disabled, who are cognitively impaired, who are illiterate, who are immigrants (people who are perfectly physiologically and cognitively capable, but don't have the language skills or cultural skills). Each of these cases will require a different kind of intervention. I don't think it's appropriate to speak of over arcing interventions that satisfy all of these conditions.

**Q: What do you think about inclusion and the term ICT?**

I'm suspicious of the notion of ITC because I think everybody who utters it means something different by it. It's very easy to have an entire discussion where 16 people in the room all have something different in mind. For some people, ICT means texting or web access. If I use the phrase, I mean something far more radical by it, something far more pervasive. There is something kind of noblesse oblige to me about the idea of inclusion.

Who is doing the including and of whom? Each local culture that encounters technologies uses them to their own end, for their own purposes, to create their own artifacts. I believe that the sort of practices around technology in emergent places like Bombay, for example, are at least as interesting as those found in mainstream culture.

**Q: Do you think that we sometimes use technology just for the sake of using technology, that we create things that aren't necessary because we have the ability to create them?**

I often get calls to design some kind of ubiquitous version of the “Life Alert” system (the “Life Alert” system is a bracelet you wear on your wrist that you can use to call emergency services if you can't get to a phone). The design would be something like biometric monitors that, instead of me having to activate it would have an accelerometer in it; it would have a magnetometer in it; it would have a pulse rate meter in it, and it would automatically log when I had fallen, maybe even if I had lost consciousness. It would automatically signal the operator. My skepticism about this is, “Life Alert” already works pretty well.

Do you actually really need to layer all of that technological elaboration on top of it? Is the incremental outcome really all that much better for all the effort you put into designing something like that? So, I believe in the potential of ubiquitous technologies, especially in the assisted context, in the domestic environment but I would really prefer that by far, the lion's share of the development go into things like contextual design, spending time with the people who are supposed to adopt these things and finding out, a.) can you use this? b.) will you use it? And c.) do you want to use it? Is it desirable? Does it communicate the things about you that you would want to communicate?

**Q: Do you think that systems can sometimes be too complicated for the average person?**

If I grab ten people off the street right now and put them in front of Amazon and gave them a credit card, and said, “here, I want you to go and order a book”, probably at this point in history, five of them could do it, no problem. It’s the other five that I’m worried about. And, it doesn’t mean that those five are stupid people. It means that we haven’t adequately explained to them what the assumptions, what the paradigms are, the bodies of knowledge that they have to master in order to do something like e-commerce. The really sad thing is that when you pursue these tests through to their end, you see people banging around the screen, trying to click on things that aren’t clickable and enter text where it’s not appropriate and then they say, “why am I so stupid?” “Why can’t I figure this out?” “An eight year-old can do this; what’s wrong with me?” And they internalize the blame for that rather than locating that blame where I think it clearly belongs, which is with the designers of the system.

What I’m concerned about with “assistive” technologies is that they have to be transparent, aside from the question about whether they are something that people will want, they have to be so transparently simple to use that they don’t in-and-of themselves cause stress, frustration, hassle, etc. And, very, very few technological artifacts that are produced actually achieve that level of simplicity. I think things need to be as simple as chairs. I know how to sit in a chair. I can see it at first inspection. I have to be pretty cognitively impaired before I can’t see what a chair is or figure out how to use it at first encounter.

I think technology should be designed to that standard. I don’t want to infantilize people and say that we need to “pad” every surface and sand down every corner and say that everything needs to be made ultimately safe at all times. But, I do think that these technologies can have a big impact on peoples’ physical, psychic, and financial well being and that as designers if we don’t anticipate what some of those impacts are likely to be and plan for the contingencies that will obviously arise, then I think that we’re faulting on our ethical obligations.

**Q: How do you think that privacy should be integrated into assistive technology?**

Any piece of technology that collects information should make it clear that it’s capable of doing that, what the intention of doing that is, on what channels it’s collecting information and of what type, what sorts of networks its connected to, who owns those networks, etc. To accomplish this, we’re going to have to go out of our way to make interventions. When a chair is capable of taking biometric readings of you when you sit in it, it’s going to have to have some way of letting you know that. I think it’s an absolute ethical consideration that any time something that I am doing is generating a data trail, that I know that and can make a choice about whether I want to expose myself to that or not.

**Q: When does ethics become involved with technology?**

Ethical considerations really need to be integrated into the planning and budgeting process very early on in the evolution of any product or service. You can't just apply these ethics hygienically at the end of the process. My experience has been that the ethical inquiry phase needs to come very early in the genesis of a product or service and that it needs to have full allocation of budgetary and other resources. That's something that development organizations are very loath to do. They don't perceive the value to them.

My concern is that as technology gets simultaneously more complex and more modular and more granular it gets easier to develop modules of functionality which are then deployed in the world and get reconfigured in all sorts of emergent ways that have never really had the process of inquiry applied to them.

**Q: Do you think that assistive technology will be made available to everyone, or do think that it will become exclusive due to cost?**

In the U.S., we're in a polity where we can't even agree that Health Care is a right. From a European perspective, universal application of assistive technology is an easier argument to make. What I would be very concerned about, however, is the right of the individual to a certain level of autonomy, that things that are rights do not become obligations. Social pressure works very effectively with a certain degree of strength and impact. If these technologies are made universal, it's imperative that we create safe environments for people who, whether they construct it as growing old with dignity, whether it's because they're afraid of the technologies, or for whatever reason, choose not to use these devices.

Personally, I am a strong proponent of national, universal health care. However, I'm not a proponent of national, universal assisted tech in general. Part of the frustration in discussing anything is, what are you talking about? Are you talking about implants so that people can hear better? Are you talking about reminder devices that live in their kitchen that maintain their schedule for them? Those are different things.

I understand the frustration of the policy maker because the policy maker would like to be able to paint in broad strokes and make clear decisions and I'm not sure that's always possible.

**Q: Who do you think pushes for advancements in assistive technology?**

The people who generally push for the use of these technologies are not the people using them, but rather the middle-aged son or daughter of the user. The question of whether or not these technologies are rights is intimately intertwined with who's paying for them, how the system is funded, whether it's national, whether it's left up to private organizations, or whether it's left up to individuals.

**Q: Do you think that assistive technology can replace human assistance?**

I think that these are decisions for each individual culture to define for themselves. For instance, my experience of informational technology in Japan is very different than my experience of informational technology here in the U.S. As a very broad stereotype, Americans like to use Information Technology to connect people to one another and the Japanese like to use information technology to prevent oneself from having to be in contact with another human being. So, the question of whether these technologies can replace a person is very, very different in New York City than in Tokyo.

In robotics you talk about the three D's, dirty, dangerous, or dull. I would imagine that there are many tasks in the context of elder care that are either too dirty, too dangerous, or too dull for many people to want to do. And so, if you're looking at it from a classic robotics perspective, you can see that there's a venue here, there's scope here. What that neglects completely is the person on the other end of that equation. We need to ask ourselves, "do I want to be tended to by some kind of automated system, or do I regard that as an absolutely terrifying way to live my final years on this planet?"

I personally don't want to be surrounded by automated systems. I'd rather pay a premium to be surrounded by human beings. My fear is that at some point augmenting that sort of things becomes very, very attractive financially to any kind of institution that is bound on reducing its costs. Questions in this domain that have an ethical component very swiftly resolve to financial considerations.

**Q: How can we develop a legal framework that takes into account the different creative, technical and financial sectors of technological developments?**

I tend to believe that each tool should be built one-by-one. It's very hard to legislate what all devices should do. I believe very, very strongly that you have to take individual cases and individual audiences and design things at that level. In my ideal world, there would be a mandatory discovery phase in the development of any proposed technology in which you'd go to every audience you're intending to market this product to and you'd understand their context (age, where they live, marital status, health status, etc.) and then you'd ask them, "what needs are not being addressed in your life already?" "How do you see the world?" "What do you want?" These questions are difficult. You can't do it with focus groups. You can't do it with questionnaires. It is painstaking and difficult and costly, but you have to send out trained ethnographers to do what's called shadowing, to follow people in order to understand their behavior and their needs. Simple, clever, idiosyncratic, beautiful, human acts are the things that get lost in technology unless you are very, very careful to attend to them. And, that's what I would like to see.



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# Assistive Technology and Senior Friendly Computing

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*Interview with Robert Sinclair*



*As Director of Accessibility leading Microsoft's Accessibility Business Unit (ABU), Robert Sinclair is responsible for the company's worldwide accessibility strategy to develop software and devices that make it easier for people to see, hear and use their computers. He joined Microsoft in 1997 and has focused on accessibility since 1998. A native of Irving, Texas, Sinclair earned bachelor and master degrees in computer science from New Mexico State University, where he focused on software usability and user-centered design.*

*Mr. Sinclair spoke with us about accessibility for the elderly as well as the need to provide ICT training to the elderly population:*

**Q: How do you define “elderly?”**

Our definition of “elderly” is constantly changing, particularly now, as Baby Boomers are entering what we have classically called “old age”. At Microsoft, we are studying current research to determine how we should now define “elderly”. Specifically, we are investigating whether or not this segment of the population should be considered as a whole or if there should be subdivisions into more specific age brackets. Presently, we consider the group as a whole, looking at the needs of those over the age of fifty.

A marked difference between the generations of those considered to be senior citizens is their previous exposure to technology. For instance, the Baby Boomers grew up with technology and consequently expect that technology will grow with them as they continue to age. As such, we are beginning to see significant shifts in the demographics of technology users. Of particular interest to us are the increasing numbers of people in older age brackets who are using computers and connecting to the internet.



**Q: Do people in different parts of the world have the same technological needs?**

In many respects, people from all parts of the world have the same technology requirements. However, cultural differences, as well as differing levels of governmental support, mean that in the end, technological needs may be quite different. For example, here in U.S., most of our buildings are handicap accessible.

However, this is not so in other parts of the world, making alternative technology necessary for one culture while it might not be needed by the other.

**Q: What is your role in world of assistive technology for the aging?**

As Director of Accessibility for Microsoft, I manage and develop our world-wide program for accessibility, which covers issues related to people with disabilities as well as the aging population. We are currently looking at the kinds of requirements and needs that these segments of the population have and what we can do to ensure that they have complete access to see, hear and use their computers. We are working in collaboration with other companies and organizations around the world to insure that there is a collective set of solutions in place for government agencies, employers and all citizens to have access to information through technology.

**Q: What is assistive technology and what are its origins?**

There was a time when the term “assistive technology” referred specifically to technologies designed to accommodate those diagnosed with severe disabilities. In reality, however, assistive technology, in the broadest sense, is any kind of tool, technique, or technology that is used to help someone be more effective or efficient in completing some task. Therefore, in the broadest definition, I would say that some form of assistive technology has been around since the dawn of time.

Today, I believe there is growing widespread use of the term to mean any kind of accommodation or customization. This definition includes the customization of features that permit someone to be more effective or to make a system more useable. In particular, electronic assistive technologies act as an alternative means of providing input into a computer system or pulling information out. An example of assistive technology is an alternative visual display that is designed for those who can't see a typical display such as a monitor or a screen. From a demographical and business perspective, we estimate that 60% of Microsoft's current customers around the world would benefit from some form of accessible technology or assistive technology.

**Q: Would you include robotics in the category of assistive technology and, if so, do you see a future use for them in the home?**

Unfortunately, the field of robotics has been misrepresented in popular culture, leading people to think of walking, talking robots. This image has sparked

an ethical debate between those who think the idea is fantastic and those who think it's terrible. As such, there is a social question surrounding the field that is perhaps more pronounced than other fields of assistive technology.

In reality, robotics is an example of great technology that, when applied in the correct situation, could be extremely powerful. Currently, there is quite a bit of research and development happening in the field, however, not many of the advancements have appeared on the market yet. Personally, I think that there are many focused areas where robotics could play an important role. Robotics as a means of replacing or enhancing some physical movement or action could be extremely valuable.

**Q: In your opinion, can assistive technology replace human assistance?**

When discussing whether or not assistive technology can replace human assistance, it depends upon the individual case, upon what the limitations and the needs are. Technology has a great deal of value and can offer many solutions. However, I don't believe technology is the answer to all solutions. There are many cases where human assistance is required and, in fact, is extremely valuable. There are other situations where assistive technology can aid an individual just as well and can allow the individual a degree of autonomy that is lacking in personal care.

**Q: What kind of advice would you give to policy makers that are going to work in this kind of field?**

Policy makers, must bring together individuals who understand the dimensions of the issue, leading experts in the field of research, members of the service industry and the technology sector and involve them in dialogue and government programs. We need to ensure that these segments work together to define effective solutions that employ the appropriate personnel, exploit new technology, and ensure timely delivery to market. The area of assisted technology presents a significant business market. As such, there is a great deal of innovation and research that is currently being conducted in this area.

**Q: What are some examples of assistive technology?**

There are many new innovative products already on the market or in development. For instance, there's a company in Switzerland that has taken several devices designed to assist the disabled in using a computer and integrated them, creating one system designed for a wide range of individuals. Whether you can't see, or don't have use of your hands, you can still operate this computer.

We see the direct benefits of the product in places like bedside care facilities where bedridden patients are now able to remain connected to those in the outside world. Microsoft is currently developing a PC with Hewlett Packard that is specifically designed to be senior friendly.

The project takes software that was originally designed for those with disabil-

ities and reformats it into a system designed to create an easier way for seniors to access information. Another project emerging on the market allows seniors and those with disabilities to access information through their cell phone in an auditory fashion. Instead of reading email on the phone, these segments of the population will be able to hear them.

**Q: How important is education in the introduction of seniors to new or existing technology?**

Technology today is too complex and it's only going to become more complex. Helping seniors, or anyone for that matter, to use technology requires a two-fold approach. First, in order to create inclusive technology, designers and companies building new technologies need to focus on simplicity and ease of use. The concept of usability needs to be a key design principle, which seems to have been overlooked by many companies in the last ten years. In conjunction with simplistic design, education must be made available.

Microsoft has experimented with two different ways of providing educational assistance to seniors. In the first, we included a two hour, one-on-one, tutorial upon delivery of the computer. This system has received a positive initial response. The other way we have experimented in providing educational assistance to seniors is through credits for courses at a local community center. In this way, the customer was free to choose which courses he or she preferred and the class was free of charge. Clearly, this method also depends upon the community to participate in the process by offering courses and encouraging seniors to participate.

Technology is important, but it cannot act alone. Education is critical, both in the form of courses and training, and in the form of raising awareness about the need for, and the existence of, inclusive innovation. At Microsoft, we believe training needs to start to become included in the purchase. Imagine someone buying a car who had never been to any kind of driving school and no one had taught them how to drive. There's this complex system in society today that teaches people how to operate a car. Similarly, we need to develop systems to teach people how to use other forms of technology as well.

**Q: Do you have any advice for designers creating assistive technology?**

Many designers, technologists and engineers love technology so much that they just consume it. However, most people don't necessarily have a hunger to learn technology just for the sake of learning technology. So, the simpler designers can make a product, the more adaptable it will be to the broader market. It is also important for designers to know their target audience. If they are designing a product for seniors, they should spend time with their family members or friends or someone in the community that is older and to watch them use technology or they should talk elderly people and try to understand their perspective on technology. This interaction and understanding of consumer needs is often lost today.

**Q: What kind of ethical challenges are in your field of work?**

Ethical challenges tend to arise when technology begins to change the constitution of the human being. For instance, some people claim that the deaf, or near deaf, should not be given calcular implants because they alter the present condition of the individual in question. Other people, however, view the change from deafness, or near deafness, to hearing as a positive and, indeed, desirable metamorphoses.

We see the same argument surrounding the possibility of an artificial eye designed to give sight to the blind and in questions surrounding technology and assisted living, particularly with regards to life support machines.

**Q: Do you think that technology can also be used to exclude as well as include older generations?**

Technology can, unfortunately, have the effect of excluding the elderly. Today, many companies are in fact building technology that, in most cases, unintentionally excludes significant populations or significant numbers of people in the population as a whole. Aging customers are a definite group of people who are excluded by technology today. Take for example a web page that has flashing banner ads. It could be very difficult for an elderly person to navigate the page or concentrate on what they are doing. Or, take for example, a cell phone that has small buttons or very small text on the screen. Someone with arthritis can't use the buttons and someone who has impaired vision can't see the screen. In these cases, technology can be exclusive, leaving segments of the population behind or left out all together. This is why one of the things that we're looking to do is help raise awareness about the need for inclusive innovation.

New technologies and new products need to be designed with the entire population in mind. In this way we can bridge, and even reduce, the digital divide.

This is a change we need to effect across the technology industry; it is not something that only one company or one product can resolve.

**Q: How important is privacy and human dignity in this context?**

Privacy protection is always a concern in modern society. Many years ago, there was some belief that either something was accessible or it was secure and private, that you could not actually do both. We want to make sure people understand that this is no longer the case. At Microsoft, our accessibility efforts are very closely aligned with our privacy efforts and our security efforts. In general, our accessibility programs are under what we call trustworthy computing.

**Q: Do you think that access to technology needs to be considered as a universal right?**

There are many cases were governments are absolutely focused on universal access to technology. However, it's not only important to ensure that everyone has access to technology. It is equally important to ensure that they can use that technology.

Presently, information is being disseminated online or in some digital form in such a way that if you do not know how to use the technology you cannot access the information. This is particularly problematic when government services require beneficiaries to access information or provide information via the internet. For example, I've heard of many cases where, to access benefits, for example, for someone who is retired, or social programs from the government, beneficiaries are required to access their benefits on the web site or through the Internet. If they don't have access to the Internet or if they don't know how to use the Internet, then they can't get access to these services.

So, this is really a critical issue in light of the digital divide and the fact that many seniors are not internet proficient. It raises the question of how do we as societies around the world really take care of our aging population? And, are we doing everything we need to do to not only provide the services they need, but to provide them in a way that each of them can access those services? I think this is a significant concern all around the world.

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## Including Elders in the Information Age

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*Interview with Paul Timmers*



*Dr. Paul Timmers is Head of Unit, ICT for Inclusion in the European Commission, Directorate-General Information Society and Media. Previously he headed the eGovernment unit. He has been a member of the Cabinet of European Commissioner for Enterprise and Information Society, Erkki Liikanen, responsible for the information society and telecommunications policy portfolios. Other activities in the European Commission included electronic commerce policy and programme development. Previously, Dr. Timmers was a manager in product marketing and head of software development in a large IT company and has co-founded a software start-up. He holds a PhD in theoretical physics from the University of Nijmegen, the Netherlands and an MBA from Warwick Business School, UK.*

*Dr. Timmers spoke with us about how society defines “elderly” and the need to include older citizens in the Information Age:*

### **Q: What is the inclusion approach to defining the elderly?**

I think, actually that it is not so much a matter of a definition but more the perception or the notion of the elderly in today’s society. What we are looking at is trying to develop, in terms of policy (that includes also the research programs, other policy measures and promotional measures) an approach that is able to deal with the diversity of needs and with the challenges and the opportunities that come with the ageing population. So, rather than considering “elderly” as one single definition and a single homogenous group, we are looking into the diversity of different groups and their needs, as well as the opportunities and challenges that come with them.

However, if I’m talking about statistical information of course we do need to have more precise definitions. Most of the time when we have these measurements they concern people above sixty-five and below the mid-seventies. However, elderly people are not typically taken into account in the realm of statis-

tics. That is certainly something that could become of more interest in the future.

**Q: When do you think old age begins?**

In the workplace, we see old age as beginning when people start to be confronted with either perceptions about ageing or problems that are coming with ageing because of their changing physical or mental condition. This is usually between fifty and fifty-five.

**Q: Do you think Europe has a different notion of “elderly” than that held by the U.S. or Asia?**

What seems to be different is the way we are dealing with elderly people, or the provisions we have. For example, in the U.S., people are creating “Senior Cities”. We don’t see this Europe, yet. Additionally, people in the U.S. manage their own old age more actively, also in a financial sense, than in Europe. In Europe, we have more of a “safety net” approach, which leads people to be less inclined to think ahead and to take measures at a younger age in order to retire in a high quality way. It is also possible in the U.S. to combine work and retirement. This is something that is less present in Europe and is perhaps not supported from the point of view of labor regulations. We have less knowledge about Asia than we do about the U.S., although we are developing a cooperation with Japan. We also know there is a strong interest in cooperation from China, but, we have less insight into both the attitudes and forms of care there.

We are thinking that we can do a great deal in Europe in terms of developing support for independent living, for example. While these solutions can have worldwide implications, they are not one size fits all. Right now, we really need to stay focused on the needs and responses right here at home.

**Q: Within the European framework, do you think that access to technology should be a right?**

I think it’s an interesting question because on the one hand, and certainly if you talk about the ethical issues, it’s closely connected to a rights framework. But, we do not need to invent new rights that have to do with privacy. We don’t need to invent new rights that have to do with dignity. Rather, we have to understand what respect for dignity means if we start using ICT (Information Technology) for independent living. This is where industry, together with authorities and users, can develop guidance to interpret a human rights framework for this new situation and new technology. I think, actually, that most of the charters that have to do with access to the internet, for example, are very much based upon these fundamental rights and then they’re applied in a specific situation. In fact, the new treaty incorporates the charter of fundamental rights which are forming a very good basis for generally reflecting on rights and the ethical principles associated with technology.

In light of this, there seem to be three things we need to do in the area of

rights: one is to recognize that the information society is a very important part of economy and society in general. Realistically, this is not very different from previous policy. We are not saying that education is a different part of the economy and society. Access to education is something that we consider to be very important. We should be able to apply those same rights that hold in the economy and society in general, and that are captured in the treaty, to the information society as well. The second step is to start translating and applying those rights to the field of technology for elderly people, technology for aging well. Thirdly, if we say first of all that the information society is really a part of the economy and society, and that we have a good human rights framework that we can apply to these situations, we need to describe what it means if we say access to the technologies. We need to look at what aspects play a role.

**Q: Has the European Commission implemented any policy decisions that might relate to this area?**

In the policy development that we have been doing, most recently in the inclusion policy that came out in November 2007, there are four types of conditions mentioned. One is immediate access to technology: that you can actually connect somewhere to the internet, that you have access to broadband. Because market force rollout of the internet and Broadband across Europe is quite fast (although it's not the same everywhere), a large part of ensuring access is actually fulfilled through demand. Second, is the issue of the usability of the technology. This applies to people who have disabilities or to the elderly; what we're talking about here is accessibility. Here we intend to take further action because we think this area is not sufficiently fulfilled and there is not sufficient progress on the part of the market alone. Third, there is the issue of affordability, which is a difficult question. Again, it is in large part resolved through the market, but to some extent there is a discussion about universal service, for example, and the affordability of telecommunications. So , it is a difficult issue to resolve. And then there is the issue of people's abilities. Do they have the digital skills, or the digital literacy? So, we call it the four A's: Availability, Accessibility, Affordability, and Ability. With Ability, you have to wonder if digital literacy isn't something that is so fundamental that everybody should have a chance to have it, like education itself. At the moment, we are not at all very advanced in that discussion. We are presently investigating voluntary initiatives to put digital literacy in place for elderly workers or those who are retirees. So, all of these issues can be broken down from rights into answering, "what is it that needs to happen?".

**Q. So, what do you think the future of design will be? Do you think design will lead to inclusion or exclusion?**

Presently, we are seeing a tendency to increasingly involve the user in technological development. Also, we are seeing that elderly people and people who have difficulties with technology are becoming a focal point for design. We are finding that by taking this approach designers are creating products that are



more user friendly for everybody. It is as if we are enlarging the possibilities of technology by tackling the more difficult problems first. We have found that products designed in this way have a good deal of commercial success. So, we are seeing, actually, that it makes a lot of sense to try to involve elderly people early, to centrally involve them in the design process, and to look at the fact that innovative and interesting products are being designed for the entire population based on the fact that the difficult needs of the elderly are being met from the very beginning. Another benefit of this type of design is that it's not stigmatizing. A pilot was done in Scotland where the users liked technology that helped them live independently, but they absolutely wanted to have technology that was not stigmatizing. Stigmatizing might be a product that is designed specifically for a certain group, "we have a middle of the road technology, but now we are developing something special for you".

I think part of the industry is now recognizing this stigmatizing factor because they are looking more at a continuum, especially in the area of medical devices and fitness. In particular, they are looking at a smooth transition from fitness devices to health devices, from independency to some form of dependency support without suddenly being classified in an abrupt manner; you're either fit or you're dependent. You're either working or you're retired. You are either healthy or disabled, as if the world is black and white. You're young or old. These are divisions that lend themselves to discrimination.

**Q: How, then, would you qualify technologies for independent living? What is assistive technology and what is not?**

Assistive technology helps to compensate for certain functional limitations. These limitations mean that there is a reduced opportunity for participating in the economy and in society. So, assistive technology helps people participate. Mainstream technology involves products that everybody uses. Assistive technology can either be used independently or in conjunction with mainstream technology. So, we can say that a magnifying glass is a type of assistive technology, or that a screen reader attached to a PC is assistive technology. We are making these distinctions between Mainstream Technology and Assistive Technology knowing that sometimes "assistive solutions" or "assistive functionalities" can very well become a part of mainstream technology. What we would like to see is that, as far as possible, these assistive solutions are already part of the mainstream technologies; from an ethical perspective it helps reduce stigmatizing; from a practical perspective it very likely helps reduce costs. So, there are very practical reasons to strive for the creation of universal products.

**Q: What is the current trend in cooperation between tech companies and governments?**

If you look at a topic like ageing, I think you will see cooperation between companies and governments because there are a lot of economic interests at play. Businesses see an opportunity. They are interested in developing products

for the elderly and in working with users. Consequently, I think there is a reasonable cooperation. Companies are working in several groups on the joint development of policies and standards and on defining experiments. If you look at something like independent living, however, you will see that it's really quite complicated. You have entities involved (like care providers or insurance companies) that have nothing to do with the tech world, so their participation in technological endeavors is quite a leap for them. When looking at something like a smart home, you can't just look at the technology. You also have to look at construction rules and regulations. Typically, I think the comment you get from the industry is that you can't see the forest through the trees. There are so many different parties and rules and regulations involved, where do we start? So, probably one of the key roles of innovation platforms is to really create clarity.

**Q: How do you think we can we protect the privacy of assistive technology Users?**

Technology connects to your personal life; it collects data and qualifications about your personal life. In one way, technology can become much more intimate than anything else; so it's important to think about privacy and personal data protection like we are doing in other environments. However, I'm not convinced that if we look purely at personal data collection that we need to think about new principles. With regard to the elderly, if you are using a search engine on the internet that involves your personal profile and personal profiling or data protection, if that search engine is also connected to the fact that you are, for example, having difficulty in reading the screen or to use your fingers to use the keyboard because of stiff fingers or dexterity problems, it is obtaining even more personal data. But, I am not convinced that this is of a different nature than what we are already seeing today in terms of personal data collection. However, if this leads to classifying people, then there may be an issue of dignity involved. If it leads to the assumption that people are no longer autonomous, then there can be a real issue of infringement on the preservation of dignity.

**Q: Apart from privacy, what do you think are the main ethical challenges of bringing ICT to the elderly?**

I think one of the main challenges is the method of addressing ethical issues in this area, which has not yet been clearly developed. I think we can list a number of the ethical issues, but we do not yet have the right kind of guidance. We do not yet know, for instance, how to go about design for all, or even perhaps what "design for all" means. How do we design in such a way that ensures respect for ethical principles? I also think that we are missing the process level. We do not yet know who should develop guidance. We don't know how this guidance is going to be adopted; how it is going to become an integral part of technology development, or of service development. We haven't determined who is responsible for applying ethical guidance and how it should be applied.

Do we need to include ethical principles in design courses, for example? Do we need them to become some sort of part of product qualification? Can we test this in some way or another? Can we involve the users in some way or another, so that you can perhaps assess in real time whether there is a risk of ethical infringement? Does guidance need to be backed up by legislation? As you can see, I think there are still a lot of open questions around the process and contents of ethical guidance in this area.

**Q: Do you think the relationship between man and technology is essentially positive or negative?**

That's an interesting question. If we look at the whole field of inclusion, where technology is meeting inclusion challenges, I think we can see today that technology is actually problematic for a number of people. Many people are feeling lost by technology; they find technological devices difficult to use and don't feel connected to the technological age. So, in some cases, man clearly has a negative relationship to technology. At the same time, I think everybody is convinced that there are many positive effects and possibilities presented by technology and that we can take measures to make technology easier, to get better explanations, to involve people in the process of technological development. Still, I think it's really hard to know what technology will ultimately deliver. For example, email in general is potentially positive, but many people will complain that their inbox is overloaded. So, how it works out in reality is something that is not fully predictable; it is emergent. We need to find out what we are doing. That's why this whole question about whether or not something is positive or negative and what is a trend might actually be phrased in another way. Let's rather work from the assumption that a lot of technology can have a positive effect, but let's be careful about the way we are using technology; let's monitor what is happening and not just assume that everything is working positively.

**Q: Are you afraid that technology will isolate the elderly?**

I don't think we are talking about technology replacing personal contact. One of the interesting results of some of these pilot projects is that people are saying, "I'm actually relieved because now I have more time for personal contact". Another benefit is that technology can tell you about the condition of the elderly person. You don't need to rush if something is happening. You know what the condition is. Technology can also enhance personal relationships. There is not necessarily a contradiction between technology and human beings. We don't need to decide between technology and human interaction; we can have both. Indeed, there might come a time when we will have to have both. There may come a time when we won't actually have enough people to administer personal care to the elderly. In the end, we may be confronted with a situation that we may not like at all. It's not the fault of good or bad technology, but simply the fact that we don't have enough care givers and we will need to have other means.

**Q: What is the best way, then, to go about educating the elderly in the use of ICTs?**

I would definitely say that we need to educate the elderly now, or that they need to be self-educated. The question of how to do this is much more difficult. If we look, for example, at the many digital literacy initiatives we find that they have a difficult time reaching a large scale elderly population. We see that elderly people are actually learning how to use technology in more informal ways, from family or from friends, rather than through formal education. We definitely need a political commitment in this area; that's what we are asking for. To educate the elderly, we will need investments. It will take funds and we will need some kind of sharing of responsibilities. We'll probably also need good examples to follow.



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## ICT, e-Health, and the Aging Crisis in Japan

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*Interview with Hiroshi Shimada*



*Hiroshi Shimada is an expert in e-Health. He presently works as an ICT consultant for Fujitsu Limited in Japan and is also working with the Next Generation Ic Card System Study Group (NICSS) on the Smart Card and e-P.O. box.*

*Mr. Shimada spoke with us about the use of ICT in coping with the needs of Japan's rapidly aging population:*

**Q: Japan is very rapidly becoming an aging society. What are the main changes provoked by this demographic revolution?**

Well, in Japan, the aging of our society has brought about many changes. Perhaps the most significant are the strains placed upon the cost of social security, pensions, health care, and nursing care. The demands presented by the vast numbers of elderly presently seen in our society are imposing a heavy burden on the government's financial basis. We are seeing that the government is beginning to scale back on health and pension benefits. The problem is unfortunately compounded by a lower birth rate. Between the two, we are seeing a serious decline in the working-age population at the same time we are seeing an increase in the needs of the elderly for care and support.

**Q: Is the use of ICT common in treatment and consulting in Japan?**

Currently, like the rest of the world, we are experiencing a "digital divide" in Japan. This divide exists between the younger and the older generations. Consequently, what we are seeing is that the older generations themselves are not using ICT as a part of their treatment, or as a part of managing their long term care needs. We have seen that people over a certain age have trouble operating technological devices and equipment. So, again, they haven't incorporated such devices into their care. However, the outlook for future uptake of ICT looks quite positive. The situation is heading in a favorable direction with wider

spread availability of user-friendly and universal-design-oriented products as well as the increasing popularity of home computers and mobile phones.

**Q: For most Europeans, Japanese ethos toward ageing is that represented in Basho's haiku and poems. Is Japanese society still respecting and valuing their elderly population as in the past?**

Respect for the elderly is no longer one of the striking features of the nation. In fact, Japan has seen an increasing number of crimes targeting elderly people. Another change we are seeing has to do with elder care. In the past, the family took care of frail and aging parents or grandparents. Now, however, we are seeing that, because of a trend toward nuclear families and a changing living climate, the younger generations can't take care of the elderly.

**Q: Is e-Health challenging the traditional Japanese conception of family and solidarity?**

It's interesting because, while on the one hand people are perhaps less likely to be providing care for the elderly, or they are less eager, perhaps, e-Health seems to really be bringing families together. This is really very nice to see, especially in light of the fact that, at least in the metropolitan areas, we have seen a loss of a sense of community. But, like I said, we think that e-Health is at least strengthening familial ties. Also, with the internet, we see that adult children are able to learn about the physical conditions of their parents who may be living far away. They are making use of e-Health as a good communication tool.

**Q: Is the electronic revolution changing the social perception of elderly people and ageing?**

I really haven't seen any cases where this is true. I think that the perception of the elderly, or intergenerational relationships have changed over the past fifty years or so, but I don't really think this has anything to do with technology. There are always generational gaps, things that identify the younger generations that are not understood by the older generations. In this way, perhaps there is a perception that the elderly are out of touch, but as far as actually changing social perceptions, no, I don't think technology performs this function.

**Q: What are the main social consequences of the introduction of the personal healthcare record system (EHR)?**

EHR brings about great changes in the society. However, mere accumulation of healthcare records may not expand the use of the system. It is essential to promote the effective use of data by showing patients how they can collect and make use of such records. For example, data that is collected by an ICT device that monitors a patient's condition on a regular basis provides a wealth of data that can provided much more information about the patient's condition.

**Q: Does e-Health require special training both on the part of the medical community (doctors and administrative staff) and on the part of the patient? If so, how is this training provided and what can we do to improve upon the assistance already given?**

EMC vendors provide training for doctors, nurses and administrative staff. Patients do not have such training, since EMCs are basically used only by medical personnel. When information services targeting individual patients (such as PHR) are introduced, however, patients will need some training such as in information handling.

**Q: Will the Japanese system for social security pose ethical and privacy problems?**

Well, this is a question that gets raised frequently. In Japan, privacy abuse is restricted under the Private Information Protection Law. So, I really don't see that there will be a big issue. Any problems that arise will be addressed by the existing rules and regulations regarding privacy and ethical issues. I assume that this is the case for Europe as well, that there are laws and regulations in place to address these concerns.

**Q: What laws or policies need to be implemented to ensure the patients' privacy?**

Like I said, the Private Information Protection Law has come into effect against privacy abuse. As for the issues of patient records handling, the Ministry of Health, Labor and Welfare has developed specific guidelines called the Guidelines for the Security Management of the Medical Information System.

**Q: How does e-Health effect the doctor-patient relationship?**

The effect of e-Health on the relationship has not yet been fully verified at present. Generally, it takes a certain amount of time for the doctors to learn how to use the system. Once they master it, however, they are usually quite effective in integrating e-Health into their practice in such a way that does not alienate the patient. In fact, monitoring systems can actually add to the doctor-patient relationship. With displays on monitoring devices, doctors are able to interact with patients much more frequently than they would be able to do without such devices.

**Q: If e-Health is used for remote doctor-patient interaction, do we run the risk of dehumanizing the patient, of turning him into a faceless entity at the other end of a monitor?**

In Japan, telepresence is an essential factor of home healthcare. The system must convey the patients' complexion and actions as they are. In a situation where doctors use network equipment to treat patients in distant locations, the



atmosphere of in-person consultation must be created and both of them need some aids to make up for the lack of senses (such as touch). For safe and secure management of e-Health, an emergency care system and person-to-person relationships must be established in advance. Moreover, doctors and patients must get used to using e-Health. This, of course, takes some time and doctors and patients will have to learn to work together on the implementation of e-Health devices. But, I think the benefits of such devices outweigh the initial period of adjustment.

**Q: What are some of the ethical concerns surrounding e-Health?**

Really, I think that the transferring or selling of the patient's medical information without consent is the top ethical concern. Again, present legislation should address these concerns, but they are legitimate concerns none-the-less. Another concern is of course the fear that medical information will be used inappropriately, that it will be used, for example, to profile a patient or to exclude him or her from certain programs or services. These are all legitimate concerns.

**Q: In what ways can e-Health benefit the elderly community?**

E-Health makes it much easier for doctors, nurses and care givers to access the patient's medical records in an emergency situation. While some patient's may be fearful of the ramifications of this information reaching the general public, many patients and their families experience a peace of mind in knowing that one's medical history is easily accessible. This accessibility facilitates rapid responses in emergencies and minimizes the risk of mistakes or complications. I think this is a great comfort to the elderly.

**Q: How do you envision the future of e-Health and the role of the patient within the system?**

I really think that patients will play a more active role in managing their own health. I think that e-Health will bring about the advent of a new society where patients are the center of the system and where they collect and take advantage of their personal records at their own will. Of course, this puts a great deal of responsibility upon the patient, but by the same token, he will be much more active in his own care. In Japan, the government is considering the introduction of what they are referring to as Social Security cards, which will enable people to access their pension information and will function as a healthcare card and a nursing care card. It will also provide access to e-P.O. Boxes (e-Post Office Box) that would function as a kind of personal electronic information box that allows card holders to check their own pension records and to collect their personal medical records from various institutions. The government is also considering a PHR system where patients can use their e-P.O. Box and Social Security card to manage their personal information.

**Q: Is there any specific lesson that you think Europe should learn from Japan in the field of ICT for the ageing society?**

I think that dynamic on-demand VPN technology as a secure communication way to exchange medical information is sure to be of some help in European countries. Also, as we discussed earlier, being able to discern a patient's complexion is very important and, so, I think that "Natural Vision" (exact color reproduction) technology is a useful element of telepresence and would be of use in European markets. Overall, I think it's important that Europe and Japan make efforts to learn from each other and to participate together in solving the demands placed upon our societies by our aging populations.



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# Privacy, Affordability and Anti-Aging: Studies in ICT for the Elderly

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*Interview with Sergio Bellucci*



*Sergio Bellucci is an expert in the field of technology. In 1989, he became Director of the Centre for Continuing Education of the Swiss Federal Institute of Technology in Zurich and, in 1993, Director of the Management and Technology Institute at the Technopark in Zurich. In 1996, Dr. Bellucci became the Director of the Swiss Centre for Technology Assessment at the Swiss Academies of Arts and*

*Sciences, a position he continues to hold today. He is also a member of several groups, commissions and projects, including the European Parliamentary Technology Assessment Network EPTA.*

*We spoke with Dr. Bellucci about the use of ICT within the ageing community and concerns over accessibility and privacy:*

## **Q: How do you define elderly?**

Today, there is a change in the demographic structure, people are becoming older and older. This is clear. What is also clear is that there is a new way to grow old. In Switzerland, sixty year-olds are often more active than thirty year-olds. In fact, this demographic has become a huge market that is generating a great deal of money. They travel, they do sports, they are involved in many activities. This is a new concept. Also, a whole new industry has developed with the objective of keeping the elderly young. Doctors, in particular, have realized that they can make a lot of money in selling products or procedures designed to maintain youth. Here, we have an insurance policy for the elderly that was introduced fifty years-ago. The original concept was that when a person reached sixty-five, he or she would have a bit more money to live off of. At that time, no one thought people would live much past sixty-five. Today life expectancy has increased from sixty-five to eighty. This is an increase of over fifteen years. Moreover, the quality of life today of a sixty or sixty-five year old person has changed. So, we have seen a great deal of changes regarding how we think of elderly.

**Q: Do you find that today's elderly are using ICTs?**

There aren't that many people using ICT. The reason why the older generation is not using these products is because they are not able to overcome the barrier of fear associated with them. The majority of those over sixty-five still have a problem with using technology. That being said, however, there are many older people who have started using the internet. Here in Switzerland, there are internet courses, older people chat on line, people are using the internet to organize travel, this is a new and very active way for the elderly to spend their time.

There is, of course, the fear that ICT, including the internet, could invade people's privacy. Realistically, everyone is free to decide whether or not to use these devices. The problem is whether or not they understand when technology threatens their privacy. The danger is that people are somehow forced to use technology without realizing potential consequences. The problem of privacy is a real issue.

**Q: Do you find that many elderly don't understand the privacy aspects of ICT?**

I am not sure how many people ask themselves where their personal data goes. I think this is a big problem and people aren't informed enough about this issue. To me, privacy is the most important and delicate issue. These technologies do have many advantages, but many risks as well, and unfortunately, people are not properly informed. Also, positive and negative aspects of technology are not transparent enough. People are not aware enough.

One particular area of concern is the medical field. Vast amounts of medical data are collected and put on a computer or sent over the internet where insurance companies can access it. This data is also shared among doctors. So, private data can now be seen by many people. This is a huge problem that we will have to face in the coming years.

**Q: Have you already begin to look at the problem?**

We recently did a report on patients' data where we found mixed results. On the one hand, electronic medical records will lead to many advantages, but on the other hand, we have the problem of misuse and of breach of privacy. Clearly, these are two very important issues.

I think it's really important that we have discussions with end users to see how they will react when faced with these aspect of technology. I believe it would be interesting to see the reactions of the different age groups and also of different cultural groups.

For young people, using technology is quite normal, older people, however, still need to get over many barriers. We are finding that many people are still afraid of technology and the implications of ICT. From an economic point of view, everyone has the potential to use these technologies, but people are afraid of them. A perfect example are ticket machines in train stations. They are a great convenience, but many people are afraid to try them.

**Q: How can we improve this situation?**

First of all, engineers should think of, and develop, user friendly systems. Then, politicians should say what their needs are and what is important for end users; this is important to have from the very beginning of the dialogue. Unfortunately, we know that things don't actually work that way. For example, if you buy a DVD drive, the instructions for installing it on your computer are not always easy to follow. This is also a problem for the elderly. User friendliness is a very important issue.

**Q: How do you decide which topics to investigate?**

We seek the topics that are important for our society as a whole. Right now, the whole digitalization of the medical sector and the concept of anti-aging is something that interests more and more of our population.

In the anti-aging research, we are interested in knowing what anti-aging products really mean for the Swiss population; what truth lies in anti-aging claims, what is false, what politicians should do regarding these products, if they should make rules, etc. All of these questions are the reasons why we decide to do a new study, or project on new technologies.

When we decide to do a study, we look at 1. whether it's an aspect that interests people, and 2. whether or not the topic is controversial. Of course, there must be benefits to these technologies, if not, there is no point in doing the study. But, we also have to sort out if these benefits are real or if they are claims that are presented by developers in order to get funding.

**Q: Is it enough for technology to extend the duration of life, or must it also enhance the quality of life?**

It's not enough to increase the duration of life, we must also increase the quality of life. Today's concept of aging is different. Today's elderly have more free time, more money, more medical resources, etc. Consequently, we are seeing that they have a higher quality of living. This quality must be extended as long as possible, and technology can certainly play a part in accomplishing this.

**Q: Will new technology replace human assistance?**

Not completely. I think there will be a switch to a very intensive use of these technologies, but they won't replace human care givers. They might constitute additional systems, but they will not replace human beings. We should not force technology, the uptake of technology should be an evolutionary process that develops naturally.

**Q: Do you think that access to technology should be a universal social right?**

There will always be people who take advantage of these technologies and people who do not. Here, "social right" is a big word. Today, the majority of cit-

izens can use these technologies. I don't know that we need to frame it in terms of rights. I think a very real problem when looking at the question is economics. Luckily, here in Switzerland, we don't have a major problem with this. Everyone can use ICT. In other countries, there are clearly economic barriers to using and accessing ICT.

I think that with time, the use of technology will become a normal part of everyday life. Today's problems are barriers, not being able to afford technology, not being able to use technology, not being educated in the use of technology, etc. Again, user friendliness is very important.

I believe that if we are able to develop technologies for the elderly that they feel comfortable using, there won't be an issue. We must consider, though, risks, costs, transparency, the whole discussion from a general point of view.

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# Ethics and Consent in ICT Research

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*Interview with François Hirsch*



*François Hirsch is an expert in Governance and Ethics. He is presently Seconded National Expert at the Unit 'Governance and Ethics' in the Directorate General for Research of the European Commission, in Brussels. He is not only involved in scientific research but also in the evaluation of its social impact. He is appointed by the European Commission to strengthen the 'Capacity' programme toward developing countries and to organize the ethical review of projects submitted*

*for funding to the different directorates as well as to the European Research Council.*

*Dr. Hirsch spoke with us about the ethical review of ICT projects and the issue of consent:*

**Q: On average how many projects submitted for ethical review directly or indirectly concern older people?**

It is difficult to answer your question, because it is difficult to define exactly what projects directly or indirectly concern older people. If you only consider projects which deal with older people directly, then most of those that arrive to the ethical panel (those which raise any ethical concern) regard information and communication technology (the information and society program) and the health program within DG Research.

Yet if you also consider projects dealing with elderly indirectly, they include projects funded by Marie Curie, within the scope of FP7 people, and the European Research Council grants. Really, I can't give you precise figures, but to be sure they are not few.

**Q: Is there any specific problem met in the ethical review of projects which concern elderly people?**

Well, there are many issues that arise when looking at ICT for the elderly. Certainly, there are consent issues and privacy issues, but these come back to the core



issue of how to protect the elderly. Frail elderly are a very vulnerable group and we need to make sure that they are not exploited or taken advantage of. Ideally, checks and balances should be put into place beginning in the research and development phase and they should continue throughout the life of the project. Protecting the frail elderly is an ongoing issue, it doesn't stop with ethical reviews.

**Q: Generally speaking do you feel that applicants are aware of the ethical context when they submit proposals concerning the elderly?**

Generally, I would say they do. However, just because applicants are aware of the ethical context, doesn't mean that they always think through all of the ethical issues or implications of what they are proposing. It's difficult to think of everything up front, but it is important that we try to be as thorough as possible in anticipating ethical issues, particularly when looking at people who are more vulnerable because of their age, be they children or elderly.

**Q: What are the main ethical problems encountered by projects dealing with older people in the bio-medical field?**

Again, applicants fail to see the elderly as being a vulnerable group. I cannot stress this point enough. When elderly are frail they really are vulnerable to being taken advantage of.

Of course, this is amplified in research that involves people with dementia. Here we have to take into account that these people in general cannot give consent to participate in studies in the same way as someone without dementia. We have to be really careful with them. As such, there are many guidelines on how to address ethical issues in biomedical research that focus on their needs.

**Q: What are the main ethical problems encountered by projects dealing with older people in technological fields (as they relate to ICT, robotics and nanotechnology)?**

Generally speaking, older people aren't as familiar with technology as younger generations may be. So, oftentimes, they are unable to give proper consent to participate in research studies because they don't understand the topic or the implications of the study.

So, it's extremely important that researchers make the scope of a study very clear to the participants, whoever they might be.

**Q: Generally speaking, do you think that there is any risk of misunderstanding when one uses criteria developed for ethical review in the medical field in other fields such as ICT?**

People might think that there are different criteria or issues of misunderstanding, but realistically, if the information sheet is well prepared and is thoroughly discussed with the participants, then I don't see why there should be any misunderstandings.

The critical part of the equation is that everything must be thoroughly explained to the participants and they must be very clear about what is being asked of them. This isn't always so easy. Sometimes researchers think the scope of the project is clear, and participants might think they understand, but down the road both parties can discover that things weren't as clear as everyone thought.

**Q: Is the notion of informed consent developed in bioethics appropriate to ICT research or should we develop a specific new notion for ICT?**

Again, there really shouldn't be any difference regarding informed consent. Consent is consent. It always goes back to the sheet. If the sheet is well thought out and presented clearly, then everyone should be on the same page. If the sheet isn't clear, if you aren't accurate in your description of the project and in what you are asking from your research participants, then you will have problems.

**Q: One of the main ethical tenets of medical research is that research should be carried out for the direct benefit of the patient in order to justify risks more than those encountered in normal life. Is this rule applicable to the ethical review of ICT projects?**

Oh, absolutely. Definitely. Only direct benefit could justify risks. This is an ethical tenet from Nuremberg on and there is no reason to weaken this tenet in the ICT field.

**Q: In ICT, also with assistive technology, we don't usually have patients but "users". To what extent may the notion of user coincide with that of patient?**

Really, users can be patients and patients can be users. This is certainly the case when looking at e-Health and telemedicine. I think this issue will continue to grow in complexity as we see an increase in the use of these systems. Again, we will have to make sure that the elderly are protected, both as users and as patients. I certainly think this combination will compound ethical and privacy issues, making it all the more important that these areas are addressed from the beginning.

**Q: Assistive technology and technology for the elderly are usually part of social care rather than medical care. Is the distinction between these two sectors, as well as the distinction between care and cure, relevant to the ethical review of research projects?**

In a word, no. We don't distinguish between social care and medical care in our ethical reviews. Social support and medical care often overlap in real life and also in research they often are intertwined.

**Q: Do you have any suggestions for future RT&D proposals dealing with senior citizens?**

I don't really have any specific advice for future projects. What I would say is that, clearly, as long as the frail elderly are considered to be a vulnerable group, any future projects need to be particularly concerned about maintaining a strict code of ethics when working on projects designed for their benefit. That, of course, also implies that research should continue to be conducted according to international declarations and international rules that apply to this type of population, to vulnerable people.

**Q: What are the main ethical aspects to be considered in research on medical ICT use and the use of monitoring devices and smart homes?**

I would say that the most important ethical aspect to look at in these cases is privacy. As I've said, the frail elderly are a particularly vulnerable group and, as such, there is an even greater risk that their privacy will be invaded.

We have an even greater obligation to protect the privacy of the elderly, to make sure not only that devices are designed to protect their privacy but also that the elderly themselves are aware of when they are giving up their right to privacy and why.

**Q: Thinking about telehealth, telecare, and the monitoring of the elderly, what are some ethical concerns we need to be aware of?**

Again, I would say the same thing. We need to make sure that these products are designed with safeguards to protect the privacy of the user, of course. But, we also need to educate the elderly and give them the tools they need to look after their own privacy issues. By empowering the elderly, we can protect them and their privacy. This is very important. They must control these devices, not the other way around.

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# The Tsunami of Elderly: How Aging Citizens Will Change Our Societies

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*Interview with Ase Keri Haugeto*



*An expert in the field of industrial design engineering, Ms. Ase Keri Haugeto is currently leading the e-Health: Future Aging project within the Norwegian Board of Technology. She has also been working with privacy and security issues related to new technologies, technology as a tool for development in non-western societies, and deliberation and involvement in development of technology and politics.*

*Ms. Haugeto spoke with us about design issues and the need for technological solutions geared toward assisting the coming “tsunami” of elderly:*

**Q: Will you explain the “tsunami” of elderly you have spoken of?**

What I mean by tsunami, is that the wave of elderly that is coming will be very big. It will create many changes in terms of our society and will really be quite scary. This is why I use the word tsunami, to make a point that this is something that will really change the way we live. There are many things that are happening as our society is aging and as the number of elderly outweighs the number of younger citizens, we will see a shift in our economy, politics, culture, etc. Really, everything that defines a culture will change as the demographics of the society change. Furthermore, as our societies age, many of the elderly will need some kind of health care, however there won't be enough younger people who are able to help them. So, we will have a gap between the need for care and the ability to meet that need. This is a very big challenge that will be happening in all of Europe. We won't be able to go to a neighboring country to get health care workers, because the people there will have the same problem, namely a shortage of care providers.

**Q: Who are our current care givers?**

In our society, we have both families and we have a public health care system that helps to take care of the elderly. I think in Norway and the northern

EU countries we have a very strong health care system, so many elderly people are taken care of by the system. But even so, I think that in Norway it's about 50/50, with half the care coming from families and half from the public care system. So, the family still bears a significant role. This is important as we look toward the future.

**Q: Do you think that the shortage of family members available to assist the elderly will create new job opportunities in the care giving sector?**

I would hope that there will be professional jobs opening up because of the demand, but it depends upon the economy and whether or not individuals or societies have the resources to pay for these professionals. But even if you can afford to pay for them, recruiting enough of them will still be a problem for the health care sector because you will not have enough younger people to accommodate the demand for care. On the other hand, you have the family care givers. I don't think that you will necessarily have fewer of them, but you will have fewer of them available.

In modern times, you have women in the work force who now don't have as much time to devote to taking care of older members as they use to have before. So, you will have recruiting problems in both sectors, among the professionals and among the family care givers.

**Q: Can ICT help alleviate the demand for care givers?**

I think that ICT can solve some of the problems in the future because you can have more effective care. ICT is a good tool to save time for the carer and it is a good tool to help the elderly live independently. So, I think that ICT can absolutely play a role, but I think there are other things that play roles too. For instance, within the elderly population, you have healthy elderly who might be able to play a bigger role in taking care of the non-healthy elderly.

Really, the tsunami will be so big that the whole of society will have to re-think their views on aging and on the elderly. I think that ICT will play a part in the solution, but it will not be a solution in-and-of itself.

**Q: What is the role of ICTs as they relate to the elderly and how can they both benefit and pose problems for the aging population?**

Well, when we talk about ICTs here, we divide them into different areas. One role is that of communication which includes internet, mobile phones and email. These communication tools are very important and will be very important for the elderly in the future. Another role is to create a safe environment and control for the elderly living at home. These solutions include things like Smart Homes. Then there are ICT solutions that create convenience. These include things like telemedical achievements that allow you to stay at home and be monitored even if you have a chronic disease. Other kinds of conveniences include robotics that can do housework for you or other devices that just generally make life easier.

**Q: What are the benefits of making social and medical ICT available to seniors?**

Well, there are social and medical ICTs, but then you also have practical tools that can do something for you at home. Take, for instance, robotics or smart homes that can check for water leakage or help with household tasks. These would constitute a third category as well. The main benefit of making all of these ICTs available to seniors is that they help the elderly to live autonomously for longer, so they are not in need of help from other people.

Also, if seniors are able to live autonomously, they are not burdening the system either. Furthermore, in light of the current dependence on technology, it is very important that seniors too have access to ICTs and know how to use them. They will be a very large part of our societies and we cannot exclude them. So, to be able to participate in what is going on today, we need to make sure they are included in the use of ICTs.

**Q: What resources do the elderly provide?**

They provide a lot of resources. Of course they have been in the workforce for a long time, so they have a great deal of expertise in their fields. But, also, they have a lot of spare time that other people don't have. They can use this time both for taking care of children and other elderly. So, in the private, non-professional sphere, they have a lot to contribute. They can, of course, contribute to the professional sphere as well. I think that ICTs can make it easier to include the elderly in daily activities.

**Q: What ICTs are already available to seniors and what products are emerging on the market?**

I have to say, I'm really disappointed by the market today. There are so many possibilities with technology that has been around for many years, like Smart Homes for example. But everything is still very expensive and the number of products are very small. You have to really know exactly what you want and to be financially well off (both as an individual and as a country) to be able to afford these technological solutions.

In terms of emerging products, what I really think are emerging are robotics for households. These products aren't particularly meant for elderly people, but for the market at large. They could, of course, play a big role for elderly people as well. Perhaps Smart Homes are too complicated for the market to expand on its own. Perhaps they would be better suited to a more public health care project. Smart Homes have been spoken about for ten or twenty years and still not much is available.

**Q: What are some of the concerns that the elderly have regarding ICTs?**

Well, one concern is that the devices might not work properly or that they can't figure out how to work the devices. This is of course a safety concern be-

cause if you should be surveilled or if you should be warned if something is wrong and the system is not working and then you are unsafe. This is a concern that I think a lot of elderly have. Another concern they have is privacy, that they will not be surveilled too much.

**Q: Who is usually the recipient of monitoring technology?**

Of course Alzheimer's patients are very important because they need some kind of monitoring. But, also people who are physically weak require or sometimes desire monitoring. Many older people are afraid to fall, which they do quite often. It's a big problem. So, a sensor that could warn someone when an elderly person has fallen is a device that many people may desire.

**Q: When designing ICT products, in an ideal world, what should the process look like?**

Well, in an ideal world, the design process would begin with analysis of the end user, who they are, what they are concerned about, what they need, how they live, etc. Once you have the needs specified, you can develop products that respond to them. The wise thing would be to start with the elderly themselves and not with technology.

**Q: Is there anything that the EC can do to help make sure that designers start with the elderly in mind?**

If you have financial support for R&D projects or research projects, you can demand that researchers provide analysis of the end user. I think that if designers do this analysis, they would build a market winner because people would like to have products that are tailored to users' needs rather than products that are developed on the basis of some kind of new technology. Probably the best long term solution would be some kind of public regulation or incentive to force the development of products into a more humanistic direction.

**Q: What are some of the obstacles ICT designers face in building products aimed at assisting the elderly?**

One important obstacle is the time and money that goes into the design of a product. The industry demands that designers be quick and so they don't have enough time to thoroughly develop things. It takes time to understand other people's needs. Many designers are young people; they need time to understand the needs of the elderly. Also, budgets are generally too small, making it very hard to make products of quality.

You are always forced to develop something new, usually at the cost of quality. If you look at mobile phones, they have been around for ten or fifteen years and they still haven't been developed in a way that is easier to use. I think mobile phones from ten years ago were easier to use than mobile phones are today, which means that today's phones have been designed with technology in mind.

The engineers have developed new fancy things that they have added to the product, but they never ask people what they actually need.

**Q: What can policy makers do to help facilitate the design and implementation of ICTs as they relate to seniors?**

I think that it is important that policy makers help to spread confidence in products. Also, policy makers can make economic initiatives available. They can help to change or to direct the market by funding sound projects that take into account the human aspects of design. I think it's very important that governments support R&D because the market doesn't do it itself. Hopefully the markets will eventually follow.

**Q: What are some of the ethical concerns that arise in designing ICT services for the elderly?**

Frankly, there are a lot of ethical concerns. One concern is that if you have a great deal of surveillance solutions around you, it could be an overload; you could feel like you can't do anything without being surveilled. Where do we draw the limits on surveillance? Clearly different people will have different opinions on where we draw the line. For people who are unable to make decisions for themselves, people with dementia or Alzheimer's, other people must make decisions for them. Then what is the preferred solution? How much technology should we introduce into their lives? How do we know if we are relying too much upon technology or if we are perhaps not relying upon it enough?

I think we also need to look at the issues of safety and of loneliness. Many ICTs are designed to make people safer, but if the electricity goes out or if you are not able to use a product in the correct way, then you might actually be less safe through your dependence upon them. So, really ensuring that products do indeed make people safer is important. The same is true for loneliness. If you are able to feel connected to society then you will feel less lonely. But, if you are living in a Smart House and you talk to people via the internet and this means that you never get to see face-to-face anymore, you might experience a great deal of loneliness.

**Q: How can we ensure that ICTs are used in a responsible way and that they don't violate the privacy or take away the dignity of the user?**

I think it's important to have choices so that you aren't required to use a product. It's also important to have good information and to know the implications of ICTs. I think if you have several choices and good information about the products then you can make responsible choices, at least this is true for those who don't have dementia or Alzheimer's. Also, elderly people should know what these devices do, what information they take and store. They should then be able to agree to have these products in their lives. It's also important that data that is taken by ICT devices is deleted when it is no longer needed. We are working with these issues in Norway now and are looking at what politicians can do



to prepare for the elderly tsunami that is coming. We are struggling a bit with the coming wave. The problem has many dimensions and people must be able to choose solutions for themselves. So, there must be a balance between the public and private sectors.

**Q: What do you envision the care of the elderly looking like twenty years from now?**

Because I know of the big demographical challenges and the lack of young people available to take care of the elderly, I believe in technology. That being said, however, I'm afraid of what a bad product could do. So, my hope is that there will be a lot of good products that can help the elderly to live their lives independently, but that they won't need too many different kinds of technology around them all the time to be able to accomplish this. Ideally, you would be able to choose what kind of products or technology you would like to use.

It's also important that these products are easy to use and that the user can maintain control over them, so that technology doesn't take over your life, but that you control the technology. It's important that these products aren't too complicated and that they allow the user to feel safe and confident and connected to society without feeling under surveillance or trapped in some kind of a techno jail.

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## The Elderly, ICT, and the Need to Close the Digital Divide

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*Interview with Anne-Sophie Parent*



*Anne-Sophie Parent is an expert in the field of aging. She is Director of AGE - the European Older People's Platform, a EU network representing 25 million older people across the EU-27. AGE aims to voice and promote the interests of the 150 million inhabitants aged 50+ in the European Union. Ms. Parent sits on various advisory committees set up by the European Commission (European Pensions Forum, Science in Society programme, e-Inclusion programme, European Year of Equal Opportunities for All, European Health Policy Forum). She is also a member of the Steering Committee of the Social Justice Programme of the King Baudouin Foundation (B) and chairs the francophone jury of their Intergenerational Solidarity Programme.*

*Ms. Parent spoke with us about the role of the elderly in today's society and the place ICT occupies in caring for our aging population:*

### **Q: What is the public perception of age and aging? Is it in a state of change?**

What makes someone “old” varies a great deal based upon who you ask. If you ask my four year-old granddaughter she will tell you that you are old when you are twenty. Many people who are in their fifties or even in their seventies don't consider themselves to be old. They may be perceived as being old by the younger generations, but they don't consider themselves to be old. Today people tend to remain pretty active, even if they are retired. When thinking about the elderly, it's important to remember that, as studies have shown, the elderly contribute more, even economically, to society than has been thought. They contribute as consumers, they contribute by transferring money to the younger generations, and through their volunteering activities. They provide a great many services that would be very costly to society if they had to be paid for. In particular, the elderly are the ones who are providing the bulk of the informal care given to their fellow senior citizens. Currently, this service is not recog-

nized as having a value even though the same work being done by professional carers would cost a great deal of money.

For us, we don't really divide the elderly into groups, it really has to do with whether or not you are dependent on others for your daily activities. If you are able to live independently, then you can be a "young" elderly person until you reach your nineties or even more. You have people who are eighty-five years-old who still drive and still help their neighbors and do lots of fantastic things. So, I would say that you have the autonomous elderly and the dependent elderly. And, you can become dependent at a very young age.

**Q: Why is it important to close the digital divide, to include the elderly in this new Information Society we are in?**

The digital divide is comparable to illiteracy. Two hundred year ago the issue was whether you were able to read and write; being able to read and write meant that your chances in life were enhanced and that you could do many more things than those who were not literate. Now, we see the same thing with the digital divide. If you don't know how to use the new technologies you are left out, excluded, from a huge sector of society and from access to many, many services. Some services now are available exclusively through new technologies. This includes many banking systems. For example, in some countries, you can only manage your account through the internet or through automatic cash machines. If you need to go inside the bank it costs you so much money that it's discriminatory. This is where the problems really start because this means that those people who do not know how to use the technology, or people who have disabilities of some sort, have to ask another person to manage things for them and that's really something older people resent very much.

**Q: How can ICT help the older population maintain an active lifestyle and enhance or facilitate their social existence?**

Well, you have two issues at play here. When older people can access and use new technology available in the form of mainstream products and services, then, indeed, they take a much more active role in society. They can keep up with progress and they can learn new things. This helps them also in communicating with people outside like friends or carers, or even making friends with people over the internet. Special websites like Facebook are now targeting people over the age of fifty and they are becoming very, very popular. And then you also have the ways in which this technology can help people with dependencies, people who need health monitoring or who need some of monitoring at home (so they can be safe in their own homes).

**Q: With things like monitoring systems and smart homes, do ICTs also have the ability to isolate the elderly?**

Yes. Problems with these systems may arise when they have been put into place by public authorities who just saw that it would help them cut costs for social care. They install the web cams and then the dependent person just connects once a day

or so with the social carer who asks questions just to make sure that everything is ok. This means that some older people who are house bound, who are unable to go outside their homes on their own, don't see anyone for weeks at a time. This is really the wrong way to provide care to older people. What new technologies are useful for is helping to save costs and making the best use of very skilled care professionals, but you do not replace the necessary social contact with communication through a web cam. When such systems are put in place, you need to replace the nurse visit with the visit of a less skilled worker or volunteer who would still come once a day or once every two days and have a little chat with the person and spend a little bit of time to check that everything is all right. We have had complaints from older people who have not seen anyone for six weeks or two months in a row. When you are totally dependent and you cannot move out of your home, you feel like a prisoner. You no longer have any contact with the outside world. So, ICT cannot replace personal interaction. It can, however, help save costs and improve safety at home because the nurse doesn't have to drive from one patient to the other everyday and you don't need a highly skilled care professional to provide some company or some social interaction with every patient.

**Q: What has been the reaction of the elderly community to ICT?**

Among the very elderly, you sometime find quite a strong reluctance to the use of new technologies. They are not always looking at ICT with a good eye. They sometimes are a bit suspicious or they just don't want, for example, to be monitored 24 hours a day or they don't want this intrusion, or what they see as an intrusion, into their private lives. But, once they learn how to use technology and once they learn what they can do with technology and what benefits it brings them, then they are quite happy with technology. When technology is applied to safety, for example, this is an area that most older people agree has great benefits. They like the idea of alarm systems and stoves that turn off automatically if you forget to turn them off.

**Q: How can we go about making ICT available to the elderly?**

Cost is one of the major barriers for many older people. This is why we keep saying that if you make the mainstream products accessible to older people then the cost will be much lower. Older people will be able to buy products on the mainstream market rather than special devices that cost much more. Also, the industry has to change their approach to the market. They tend to produce new technologies on a very regular basis with new features that only few people use. For example, most of the people only use 10% of the functions available on their computers.

**Q: Do you find that there are many elderly people who would like to continue working past retirement age, but who feel like they are closed out of the workforce?**

Oh, yes. There is a case, the Heyday case in the U.K., that is currently being examined by the European Court of Justice. A person was forced into retire-

ment when he reached pension age. His employers claimed that he had reached retirement age and therefore they could force him to retire. We are waiting to see whether the legislation really states that the age at which you become eligible for your pension means that it is mandatory for you to retire or if people should be allowed to continue working. We know that more and more people would like to continue working, particularly if they have an interesting job, and if they are healthy.

Many of them would like to retire in a progressive way, so instead of going from fulltime work to fulltime retirement they would like to cut down to part time and slowly move to retirement without having this very sharp change. Here, new technologies could help. Often older people resent things like being stuck in traffic jams every morning and evening, but they would be happy to continue to work if they could do some telework and split their working time between the office and home. This would work well too for informal carers, people who need to be home with a dependent relative but who still need or want to work. So, having more flexible working conditions is something that many older people would welcome and then they would be happy to work a few more years.

**Q: As our society becomes saturated with the elderly, do you think that we will change our perception about keeping them in the workforce and that we will start to accommodate them?**

Yes. And, the first people who want to change the exclusion of the elderly are those employers who are realizing that they have more and more difficulty finding a skilled workforce. When this human capital is available among the older workers you want to take advantage of it. So, some employers are now starting to realize that they should be more open and try to maintain their aging workforce. Again, ICTs can help. ICT training can help them stay in their current position, but it can also open up possible second careers for them. For many people, if they aren't trained in ICT, they are typically in low skill jobs and don't usually feel too much like continuing to work.

In fact, I would say that lack of ICT skills is one of the major barriers that force people out of the workforce. The problem is that often, after the age of forty or so, you have no access anymore to training, so your skills become obsolete and you're kept in jobs which are becoming less and less important in the company. When this happens, you often lose interest because you are not valued in your work.

**Q: Can the EU mandate that companies give equal training to all employees?**

The EU has a general target where at least 12.5% of the workers should get training every year. The commission wanted to make sure that this target was also applicable to the different age groups but member states refused. In fact, we know very well that with older workers we are far from reaching this target. Now, however, there is a focus on the need to provide training to older workers.

So, the EC knows that it is an objective, but it's up to the member states to set targets that companies must meet and dictate how companies can prove that they are meeting the requirements.

**Q: What are some of the policy initiatives that the EU could take to ensure that older people receive training on these devices?**

Well, this, unfortunately will remain at the discrepancy of the member states or even at the local level. This is due to the way in which power is divided within the European Union. What the EU can do, and we hope that it will do, is to make sure that there is some accessibility criteria for all providers and for the industry which are binding. This would ensure that everything that is available on the market (mainstream products and so on) are built with older people's needs in mind. That would ensure that whatever comes on the market will be usable and will be of use to older people as well as to the public at large. But, to provide training, this would be left to individual initiatives from member states or local authorities, or NGOs. You have a lot of older people's organizations who are organizing classes to teach older people how to use a mobile phone or how to use the internet and so on.

**Q: What are the expectations of ICTs in the elderly community?**

You have the demand to be able to access the mainstream ICT devices like mobile phones, internet, computers, etc. But, they want the products and services to be designed in a way which is accessible for people who have some visual impairment, who are maybe a little bit hard of hearing, who have dexterity problems and things like that. And then, of course, older people start looking for new technologies to be safe at home, like burglar alarms, fire alarms, or fall detection systems. The question arises, when people really need monitoring, can these ICT systems help them stay at home? This is something that they value, of course. Rather than spending days in a hospital or being put into a nursing home, they would rather stay at home.

People want to be autonomous as much as they can, for as long as they can. Of course, if you have dementia, it becomes difficult to lead an autonomous life. But, ICT can help by making sure that we minimize the risks associated with living autonomously and help them with tasks that otherwise might be difficult for them like being reminded to take medication or to lock the door.

**Q: How do you envision a solution that provides the services people need while at the same time respecting their privacy and dignity?**

We need to identify and develop what people need together with the end user. Often, if you ask ICT service providers, carers, or the dependent themselves, you will get a very different opinion of what a dependent person needs. Often if the final decision is made by the carer or the funder, they will usually opt for ICT solutions because it saves them time and money. But the older person may refuse to use the device.

So, first you need to identify the needs and the best way to do that is to make sure that the end user really gets involved in decisions and really understands clearly what benefits he or she will get from these services.

**Q: Do you find that people make policy without addressing the real needs of seniors?**

Yes, that's often the difficulty. And, in particular, in the new technology sector, designers, technicians and service providers tend to develop products to meet the needs of older people but they very seldom involve the end users. For example, ten years ago, they developed, with EU funding, very interesting products, or systems from the technical point of view, but these were seldom used because they were totally disconnected from the needs and desires of older people. Now, with the new ICT and Aging project, they are trying to redress this problem. The Commission has made it compulsory for grant applicants to consult with organizations for the elderly to be able to test whether or not a proposal will meet the needs of the end users.

**Q: Do you think that ICTs will ever be conceptualized as a fundamental social right within the context of the European Community?**

The right to access new communication technology can be recognized as a fundamental social human right, but the right to use or to benefit from e-health, for example, is something different. E-health is a tool to deliver medical services. The end user is only concerned about receiving good health care, and is not interested in the tool that delivers that service. But the right to communicate and to participate fully in the information society is indeed a social right.

Just a century ago, radio and postal services were the only communication tools we had. They were considered services of general interest and, therefore, everyone had a right to access them. Today it is as essential to have access to the internet and to mobile phones as it was essential to have access to the postal services a century ago. Therefore, access to these forms of technology should be included in the Services of General Interest and should become a fundamental right.

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# Ethics, ICT, and the Elderly

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## *Interview with Pīteris Zilgalvis*



*Dr. Pīteris Zilgalvis is Head of the Governance and Ethics Unit, Directorate Science, Economy and Society at DG Research, European Commission, Brussels. Until 2005, he was deputy head of the Bioethics Department of the Council of Europe. In addition he has held various positions in the Latvian civil service and at the World Bank in Moscow and Riga. Dr. Zilgalvis studied political science at the University of California, Los Angeles. At the Law Center of the University of Southern California he obtained his JD. He is a member of the California State Bar. He*

*has published over 25 publications on bioethics, economic reform and environmental law in English and in Latvian.*

*Mr. Zilgavis spoke with us about ethics and ICT for the elderly:*

### **Q: How would you define ethics?**

In looking at the context with which we deal with ethics, the context of research, I would say that ethics are the practice of non-infringement upon the fundamental rights and human dignity of those participating in a particular study or procedure. Furthermore, ethics involve open disclosure of information. Information cannot be presented in such a way as to conceal, through legal jargon or other methods, the practices, intents or usage of personal information or data collected by the study. Language needs to be frank and clear and all information must be transparent to the individual who is involved with the study. They need to be able to understand exactly what the study involves and to be able to give free, informed consent. It also must be clear that there are no external pressures to consent, such as economic factors, language related issues, social pressures or other such influences. We are currently seeing in Europe and in more developing nations a tendency to promise better care for participating in studies, not only better treatment, but such incentives as a better room or more services. Contrarily, if you do not participate in the study, you will be pun-



ished with an inferior room, crowded conditions and a generally unpleasant experience. This is the part of our ethical concerns.

**Q: In what way does your work at the Governance and Ethics Unit in DG Research engage with the elderly population?**

One way in which we engage with the elderly population is in ethical reviews of research proposals. Through this process it is possible to determine if the elderly can be categorized as a vulnerable group. This is a difficult designation to make as it must be done on a case by case basis. For instance, Alan Greenspan in the United States and Italian Prime Minister Silvio Berlusconi are both over the age of seventy, but I don't think there is anyone who would consider them to be in a vulnerable group.

However, there are other elderly who aren't so fortunate, people who aren't even able, through physical or mental imperatives, to give consent to be the subject of study. It is our job to make sure the rights of these people are not abused. It is important that we make a differentiation between the various members of the elderly population. In the Baltic States, for instance, there is a clear difference for those elderly who are still at work and those who have retired. In an ethical review, we call upon experts to advise us on the vulnerability of the group we are dealing with. If it is found that the group has special needs or in some way requires protection, we develop a way of implementing solutions.

Another way in which we interact with the elderly is through our responsibility for engaging the civil society organizations outlined in the 7<sup>th</sup> Framework Program. My Unit developed a system whereby we disseminate information about research projects to NGOs who are then able to participate in studies. For instance, we have active participation from AGE, the European Older People's Platform, which connects us to the elderly population and provides an opportunity for us to participate together in outlining issues relating to our aging population. We also partake in studies relating to governance, which can, at times, relate indirectly to the elderly.

Finally, we conduct research on fundamental rights and on bioethics, where, particularly in the latter category, we deal with the elderly. But, within the field of bioethics, as it relates to the elderly, we see a wide range of issues. For example, people who are in nursing homes or people with Alzheimer's will have very different ethical concerns than someone who is active within society and/or someone who continues to be a part of the workforce. I must also add that our work on fundamental rights research and on data protection, which is relevant to the population at large, plays a particularly important role when we are talking about vulnerable groups like some segments of the elderly population.

**Q: Is the issue of consent important in research on older people?**

Primarily, our concerns center around whether or not a person can consent to certain treatments or studies. People are frequently unable to give consent for a variety of reasons, for example, if they have dementia and cannot under-

stand what treatments they are being given or what studies they are taking part in. This is clearly a concern for us.

The difference between children and elderly regarding consent is that children as a whole cannot give consent and no exceptions are made, whereas the elderly as a whole can give consent unless that right is taken from them in some way.

So, the elderly are considered a group of people who are able to consent unless they have lost this status. In some countries, this is regulated completely by law. In Britain, I think, it used to be that one is independent and capable of consent as long as this right has not been taken away. In other countries, however, it is the medical professional who can decide whether one is able or unable to consent.

**Q: Do you find that sometimes people will consent to treatment or to participate in a study out of economic necessity? Could this be considered another form of vulnerability?**

Yes, in particular I have seen this issue arise in relation to biomedical research, where people often are economically disadvantaged and consequently vulnerable to making decisions based upon finances. As most elderly do not have a disposable income, they are perhaps more vulnerable to making decisions out of financial concerns than other segments of the population. However, if you look at a wealthy citizen from the UK who retires in Spain, or any other non-English speaking country, you will see that they too are vulnerable to make medical decisions without sound judgment. Here the barrier, of course, could be language, not money, but the outcome is the same.

So, when we look at individual research proposals it is extremely important to see who is being involved, how the research is being proposed etc. Economic advantage/ disadvantage, age, whether one is active or less active, mentally acute or unable to understand what is happening, these are all crucial aspects of ethical consideration. Also, how the data is used afterward must be taken into account. If this data is used by outside sources we can expect to run into ethical issues. For instance, if banks get a hold of medical information and use that information to determine granting or denying loans they would clearly be using data in an unethical way. There are many studies that come up that don't directly relate to the elderly, but that certainly have an effect on the aging population as well.

**Q: Is it important that the motivations of a study are ethical? Do you feel that inclusion should be behind ethically motivated research?**

Yes, of course, ethical motivations are essentially important to any study. If a particular study can be used in a non-ethical fashion, then we must look at the motivation behind it. It is also true that inclusion should be a factor, but I think too, that we need to look at each case individually.

Also, I do not think there is anything wrong with the idea of making a profit or recuperating costs when providing a service, as long as the service is actu-

ally needed. If the service one provides is not needed, if a service is created just to make money but there is no benefit on the part of the user, then it is certainly not acceptable.

But, it is important to make an individual evaluation of each case, as I said. Also, another issue here is looking at the application of research or technology. For instance, looking at assistive technologies, we need to consider whether their use will create dependencies, situations where people can no longer live without these devices. Would such dependencies risk our fundamental human rights?

**Q: Is it difficult to determine if a study has an ethical motivation?**

Yes, it is. For this reason, it is the role of the independent evaluator (the person we call upon to analyze research proposals) to be skeptical. To date, motivation is not a cause for the rejection of a proposal, but indeed, this is an area that we need to elaborate upon.

**Q: Is there a relevant article about fundamental human rights that pertains to the elderly on the EU level?**

Well, fundamental human rights touch upon this issue, but articles really exist in national legislations. Basically there exists a practice and so they differ from country to country in the EU. We have a standard for what we finance here in the EC and that must comply with the host country's legislation as well. But, if something is funded by Germany, for instance, then they have their national laws. They have to follow the relevant articles of the German legal system.

**Q: Is there any message that you want to convey to the readers of this interview?**

I think that the message could be that we should be positive about new technology, although it is clear that there are many problems that should be eliminated from the beginning. Problems are normally addressed upstream when a new technology is being developed, thus the aim should avoid any ethical risks in a preliminary way. Ethics should address problems rather than fixing them when they explode. This is what we are trying to do in our Unit and I am rather satisfied with the results that we have achieved up to this point.

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## The Need for Standards in Elder Care

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*Interview with Andrea Gulacsi Gologan*



*Andrea Gulacsi Gologan is Programme Manager New Opportunities and Pre-Standards with CEN - European Committee for Standardization. Her position involves the strategic development of new standardization areas, focusing on services, in order to facilitate the cross-border trade of services within the Internal Market. Andreea is also the Secretary of the European Working Group CEN/BT/WG 163 'Service Standardization' and active member of CEN/BT/WG 192 'Qualification of Personnel'.*

*Ms. Gulacsi Gologan spoke with us about the need for standards in the area of elder care:*

**Q: Can you tell me a bit about CEN and how you came to be involved with the SENIOR project?**

CEN is the European Commission for Standardization and is built on European membership. Our members are the national standardization bodies of the EU and EFTA, with one member representing each member nation. We have two councilors, the European Commission and the European Free Trade Association. We are an interface between the EC and EFTA and our members. When we publish a European standard, all of our members have the obligation to withdraw the conflicting national standard and put the European one in place.

In 2006 we began working on eleven new projects for the EC, four of which are customer related projects, specifically, home services, residential services, accessibility, and a project on the Smart House. It is our job to interface with stakeholders and identify what the European relevance is of their business, and (if they have a European implication) whether or not they have any problems. We then determine if those problems are related to legislation, if so, they go back to the Commission. If not, we look at whether or not they can benefit from European Standardization.

We look at the nature of problems, if the problems are in terms of service pro-

vision, the quality of services delivered from one country to another, or the mobility of services, “Can I provide my services to another country?” “If I go from Belgium to Italy and provide my service, will you understand what I am providing?” Is there an understanding? Is there a common terminology? Are we talking about the same things? If these are all elements that we can identify, then they of course would benefit from European Standardization. We aren’t working directly with the standardization of ICT, however, we are working on other projects that concern the elderly, particularly in the realm of quality of care.

**Q: Is it possible to establish standards for elder care?**

Yes, I think it is. But there are many factors involved. In many countries, particularly the new member states, there are no standards regarding the quality of care for elders. I think that every document that we produce that sets guidelines can help. Of course, it’s up to all CEN member countries to define what is a common accepted quality and what is not. And then, of course, because we have an obligatory implementation incumbent upon all of our members, we will ensure that even countries who don’t have any standards would then have a reference document.

**Q: What are some of the service concerns the elderly have expressed?**

One of the areas we are looking at is the migration of elderly people from the Nordic countries to the South and what expectations they have in terms of the quality of care they will receive. They are concerned about what services are provided to the elderly and whether or not the quality of those services is the same in the North as it is in the South. They want to know if the qualifications of those working with the elderly in the South is of the same standard as those working in the North. Is the standard the same throughout Europe? Are people qualified or are they not? We are looking at the quality of the homes themselves and what services enter into these homes. Catering services have to be specialized for elderly people. Is there a common qualifying criteria for these companies since they are multinational, global companies? Do they have a certain check list that someone can look through and say, “well this is a high quality, I like that for my residential home?”

There is a great deal of concern raised by organizations or federations representing elderly people on the information available to the elderly before they move into a residential home or when they buy into home services. Therefore, we investigate what kind of pre-information is available. Is there a whole package of information? Can the individual go and visit the residential home before they sign on to live there? Can they access the entire facility before they actually make a decision? A great deal of concern was raised through complaints and follow-up investigations. We are also trying to determine, if there is a problem, how is it dealt with? What is the delay time? Does the individual get an answer immediately or do they get an answer in six months? In short, we are investigating these outside services and trying to determine if they would benefit from a reference document that highlights standards and practices.

**Q: Does your current work deal with ITC at all?**

No. When we received the contract and financing from the Commission one of the specific requests from the Commission was not to look into e-Europe and ICT. We can look into solutions in a joined consortia by providing information or expertise. ICT specific standards are produced by our sister organization, ET-SI. For example, CEN might produce standards relating to the quality of ICT tools that are being used in these residential homes. Are they available for everyone? Who is using them and what are they for? These are the areas that we might investigate.

**Q: What would like to see as a focus of the SENIOR project?**

To me, it would be very important for this particular project to identify the real needs of older people in terms of ICT. You would have to establish whether or not you do that directly or indirectly, by going through service providers or by directly asking the elderly what their needs are.

What we have found, particularly with these areas, is that they are so basic today that we have to start with the essential questions, such as is the quality of life being considered? Are the social aspects being addressed? Having a social life is very important. Does my social life continue even if I can't move anymore or if I need someone to come into my home? There's so little that's been done on quality and on preserving the quality of life for the elderly, that the people we met with wanted to make sure that whatever the elderly have in their home or a residential home is of good quality and that the elderly can continue to live their lives. It is very important that this group doesn't feel marginalized by society.

It's a very complex field. It's completely new for CEN, and it's a very social field. Also, if we look at it in terms of standards, we have to look at it from a pan-European perspective and the differences are huge. New member states compared to Nordic countries or compared to Southern Europe, are completely different. They all have very different definitions of what home service is, what a residential service is, what type services are provided, is the catering adapted, is it not? And that's why I think it's very interesting and probably why you'll have different results as well in terms of ICT.

**Q: What are some of the ethical issues that surround standards for the elderly?**

Again, the social life of the elderly person is of concern, the quality of life. Life of the elderly doesn't stop the moment they have to spend more time in their own homes or to be in a residential home. The social aspect is very, very important. The whole interaction with the outside, the interaction with other people, the social implication of doing something rather than just being confined to a room. We should ensure that there is a quality of social life that continues well into old age, that the elderly aren't just cut off from society at large.

**Q: How do you define “elderly?”**

The elderly population is not as “old” as it once was. Many of today’s elderly are fully functioning until eighty-five or even older. Consequently, whatever we develop as quality referential tools, be it ICT or other, they can’t simply cover the elderly as whole but rather should target groups within the elderly bracket. For example, there are people with physical problems that are mentally sound, or there are people who need mental help, but are physically just fine. So, whatever we develop should not look at the elderly as a whole group, but should look at specific groups with specific needs.

Also, it’s important that we talk about quality of life. Who is an elderly person? Who is not an elderly person? Are they dependent? Are they independent? It’s critical that we respond to needs, to develop a roadmap based upon feedback attained from elderly representatives who are involved and are expressing their needs. This is how we should approach a roadmap. Of course, if there is a new tool or new training that needs to be implemented, then many of the solutions to these needs can be standards for the European community to follow.

**Q: Are you looking at standards relating to privacy issues and the elderly?**

Our study looks more at safety and security concerns. The stakeholders we talked with were very concerned about the qualification and training of the people who enter the home. They want to make sure that aids who come to someone’s house are of a certain level or standard. The issue of privacy, again, is more of an ICT nature. The differentiation between public and private social services is an interesting subject, but not one we are particularly delving into. We spoke to representatives of elderly people, like the International Association for Geriatrics and Gerontology, the Alzheimer’s Association, and we asked them, “what are your concerns and problems?” We didn’t raise more academic questions that would have investigated the social and ethical aspects of the topic. We went about our research in a very pragmatic way. So, privacy wasn’t an issue in our study, but then again, we didn’t ask ICT questions, so perhaps that is why privacy didn’t come into play.

**Q: How do economics and Standards work together?**

The economic aspects of our work would be benchmarking, making an assessed decision and choice. The potential economic effects of European Standards are an increase in productivity and sales. For instance, if more service providers, such as home nurses, adhere to a universal, high quality of service, more people will pay for that service. Additionally, a European Standard means that someone knows he or she will receive the same quality of care in their home country as they would somewhere else in Europe. This works as well for the aid who, by abiding by European Standards can move within the EU and continue to be employable. Thus, it allows for a social mobility which can lead to economic stimulation. Without standards, as is the case now, there is no transparency of information, so people are hesitant to move from one location to another as they don’t know what to expect.

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# Universal Accessibility, Design and the Elderly at Work

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*Interview with Michael Takemura*



*Michael Takemura is director of the Accessibility Program Office at HP, responsible for developing and implementing strategy for HP's corporate-wide accessibility efforts, including product design, engineering, product development, marketing, web, services, support and programs for persons with disabilities and age-related limitations. He is currently involved with the JTC1 Special Working Group on Accessibility Task Group, Information Technology Industry Council (ITI), National Spinal Cord Injury Association (NSCIA) Business Advisory Council and Electronic Information Technology Advisory Council (TEITAC). Additionally, Michael serves on the board of directors for the Assistive Technology Industry Association (ATIA).*

*Mr. Takemura spoke with us about accessibility, design, and helping the elderly in the work environment:*

**Q: How do you define elderly?**

When we talk about the elderly, we don't refer to a ubiquitous group. There are generally different stages of life that occur from forty-five to about fifty-two, from about fifty-two to about sixty-two, from sixty-two to seventy and then above. We find that there are people with different skills, different interests, and different needs in each one of those age segments that can change as you go through these stages.

**Q: If we have these segments of elderly, are we putting people in the category of "elderly" who might not need to be there?**

Is sixty the new forty, right? It's hard to say that one size fits all. You have people who are in their fifties, sixties, and seventies who are very active. Even into the early 70s, you see people going into new careers. They're finding new things that they want to do. They're living longer. There are more opportunities available to them. We are seeing changes in the family dynamic where some-



times you have multigenerational families living under the same roof. What we're seeing is that different people are responding differently at these various stages of life. The thing that is common amongst them all is that whether they are "retired" and doing something for enjoyment or whether they're still in the workforce, or perhaps helping the next generation, technology and information can play an important role in their lives. It can enhance their capability to improve their health care. It can give them access to services and commerce. It can help them manage their finances and give them access to news and information. Perhaps the most important thing is that it empowers them. It can do that through facilitating communication and connectedness.

**Q: What products are HP currently developing to assist the elderly?**

At HP, we don't only look at the physical product. We consider the "Total Customer Experience" or TCE, where we look at every aspect of where we touch a customer's life. This begins when they are investigating what products exist and which one might be appropriate for them. It continues on in their buying experience, and extends to when they take the product out of the box. It also encompasses technical support, and then, eventually, when they look into getting a new product and want to recycle their old one. We look at accessibility and aging at all of these different touch points and try to understand what the user needs are and how we can improve a customer's experience so that people who are facing age related limitations, for example, have a better experience. One example is in keypad design. We consider how large the buttons are and that color and contrast aren't the only means to identify something. Additional design elements we might incorporate are tactile cues, different shapes, different sizes, and colors. We provide product documentation in an accessible format so that it can be read by screen reader applications, or used with screen magnification, or Braille embossed for persons who are blind or have low vision. We provide customer support that includes TTY (Text Telephone services for the hearing impaired) and training for customer support agents in helping people with disabilities or people who experience age related limitations. We have also adopted W3C and Section 508 Web content accessibility guidelines for HP.com and our internal HP Web properties. At HP, we also want to make sure that our products work well with third party hardware, software, applications, and "assistive technology" (AT) that is designed to provide access for people with disabilities. We know that no two individuals have the same disability. We always ask ourselves the question, "It has to be accessible to whom, doing what, in what environment?" You find that there can be a significant number of combinations or permutations.

**Q: How would you differentiate between the needs of the disabled population and older citizens? Do you think that there is a risk of confusing the two?**

There is an international standards body which is called JTC1 (Joint Technical Committee Number 1) and they have a special working group on accessibility (SWG A). I chair the U.S. study group on accessibility and one of the things that we've been working on for the past three to four years is a User Needs Sum-

mary. To develop this User Needs Summary, we collaborated with advocacy groups representing people with disabilities, government policy makers, researchers, and the IT industry and we looked at different user needs. Our goal wasn't to describe design standards, but rather to identify specific user needs. What we found is that this universe of needs for access experienced by people with disabilities included all the needs for people who are aging. So, if you use the term disability, which could include problems with cognition, manual dexterity, sensory, sight, hearing, smell, touch, and so on, and you categorize the needs for accessing information and technology, we could not find an impairment that was unique to people who are aging that wasn't in the universe of needs of people with disabilities. Using the labels "disability" and "aging" can be a sensitive issue. For many people it's a matter of a product or information being easier to access or simpler to use, rather than being identified with a label. For example, my father-in-law who is in his sixties wouldn't necessarily consider himself a "senior", but he does want a computer that's easier to use.

**Q: Do you feel that, in the US, businesses are trying to retire their elderly employees sooner than the employee may wish?**

One thing that we've heard clearly from our customers is that there's a growing shortage of qualified workers as they look into the future. So, it's our belief at HP that there are talented people within the aging community with great work experience who can fill roles that can help us be more profitable and help us meet our customers' needs in a more effective manner. While some companies may not value older workers, many of HP's large corporate customers – as well as small and medium size businesses – realize they are facing a shortage of qualified employees regardless of age. Additionally, in America and in other countries, we are seeing people entering second and third careers now. In fact, now you don't usually see people in the same job for more than ten years. So, when you have someone over the age of fifty or sixty and they bring with them incredible work experience and can bring something to the table that a twenty-five year-old can't, that's pretty valuable.

**Q: So, then, do you think that more and more companies are providing assistive technology to their older employees?**

Yes. The demand for this technology has grown exponentially, particularly in the last 18 to 24 months. We've seen a slow growth from the late '90's to the mid 2000's, but over the past 24 months, the number of customers who are asking for help in making their Internet and extranet sites accessible and asking for devices designed to help their employees with accessibility has really exploded.

**Q: If someone in the office needs a special device of some sort, for example, a device for those elderly who are visually impaired, who pays for such a device?**

In general, the Americans with Disabilities Act places a level of responsibility upon the employer to provide appropriate assistance to their employees.

Most of the required devices cost under \$500. At HP, we provide accommodations for our employees and we think that's important. So, we have a group that does nothing but work with our employees to make sure that they have the right tools to do their job. As more and more features are designed to provide accessibility out of the box, it clearly becomes easier for companies to address employee needs without having to buy any additional products. One thing that impacts seniors is the cost of a product. When the cost of assistive technology is more than the cost of the computer, this can create a significant barrier to accessing information and technology. We work closely with assistive technology companies to try to reduce the cost for assistive technology and improve the time to market for these products. When Microsoft Windows Vista and XP were launched, they included integrated accessibility and Ease of Access features such as screen magnification and speech to text. These features are available on all HP products that ship with Microsoft Windows out of the box, so that customers who are older can enjoy these basic features without having to purchase additional specialized products. But for those customers who do need more specialized access, we have many assistive technology vendor partners who can provide those solutions to meet individual customer needs.

**Q: What is the development process at HP and who is taken into account in the design of a product?**

Looking at accessibility and design, we have a Global Accessibility Team that's made up of incredible men and women across all of HP's product divisions. So, whether you're talking about the design of a desktop, or a notebook, a display, or a printer, a handheld, an all-in-one printer, a software product or a scanner, all the way up to our large server products that run stock exchanges and ATM machines, there is someone from the Global Accessibility Team that has responsibility for taking the design guidelines that we define and integrating them into each of these different products. Then, once a product is finished, we test it to make sure it conforms with Section 508 standards (Section 508 requires that all products are accessible). We understand that no product is ever going to be 100% accessible. We understand that accessibility is not a destination; we don't ever arrive and sit there and say, "we're satisfied; this product is 100% accessible". It's an improvement process because we understand that as technology changes it can create barriers in how people use that technology. We are trying to make our products as accessible to the largest percentage of the population as possible, right from the beginning. We know that different people have certain needs and combinations of needs that are specific to them. One of the problems we encounter is that there are no industry standards for accessibility. Because companies develop their own standards, companies like HP and Microsoft are partnering with the AT (assistive technology) community to try to develop standards so that customers can have some confidence when they buy some type of AT that it will work well with their IT (computer, notebook, etc.). There's also an initiative called the Accessibility Interoperability Alliance that Microsoft and HP and others have initiated to try to extend this to a worldwide level, so that any screen reader you buy in Brussels will be compatible with a computer you buy in Boston or Beijing.

**Q: Regarding assistive technology in public places, how do governments and companies interact in the design and implementation of such devices?**

In the U.S., some funding comes from federal dollars earmarked for research, but a lot of design and development comes from within the disability community. Some funding and development come from just pure research. There are people in our HP Labs that are creating new products. There are third party vendors who are creating new products. It's just a matter of how you commercialize these things. There's a lot of government funding that goes into research for assistive technology, but the important thing to keep in mind is that this money shouldn't be spent on research for the sake of research, but should be spent on research that can be commercialized.

**Q: Is there legislation you would like to see implemented that can help companies when designing products for the elderly?**

With many other standards, there are objective measures for those standards. When talking about accessibility, it's very hard to create standards that regulate, say, the dimensions of tactile cues on a keyboard. You need to have some level of flexibility in the standard to account for the varying needs in the disabled and elderly communities. If I have 20 people with disabilities or age related limitations in a room and I put 20 of the same computer in front of them, and I ask them if the computer has tactile cues on the keyboard that they can recognize, you might have 12 of them who say "yes," 5 of them who say "no," and 3 of them who say "I'm not sure". The key is to provide standards that allow the IT industry to innovate and make products that are easy for customers to access and simpler for them to use.

**Q: How can we make sure that the elderly will be able to use these products?**

One of the biggest problems for an older user isn't so much accessibility as the fact that they don't have the proper training in how to use the product. I've seen many individuals purchase products and or assistive technology, become very frustrated with the experience because they didn't have the appropriate support and the appropriate training. Even with the simplest designs, people who are not used to using technology can become frustrated.

**Q: Generally speaking, how can ICT affect the lives of the elderly?**

Information and Communication Technology, or ICT, can have an impact in very significant ways. They can help you remember when to take your medication. They can allow you to do video conferencing with your doctor and to receive health services. When an elderly person goes into a hospital, they encounter a vast number of technological solutions and services that provide care for them. Looking at the connected home, at advancements in media technolo-

gy that allow older people to access video on demand or access video or the Internet from any room in the house, we see that technology has the ability to bridge generation gaps. It's easy for people who are aging or older to get disconnected. ICT gives elderly people the ability to communicate and to form communities. Interestingly enough, one of the things we are finding is that this generation of elderly is used to some level of electronic communication and their ability to communicate with family, with friends, and with their peers through the Internet is important to them. Access to news and information through ICT is also important to many elderly people.

**Q: What are some of the ethical concerns surrounding ICT and the elderly?**

The concerns that we've heard are that, obviously, as technology is changing very rapidly, it will put up barriers that will make it difficult for older people to use technology and access information. I think that advances in technology and information always vary between individual users, regardless of age. I think the problem is magnified and more profound for those who are aging because of the learning curve and because of the complexity of technology. I think the concern from an ethical standpoint is that we need to level the playing field; we need to break down the barrier; we need to build a ramp that affords them the same access to technology and information. I think then, the greater benefit to society is that you'll reduce health care costs; you'll have a greater availability of those experienced employees in the workforce who will be more productive; and you'll have a society that has a greater level of fulfillment than you would if people were excluded from the Information Age.

**Q: Are you saying that we have an ethical obligation to include the elderly in the Information Society?**

If you look at it from an economic perspective; if you look at it from a health care perspective; if you look at what society should be doing, I would say yes. We should have an inclusive society that does specifically consider the needs of people who are older or aging. This is especially important when you look at the changing demographics. The elderly are going to make up the majority of the population. As such, I think it's incumbent upon us to ensure that we include them in the Information Society. Even just from a business perspective, it's a smart thing to do; but culturally, if we don't include the elderly, we risk a pretty big divide not only across age, but also across socio-economic boundaries as well.

**Q: Do you think we will ever reach a point where, as a society, we've caught up with technology?**

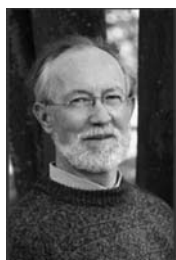
No. Technology is going far faster than we are capable of keeping up with. I think that's why we see accessibility as a process and not a destination. There are new technologies; there are new needs; there are new customer requirements and those will always continue to change.

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## Slow Medicine: Getting to Know Our Elders

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*Interview with Dennis McCullough*



*Dennis McCullough, M.D., has been an “in-the-trenches” family physician and geriatrician for thirty years. He is a graduate of Harvard College and Harvard Medical School, and trained in the Department of Family Medicine at the University of Western Ontario. Presently, he serves as a faculty member in the Department of Community and Family Medicine at Dartmouth Medical School in Hanover, New Hampshire. He is a member of the American Geriatrics Society, the American Academy of Family Physicians, the Society of Teachers of Family Medicine, and the American Medical Directors Association, as well as the coauthor of “The Little Black Book of Geriatrics” and author of “My Mother, Your Mother: Embracing ‘Slow Medicine,’ The Compassionate Approach to Caring for our Aging Loved Ones”.*

*Dr. McCullough spoke with us about the need to slow down and embrace the natural rhythm of aging:*

### **Q: What are some the major challenges families face as people age?**

I think the first one is understanding. Families have to begin to listen again to discover who their older family members have become. We get so caught up in our own lives that we forget that our parents are also maturing and changing. We have to get to know them well to help support them and help them make good decisions. So, I think understanding is the first thing. Another issue is financial interdependency. In the U.S., the safety net to help older people who need care giving is not strong. Families start to realize that their parents don't have enough money for something like an assisted living facility. Consequently, about 40% of middle aged people are helping support their parents financially and, at the same time, about the same percentage are supporting their children. I can't tell you how many people I know who are relocating to take care of their parents or having their parents come to live near them. So, suddenly, this becomes a very big part of your life. Today, there are people in their seventies still taking care of their parents in their nineties.

**Q: Can you give us a sense of what an elderly person may be feeling in terms of aging, health and life in general?**

I have learned through years of medical practice that older people in general want to look at the near future rather than the distant future. Those of us who are younger tend to think of longer term planning.

The elderly want to focus more on how things are going to be better today and how can they live the way they want to right now. Many will tend to avoid the longer term questions, which is why it's so hard to work out things like living arrangements.

**Q: What are some of the physical and mental things we experience as we age?**

There's growing physical frailty. All systems begin to decline. I can look at my skin now and see that it's thinner than it used to be. If I'm out in the garden and I get a little scratch, it becomes a real wound now. If you multiply that many times over, these are the things many older people are facing. They have less resiliency. It takes them longer to recover. Similarly, people find that their thinking slows down a little bit. There was an interesting New York Times article about how older people make decisions. Research suggests that older people make good decisions if you give them enough time. This article talked about research that looked at why it takes them more time to make decisions. The conclusion was that older people simply have more things to sift through in their memories and more experiences that may relate to the decision that they're about to make. They have more things to process than the rest of us. Processing a decision takes a longer time. But, if allowed that time, a good decision usually emerges. Having said that, though, we also must remain aware that 25% of people over the age of eighty-five are showing signs of brain disease that we would term cognition loss or dementia. By ninety, that number jumps to nearly 50%. We need to be on the lookout for these losses.

**Q: What are some of the emotional effects that accompany aging?**

One of the interesting things to me is that the emotional part of life is often times better in old age. There is less volatility. There is more of a sense of acceptance of change. Emotional and spiritual maturation are really what keep many older people going when their physical and mental capacities are in decline. They can see the bigger picture better than the rest of us. On the other hand, they can experience depression in response to social isolation. Depression also comes from processing all of the losses experienced along the way--loss of friends and family members, but also loss of hearing, eyesight, balance, etc. Overall though, older people are quite resilient. Sometimes, too, we label as depression that which is the natural grieving that comes with loss.

**Q: Can you explain what you mean by “Slow Medicine?”**

Slow medicine is directed specifically toward older people, people over seventy-five or eighty. It's meant to be a way of helping them to really understand more fully the range of choices that they have to make as life goes along. These choices can relate to housing, to driving, to medical problems, a whole range of things. The essence of the practice of slow medicine is to allow older people to take the time they need to make decisions and to understand things. This really involves being more patient, having family more engaged with their older member, listening carefully to their needs and concerns. It's meant to be an expansive idea and not something which limits choices in any way.

**Q: What is happening in our society that makes Slow Medicine necessary?**

In so many areas our societies have speeded up more and more. Yet, an individual elder's world gets slower and smaller. This is because, at a certain point, aging itself leads to some limitations. More than ever before older people are having to contend with a world which is moving faster and faster and focused more and more on efficiency. When we think of time, we think of time and money and efficiency. But, when I think of time in Slow Medicine, I think of using time as a way of better understanding a situation and of using time to allow older people to better adjust to and cope with situations they face.

**Q: Do you think, then, that the elderly are trying to adapt to our quickening world, or do you see a conflict between the pace of modern society and the slowing down that naturally comes with age?**

Older people are always trying to adapt, but there's a point at which they can no longer adapt easily. There comes a point where they don't have the capacity to absorb everything that's new and complex. What people seem to have the most trouble with are the automated systems, like receiving an programmed telephone call to remind you of an upcoming doctor's appointment. Many times, the older person is so stunned by the pace of the recording that they don't really hear it the first time and they don't have the time to respond to the call; they don't have an opportunity to ask a question. Many are ending up very confused by these systems. I think that as a society, we have to understand that adaptation cannot go on forever with aging. For example, when we become eighty, we might not be able to use the newest generation of computer, even though we might be very computer literate today.

**Q: Do you think that by encouraging elders to defy the limits of old age, we are adding stress to the human psyche and denying them an opportunity to fully experience old age?**

I think that there is less reflection time in our society in general. Fortunately, there's something about older age that begins to stimulate reflection. So,



when you look at the retirement period, for instance, people are talking about there being an early recreational phase. This period is followed by a non-recreational old age where one is much more limited physically. In this phase, one might focus on reading, thinking, being with people. There have always been some people who have lived to a very old age. What we're facing now is many more people who are living to older ages. I think those who age successfully are mostly happy and it's wonderful for all of us that we have more elders. It would be even more wonderful if we connected with them to understand what we could learn from them.

**Q: Do you think, then, there is a role for the elderly within the community?**

Very definitely. Older people really are remaining active longer and longer. We are seeing not only an extension of life, but an extension of a better quality of life. I don't think we've really drawn upon the talents and resources and presence of older people. There was a nice study done at John's Hopkins where they took groups of older volunteers and trained them to be teaching aides to schools. Part of the training was also to function as a team of older people; so there was a lot of social interplay between the team members as well as with the younger people. The other half of the study was the control group; they didn't work in teams. What they found is not only did the kids benefit from the tutoring that they got from the older people, but the health measures of all groups improved. These intergenerational activities are beneficial to both parties.

Unfortunately, we don't have enough of these programs. It's interesting to note that the biggest improvement in overall health was seen in the elder group that interacted with one another, the team that worked together.

**Q: How has the role of the elderly changed within the mobile society?**

Elders have banded more into peer groups. Friends substitute for family. There's a big movement in the U.S. to create neighborhood associations of older people, to bring in services to help them at home so they don't have to move. I've written about something called a Circle of Concern, people who are close to you and who care about you but who are not blood relatives. What's emerging here is that we turn more to our peers.

But, that ultimately changes some toward the end of life as families are once again called together to re-engage. There are clear migration patterns in the U.S. that show that people who move to a warmer or sunnier place for those recreational retirement years, are returning in large numbers when they enter their declining years.

**Q: How does the media's portrayal of the elderly effect the way in which we view elders in our own communities?**

A lot. We're very influenced by the media. An indication of good news is that if you track new cinema, there are more and more good films about older peo-

ple, and they're much more accurate than they use to be. They're not caricatures. Filmmakers must be noting that there is increasing interest in films about older people. For example, "The Savages" is a film about a brother and sister (one on the U.S. east coast one on the west) who have to help their estranged father as he struggles with dementia. Films like this are attracting younger viewers who are facing these sorts of dilemmas in their own lives.

**Q: Do you think that ICTs can contribute to or alleviate isolation?**

I think that's the great unanswered question right now. I have seen (and been surprised by) how some elders do very well with the sense of being connected, lets say, with an automated telephone call that checks on their blood sugar and blood pressure. On the other hand, I think that if it's a substitute for human contact and interaction, it's not going to serve people well in the long run.

**Q: What role do you think ICTs should play in the life of the elderly?**

Of course, there are so many different technologies. I think we should do everything we can to help older people maintain their sense of independence and their connectedness to other people. But, I think equally that we should not think that these are a substitute for somebody to stop by and hold your hand and have a cup of coffee. Touch is one of the things that older people talk about missing. When people are quite frail or bedridden, touch becomes an extremely important way for people to communicate, and I don't think that our technologies are ever going to replace that need.

**Q: In our desire for efficiency, do we often create technological solutions that fail to take humanity into account?**

I think so. I don't think we have yet come to realize that efficiency has some extremely negative aspects for elders. Making things go faster and faster and better and better from a speed, and efficiency, and a financial perspective doesn't take into consideration human needs.

I think this is a big problem between elders and medical systems right now. Medical systems are so focused on efficiency, with the objective being to move people through faster and faster and faster, that patients no longer feel the sense of human connection that is such a very important part of healing and recovery.

**Q: Do you think in general there's a problem with communication in the medical field?**

Yes. Certain kinds of information are communicated better and better through electronic medical records. But, the kind of information that's getting lost or is not being gathered at all, has to do with communication related to our thinking and finer judgments and differences of view and opinion. For instance, it's very hard to get specialists to talk to one another. And, there isn't someone

in the middle who's doing the balancing of different perspectives, who knows the older person well enough to help them make decisions.

I think that the push for efficiency is resulting in more and more testing and less and less thinking and reflection upon the results of tests. The U.S. system thrives on efficiency and excess utilization of technical services.

**Q: So, do you think that the cost of these high tech devices and the fact that we have these technical systems changes the way in which we treat the patient?**

I think so. We don't often look at the alternative ways of using our time and other resources. For instance, you can immediately get an MRI for an elderly person who has had a little dizzy spell. If you took that same amount of money you could provide care in the home so that they might not be declining so quickly and not need these repeated technological interventions. In the U.S., systems are set up to handle acute and emergency situations, but fail to allocate resources for preventing emergencies from happening in the first place.

**Q: What ethical issues are raised by the use of ICTs in the medical field?**

I think that the ethical issue is more one of neglect than intrusion. That is to say, by monitoring older people, are we neglecting other needs that they have? We're getting some information about them, but it's a limited kind of information. It's information about physical movements and what their activities are like, but we really don't have any more insights into their mental, emotional and spiritual lives.

Clearly, there are two sides to the use of ICTs. The good side is that, through monitoring, we are more aware and we can intervene when we see things happen to older people. But, monitoring must always be accompanied by human contact, so that we don't become neglectful. It's important to recognize that if you think that you can understand the complexities of your parents' condition by watching them from time-to-time on a home monitor, you're making a big mistake. You have to spend time together.

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## The Elderly in TV and Film: How an Actor Plays “Old”

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*Interview with Erik Passoja*



*A graduate of Yale University, Erik Passoja is a classically trained actor and a lifetime member of the Actors Studio. He recently starred in the Actors Studio West’s production of “Who’s Afraid of Virginia Wolf?” directed by Barbara Bain and has worked extensively in television and film. In addition to his film roles, Erik has appeared in episodes of “CSI”, “Charmed”, “Nash Bridges”, “Nip Tuck”, “V.I.P.”, and “Lyons Den”. He also played the role of Charles Manson in ABC’s “The Beach Boys: An American Family”. A voice over artist and nationally touring standup comedian,*

*Erik regularly tours colleges and universities throughout the U.S.*

*Mr. Passoja spoke with us about the elderly in the media and how he prepares to take on the role of an older person:*

**Q: In the past, how have the elderly been portrayed in both the theater and in television and film?**

I think the answer to that is: “every which way”. Citizen Kane was a lonely old tyrant who hid himself in an exorbitant castle. In “Whatever Happened to Baby Jane”, Bette Davis and Joan Crawford were feisty old broads who packed a wallop. “On Golden Pond” was about two people in the twilight of their lives. “Space Cowboys”, “Cocoon”, you name it.

I would say that the elderly have been respected in film, much more so than in life. In the real world, in the United States, the elderly are often marginalized, ignored, abused, and disrespected. You can’t get away with that in film.

**Q: Do you think that there has been an evolution in how we portray elderly people in the theater and in television and film?**

Not really. I think there has been much less of an evolution in how we portray the elderly than the evolution we’ve seen in how we portray people of col-

or. Just look at how African-American roles have evolved in the film industry compared to fifty years ago. The elderly have traditionally had pivotal roles in theater, TV, and film. So, I think we've made far greater strides in other areas.

**Q: Why do you think we are seeing so many films now with older characters in them?**

I think it's probably because the actors we love are getting older. Some of the greatest actors alive: Robert DeNiro, the Al Pacino, the Meryl Streep, Tommy Lee Jones, etc. are now in their sixties and seventies. These stars were the icons of our past and while they still have something to contribute, we still want to watch them.

The movies of the 1970's revolutionized motion pictures, and the decade was arguably the most transformational decade of film since the talkies came along. Many of the older actors now were major players in this era, and people still want to see them do their thing. I think the same is true for writers and directors. Think about people like Francis Ford Coppola or Martin Scorsese. They revolutionized cinema.

**Q: What would constitute an elderly character?**

Well, if you look at the dictionary, you'll see that "elderly" is defined as someone who is near old age. I assume that means someone sixty or older. So, an elderly character would then be someone sixty or above.

**Q: How do you prepare for playing an elderly character?**

How do "I" prepare? Well, I would become less energetic physically. In terms of technique, this means that I would do some serious relaxation as preparation. Sensorial I would create a few nagging injuries that would make it a bit harder to move, get up, sit down, etc.

I would absolutely work with my voice. Elderly people often have deeper or lower voices, with some cracking to them. I may make some modifications to posture. It really depends how "how" elderly the character is.

If we're talking about a character who is sixty-five, there are some minor modifications. If we are talking about a character who is eighty, there are some major ones. Above all, I would start talking to people around the age of the character I was playing and study these people very carefully.

**Q: Is there anything different you have to think about in constructing an elderly character?**

Absolutely. There are questions I would ask when playing an elderly character that I would never address when playing someone my age: do I have grandchildren? Is my spouse still alive? How many times have I been married? Do I have any old injuries that act up when it rains? What is my relationship with my grownup children/children? How often do I see them? Am I a veteran

(WWII, Korea, etc.)? These are all age specific questions that I wouldn't ask about a younger character.

**Q: Is background research any different for elderly characters?**

It is much more vital. If a character was blacklisted during the McCarthy era, then the actor has to study McCarthy and blacklisting. Somebody who was in the prime of their life in 1960 often has a much different sensibility than somebody who grew up in the '90s.

Right now, I'm playing a man who ranges in age from twenty-five to fifty-five, and the bulk of the story takes place in the '70s, so I have to know a lot about that era. If the character were eighty, I would have to know about many more eras.

**Q: Do you find that you are able to add more richness, more layers, to an elderly character than you might to a younger character?**

Not necessarily. I think the stereotype about the elderly is that they are "wise" and "deep". But just because somebody is elderly doesn't mean they are deep, or wise, or worldly. And just because somebody is young doesn't mean they are more superficial. It really depends on a character's nature and their life experiences.

A role like Hamlet has an incredible richness, multiple layers, and numerous contradictions, which have challenged actors for centuries and he wasn't old. On the other hand, look at "Grumpy Old Men" and you'll see quite a different type of character.

**Q: Have you seen any relationship between the elderly and technology being acted out on stage or in the cinema?**

In Albert Brooks' movie "Mother", his mom doesn't understand how to use her call waiting feature. In real life, I have noticed that many of my elderly friends have had challenges learning the ins- and outs- of the Computer Age.

In particular, they've had problems learning how to use their computers to enhance their productivity. I just heard a story about somebody who bought their grandmother a cell phone for her birthday. She talked on it and loved it, calling everybody in her family and talking for hours. A month later, she was outraged that she got a bill. She didn't understand. She said if a phone does not have a cord, why would there be a bill? So, clearly there are gaps for the elderly who are trying to come to terms with our technological age.

But let's look at the word "technology". The dictionary describes technology as the branch of knowledge that deals with the creation and use of technical means and their interrelation with life, society, and the environment, drawing upon such subjects as industrial arts, engineering, applied science, and pure science. So, looking at the interrelation between cinema and society, I can see that I am out of touch. In the '80s I knew exactly who Rob Lowe, Andrew McCarthy, Demi Moore, and Molly Ringwald were. Who are the analogous actors in 2008? I have absolutely no idea.



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# The Needs of Carers: Caring for Our Aging Loved Ones

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*Interview with Madeleine Starr*



*As Strategic Projects Manager at Carers UK, Madeleine Starr is an expert on the needs of carers. From 2002 to 2007 she managed the innovative Action for Carers and Employment (ACE National) partnership, which developed and tested support in and into paid work for carers. Madeleine recently represented Carers UK on the Employment Taskforce for the review of the National Strategy for Carers.*

*Ms. Starr spoke with us about the interdependent relationship the elderly have with those who care for them and the benefits ICT can present to both:*

**Q: Who are carers?**

Carers are people who look after partners, family or friends in need of support because of illness, disability or age. They are unpaid.

**Q: How will the changing demographics effect carers in the near and distant future?**

Well, we have more people living longer, more people potentially in poor health and more people living longer at home, so there will inevitably be a greater need for care, both paid and unpaid. And, of course, along side rapid population aging we also have more people living with disability and illness because of advancements in health technology. Disabled children who at one time might not have lived into adulthood now do. And again, because of the move toward greater independence and a high level of support at home, you have more people living at home with a long term condition. All of these elements mean a greater need for care.

**Q: What are some of the major challenges that affect carers?**

There are three major challenges that affect carers. They face financial disadvantages. They face health disadvantages; and they face social exclusion. Peo-



ple providing unpaid care, when they're providing heavy end care (more than 35 hours per week), are twice as likely than the general population to be in poor health themselves, as a result of caring. We know that there are significant financial disadvantages; very frequently people have to give up work and therefore give up their income. So, this affects not only their working lives, but it also affects their ability to put into the pension system. This creates a situation where carers themselves might go into poverty in their own retirement. There is quite a bit of research that has been done on this.

There are social exclusion penalties whereby people very often find themselves isolated. They are unable to participate in the normal activities of daily life because all of their energy is fixed on caring. They are not able to undertake any kind of leisure activity, they are unable to engage in learning activities, and they find themselves increasingly isolated and marginalized. Then, when they try to reengage either in the social world or in the workplace when their period of providing care has come to an end, they can find it to be very difficult. We have mental health issues related to carers who suffer from social exclusion. This can be a long term effect. In our experience surrounding carers returning to the workforce, they need quite a lot of reengagement activity (help with building confidence, motivation, etc.) before you even begin to look at workplace and skills. What is really interesting is that it doesn't really matter what level of skill or qualification that a carer had, from an executive to a manual laborer; the psychological and emotional impact was the same.

**Q: How do ICTs already help carers and what might be useful to them in the future?**

Well, there's a very direct effect that ICTs have on carers. For example, if we're talking websites, or computer based technology, at Carers UK, we have an information based website that allows carers to access information on a whole range of issues and it also links to related sites. We've also created a community of carers on line. We have a carer forum which is a place where carers can actually exchange experiences, compare frustrations, ask questions, etc. These types of communities are very popular and they exist throughout Europe. Getting information, I think, is probably the most straight forward example of how ICTs benefit carers. But, also creating social networks and opportunities and communities of carers where people can exchange experiences, exchange information, support each other, these are the other ways in which ICTs effect carers.

**Q: Are medical ICTs of use to carers?**

They absolutely help carers. We work with both telehealth and telecare advances. In telehealth systems, technology used to carry out monitoring of heart rate, or blood pressure, or blood sugar, can have a profound impact if you have someone, for example, who has an ongoing cardiac condition that would normally involve regular visits to the hospital. If that person is able to monitor themselves on their own, or through the help of a carer, then that cuts out a lot

of the need for face-to-face contact with professionals. There are great examples, too, of telehealth being backed up by webcam “visits” whereby health care professionals can follow up with patients through the use of computer technology. In this way, they can have a conversation with the person who is being monitored. There have been huge successes in this area. Of course, if you are reducing the anxieties of the person with the condition, you are inevitably reducing the anxieties of the person who is providing their unpaid care and also, potentially, freeing the carer up to do other things.

We know that with Alzheimer’s or in situations concerning people who are frail elderly, the ability in families to actually carry on their normal activities, can really be transformed by telecare monitoring. If you are able to tell not only when Mom has gotten out of bed but whether or not she’s gone back, for example, or if you have a sensor that lets you know whether or not she’s left the gas on, you are going to be more likely to be more comfortable supporting her to be independent and at home than you are otherwise. This is really what these devices are all about, alleviating anxiety for those needing care and those providing it. These solutions can be really crucial, particularly when it comes down to the decision about whether or not elders live with you or whether or not you continue to support them to live independently.

**Q: Regarding monitoring devices, what are some of the ethical concerns that people have voiced?**

The ethical concerns surround the issue of privacy, I think. When you’re looking at sensors that monitor people’s movements, either in and out of bed, in and out of a room, or even out of their own home you have to ask if that’s an invasion of privacy. Is it an invasion of privacy, for example, to know whether or not someone’s been in the shower?

It’s a fine line, isn’t it, between insuring that people are safe and interfering with the business of their daily lives? I think we need to look at the scale of what’s acceptable and what’s not, where it makes a difference between someone into residential care (when that is not their wish) or being able to remain independent; we have to put everything into context. We can argue that going into residential care is far more intrusive than an element of monitoring in your own home.

**Q: Ethically, who decides if ICT solutions like Smart Homes and monitoring devices are appropriate solutions for a dependant elderly person?**

In our experience, people are not wholly dependent or independent. They are interdependent. I think that realistically, these decisions are made by families. They’re made within relationships. It would be very rare for a decision to be made in isolation. For example, as a family, at the moment, we are very occupied in decisions involving the care of my parents. In recent years, our lives have really been transformed by their changing need for care. My dad is now in residential care and my mom has recently had to move to accommodations with a degree of telecare monitoring. We found that the decisions that we made were made very much together.

I think that we need to look at these decision in the context of people's real lives. On the whole, people don't live in isolation. I think that in reality people make decisions within relationships and I think that as such there is always that element of comparison, the weighing up of the pros and cons and the elements of intrusion or invasion of privacy against the real loss of independence if something goes badly wrong. I think the same is very true of learning disabilities, where you're looking at supporting the independence of young adults who might not otherwise live independently. You have to weigh up the use of monitoring devices and sensors with the loss of independence. In both cases, it's a very complex situation of setting up mutual benefit, looking at interdependence and at independence, looking at comparative benefit, looking at risks.

**Q: How can we take the needs of the carer into consideration while simultaneously ensuring that we are maintaining the dignity and privacy of the dependant?**

Both parties have rights. Both parties have human rights. I don't think that you can look at the rights of one group over the rights of another. It's important to look at the interrelationships and interdependencies of relationships and to ensure that services provided are appropriate for both parties. We can't make assumptions about what people need. The personalization agenda means that people are being asked what kind of services they want. The issue becomes about want as well as need, which is perfectly legitimate. What I think is most important is that you don't replace the rights of one group above that of another and that needs are assessed in context, so that you are looking at the needs of the family, the needs of the relationship, household needs, friendship groups, etc. That seems to me to be common sense, really.

**Q: What happens when a decision is beneficial to the carer but is not wanted by the dependant or vice versa?**

I think that does happen. Not all interdependencies are positive. Sometimes a decision might be taken for the benefit of one party over another. I wouldn't deny that that happens. There is no such thing as the perfect family or the perfect caring relationship, but I think on the whole these decisions are made looking at mutual benefits. I think that interdependency is positive.

**Q: Is there a need to educate carers in the use of ICT?**

First of all I think that there needs to be a really good awareness about what's available in terms of telehealth and telecare options. When there is a need for support, it is likewise really important that dependents and carers have access to that kind of learning. We do have examples of courses being developed for professional care workers in the use of technology and those courses may be extended to family members. But, I don't think that people are aware enough of what the opportunities might be.

In the UK right now, communities are really being sensitized to social ICTs and

familiarized with their use. This is being done in a very accessible way, for example, internet access through the TV rather than computers. Many people feel more comfortable accessing the internet through their remote control rather than through a computer. Once they've gotten over their hurdles and the community has helped them access the internet, then they have a whole world of information open to them.

**Q: What have been the results of these initiatives?**

Kent County Council in the UK has been leading this project on digital access and the up take has been enormous. It's very clear that good information, good support, and good access has had significant results. There's also been training of district nurses and community nurses to work with families who might not be using telehealth and telecare solutions to engage them in looking at how they can use these solutions and to help with educational support. In this way, take-up is bound to happen.

I heard a presentation recently from some Kent users of telecare who were a very ordinary bunch, middle aged people with heart conditions, older people with long term conditions, there was at least one who reported that telecare had transformed their lives.

**Q: How are ICTs helping carers cope with their roles?**

Well, obviously, if you're looking at telehealth and telecare applications that make life easier for the person being cared for, it will also have an impact on the carer. If you have ICTs which actually facilitate the activities of daily living, you've just made life easier and that will have a similar effect on the carer. We've heard reported, also, that there has been a significant decrease in the number of hospital admissions as a result of telehealth monitoring. That's a really significant outcome. Hospital admissions are dreadfully stressful. There is evidence that suggests that telehealth monitoring has reduced cardiac admissions by as much as 75% a year, which is an extraordinary outcome.

There are also systems in place where when someone pushes a panic button they are put through to professional call centers where professionals can judge whether or not a problem is a medical emergency or something which could be dealt with more easily. With these systems you have a win-win situation whereby you are saving someone from emotional and financial stress and whereby you also have cost savings to the health services industry as well.

I think people are accepting that an investment in telehealth and telecare services is positive. It doesn't replace the need for professional care, or for human contact because that is obviously quite important, but it is helping people live independently.

**Q: What are some of the drawbacks of ICTs as they relate to the elderly or to the carer?**

Obviously, the elderly are rather anxious about using technology that they may not be familiar with, this is true also for the carer. I also think that there is

genuine fear that technology will replace people. We hear this argument a lot, that ICTs are a move on the part of Health Services to save money on people. But, ICTs aren't designed to replace people, they're designed to complement them. In fact, there are actually wonderful ICT products that allow you face-to-face contact where you might not have it. For example, there is a project going on in Australia where careers and families can communicate over really quite long distances with people in rural communities. With these ICTs, they can also have face-to-face contact with health care professionals. It is important that frontline professionals, community care workers, in particular the ones who are doing this stuff on the ground with people in their homes, have the right kind of training to support families in their use of ICTs.

**Q: What are the ways in which ICTs can or cannot replace the carer?**

I don't think they are a replacement. I think they are a compliment to the carer. When we're looking at telecare monitoring, if sensors make it possible for people not to be there, that doesn't mean that they remove themselves from the care of the person that they're concerned with. It just means that they're not there for a specific period. So, for the husband of a young woman with epilepsy, installing a monitoring device doesn't mean that he is not involved in her care thereafter, it's just that with the monitoring, he was able to go to work, which was beneficial to both of them. So, there's something about that balance between wanting to get on with your life without a million people coming in and out of your door or without being in hospital or residential care, and still having human contact and contact with professionals who could be reassuring and competent about managing your care. But, I don't think that any form of care, whether it be telehealth, telecare, or a professional care giver who comes in a few hours a day, can replace the care given by the family or by a partner.

**Q: What do you think that policy makers can do to make people aware of ICT solutions that benefit to carers and the elderly?**

They need to really pro-actively promote them in places where people will get the information they need. Obviously you need national drives and various financial commitments. The UK has funded telecare pilots in every local authority area. But, all these initiatives are only as good as the community support behind them, the frontline professionals, the people who are actually meeting the public in their homes, etc. I think too, that general practitioners, as the first port of call, have a massive role to play in helping people to access information and technology. Also, I think we should normalize ICT. I don't think we should confuse, particularly with older people, "ICTs" with computers. We're talking about a lot of ICT applications which aren't about computers, but if you say to my eighty year-old mother "computer" she says she would never use one. But, she actually uses quite a lot of complex things in her life, she just wouldn't call them "ICTs". So, I think there is something here about promoting these things to people in their own language and actually using portals, or access, which is

familiar. I am a huge fan of using internet access through the television because you get over so many hurdles with older people.

**Q: Do you think that policy makers also need to educate doctors and hospitals about available ICT products?**

Absolutely. My Dad had a long term heart condition for many years and not once in all that time did anyone suggest telemonitoring, and yet it would have reassured him enormously. And, we're not alone, are we? We're just an example of an average family. I think that doctors and hospitals have a very big part to play in educating the public about what devices are available to them. My feeling sometimes is that telehealth and telecare are promoted as being about social care, as a way to promote independence, and as a preventative public health agenda, but not 'landed' in health services or promoted through them.

**Q: Do you think that as the number of elderly increases, more jobs will be developed within the professional care sector?**

It's going to have to. When you look at the demographic projections, it would be very surprising indeed if we were to manage with our aging population and the increasing numbers of people with long term disabilities. However, we feel quite strongly that the care market should be stimulated in a very particular way, not by assumptions made by local authorities about what the population might need, but actually through the demand of individuals and families for particular kinds of service. We're hoping that future projects will take into account the individual even more and that this will stimulate a different kind of care market.

I do think that ICT has a real role to play in all of this. We know that care workers do incorporate the use of monitoring systems and telecare systems. We're quite interested in looking at how ICTs might actually support workers themselves. There are some examples where care workers are using ICTs quite creatively to build up a bank of knowledge, or to monitor a group of clients, or a situation where different care givers are sharing clients and thus they swap information. We do have an example of training courses being provided to care workers so they can support the use of ICTs by clients. So, I would say yes, we would envisage a care market forming in response to demographic change and one would hope that ICT would be a part of that.

It's interesting that we accept all the extraordinary technological advances in medicine, thinking about heart transplants and things like that, but we get worried about telehealth and telecare. If someone is in the hospital and being monitored, that's alright, but we don't seem to be able to accept that level of intervention at home. I would argue that there isn't really an awful lot of difference and I think that what we should be looking at is the ultimate benefit to the person in terms of increased independence and quality of life. I would take a bet that for an awful lot of people, they would rather continue to be independent with the help of some kind of technological invasion than to be living in a residential home or totally dependant on others.



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## Contributing Seniors: the Contributions the Elderly Make to Society

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*Interview with Renée Coen*



*Ms. Renée Coen is an expert in the field of aging. She is currently Manager of the NPO “Espace Seniors”, a continuing education service for seniors of the Belgian socialist sickness funds. In addition, she is the vice-president of the Coordination of the French-speaking Associations of Seniors. In the early 70’s, Ms. Coen co-founded three Family Planning Clinics “Aimer à l’ULB”, “Leven met twee” at the VUB and “le Plan F”. She also took part in setting-up the Belgian chapter of the non-governmental organization*

*Doctors of the World.*

*Ms. Coen spoke with us about the contributions the elderly make to society and what the European Union can do to keep them active in today’s Information Society:*

### **Q: How do you define “elderly?”**

There are huge differences within the senior population. What we tend to do is, we tend to look at younger and older seniors. Among our numerous activities, we train the younger seniors to help older seniors, their parents in particular. There are a great deal of mental and physical illnesses present among older seniors, which cause them to become dependent. As people are tending to live longer and longer, we are seeing that younger seniors can, and are, helping the older ones. We train them, the younger seniors, in how to interact with older family or friends to make the relationship successful and fulfilling for both parties. It is important for me to note here that, in general, in today’s society, I believe that people who are not productive are put aside, and in the end are marginalized. What we at Espace Seniors believe is that it is not only ethically problematic to marginalize these people, but that the assumptions that lead to this marginalization are often times false. We believe that the older population has an immense potential in our societies. Society should be more aware of this potential and give the elderly more opportunities to do useful things, to stay active in society. There are, in reality, so many things that can be done.



**Q: What sort of initiatives do Espace Seniors implement to keep the elderly active in society?**

We primarily initiate continued learning, social, cultural, sportive and leisure activities. We consider lifelong learning to be fundamental. But more interestingly, and what is more important to us, are our cross generational projects such as training for volunteers to become "storytelling grannies granddaddies". The objective is for the elderly to visit hospitalized children and tell them stories. We have been training hundreds of storyteller grannies.

Another training we provide is the so called "Troubadour" training. We teach the psychology of older people to younger people, to train them in how to relate with the elderly population. Then they make weekly visits to nursing homes for elderly people and read books to them, or news from the news papers, or just interact with them so that even those who do not get visits from friends and family can feel more social. We have more than 90 volunteers for this work. But more importantly they all have meetings with a psychologist, who meets with these Troubadours to exchange ideas and analyze what experience they had each week, and what might still be improved. We found that both the Troubadours and the elderly who receive this service became interested and active in this mutually useful and helpful activity. So our main goals are to gain recognition in society, to bridge the social divide.

**Q: Why did you chose to work with the elderly?**

It is an interesting question. I am a psychologist, I used to work in family planning and I have always been touched by older people. I don't really know why. Maybe because I was raised partly by my grandparents. In general, I've always wanted to work with and help people who are not taken care of by society, people who are in one way or another marginalized.

My main life motivation is to help living beings who cannot defend themselves whether they are children, women who have been abused, old people, or even animals. My concrete work with older people appeared because I felt I could really help. Trying to contribute to a better integration and recognition of the elderly is a cause that can contribute to a better society and better the lives of people, both old and young. So my main aim is to create a win-win situation for everyone.

**Q: Do you see a great deal of collaboration between your organization and EU policy making bodies?**

I think the collaboration could really be improved. I think it's important that the EU work with the senior population and not simply about them. One thing that would help would be for the EU to make things simpler, to make things less bureaucratic. Also, I think that the EU needs to not only help with funding projects, but also with promoting projects and opening them up to the public. In this way, EU projects can help encourage others at the national and community level to become involved as well. This is one of the main issues. I think what

the EU should do more of is to contribute to making good practices that are simple and accessible to those they concern.

We actually were involved with a very simple and effective project with the EU some years ago. We had a very interesting transnational exchange project where Belgium, Greece, the UK, France, Germany, and Holland took part. There were exchanges with about twenty-five volunteers, whereby volunteers from one country went to work in another. We sent our storytelling grannies and granddaddies abroad. It was a great project because each nation was able to learn from the experience of another; this is very important, to be able to learn from one another. These are the sort of projects the EU could arrange.

**Q: So you mean you would like to have more exchange of ideas?**

Yes, exactly. There are lots of good projects in other EU countries and it would be wonderful to share these experiences in the context of the elderly. For instance two or three years ago I went to France to talk about our project on training the Troubadours. People were there from elderly associations throughout Europe and even Israel; they all said that the project was so simple and so good that they wanted to implement similar projects in their own countries. We need more of these types of exchanges within the EU, simple meetings where we can see what's happening in other parts of Europe and implement good ideas at home. These types of projects do not cost much at all and the benefits are tremendous. This is what I think that I would like to emphasize regarding the EU. There should be more initiative on the exchange of ideas and ongoing projects between member countries.

**Q: What do you think the role of the elderly will be in the market oriented world regarding technology and ethics?**

Well, normally, marketing is designed to make you feel that you need a certain product, even if you do not actually need it. I don't think that this is very ethical. I think it's always more important that people feel good about themselves than that they have a particular product. Regardless, I think that companies need to create more products that are elderly-friendly, products that are easy for the elderly to use.

**Q: What does 'being ethical' in the society mean to you?**

For me, to be ethical is to be honest with myself and with the others, and not doing anything that I would not feel good about. Even if no one will ever know that I did it. This is very important to me in my relationships with others as well. So, if we would all take ethics seriously, we would be living in a much better society.

For me, it is ethical to allocate funds to developing countries. It is ethical to respect nature and all human beings. It is ethical that we treat animals in a kind and compassionate way. Of course I do not say that I never tell a lie, but I try not to. Every time I interact with another person it is very important to me that

we both feel good about the interaction. The basic issue is to take care of oneself and if you feel good about yourself then you can take care of others. So, people who are sacrificing themselves are probably not able to take very good care of other individuals. We need to take this into account when thinking about carers and to make sure that we provide them with the support they need.

**Q: What are your views on the relationship between the technology and the human being?**

Well, even to set a radio alarm clock is so difficult nowadays. They create so much complication over such a simple thing. A radio with an alarm clock, and you need a big booklet to understand how it works. So, for me, I think that technology should be made accessible – accessible for everyone, including elderly people. Technology for me is neither good or bad, it depends on how you use it. If technology is used to exclude, which is happening at the moment, clearly that's a bad thing. Technology needs to include people, not exclude them. That is why we are actively organizing cell-phone lessons. You just cannot imagine how happy these seniors are when they learn how to use such technology.

It is important to learn at any age. We collaborate with the University of Third Age, and it is incredibly nice to see how people at age of seventy and eighty are studying English, Russian, German, even Chinese. It's very exciting. We need to keep this in mind and make sure that, as new technologies are introduced to the market, we are providing the elderly with the support and education they need to take advantage of these technological advancements.

## **FINAL REMARKS**

*Emilio Mordini, Coordinator of the Senior Project,  
Director of the Centre for Science, Society and Citizenship*



We began with only one certainty: our societies are aging. Throughout what has hopefully been a pleasant journey among experts' opinions on aging, ethics and Information and Communication Technology (ICT), we must confess that we are perhaps more confused now than when we began. We know that our societies are getting older, but we are still left with an obtuse idea of what "aging" actually means.

From time immemorial the human species has revered longevity, prized youth and sought eternal life. This quest for life everlasting is reflected in our religions, our literature, and our mythology. From Achilles' bath in the pool of immortality, to the Biblical Noah who reached 950, to the illusive fountain of youth, man's desire to reach eternity is as evident as it is impossible. That being said, however, we cannot deny the fact that, today, we are living longer than ever before.

Twenty percent of all human beings who have ever lived past the age of sixty-five are living today<sup>83</sup>. But what makes someone old? Typically, chronological age has been the determining factor in deciding when old age begins. If we look at this definition, then we must concede that old age commences somewhere near the end of the life cycle. Consequently, as life expectancy increases, so too should the markers of age. At the end of the 19<sup>th</sup> Century, the average life expectancy in Europe and North America was fifty<sup>84</sup>. This would hypothetically place old age somewhere near forty-five. Today, the life expectancy for most Europeans is between seventy-nine and eighty<sup>85</sup>. What, then, becomes "elderly"?

If we cannot look to chronology for an answer, we might look to the body instead. However, here too we fail to find stanch markers that would indicate a clear metamorphoses into old age. Unlike puberty where specific changes in the body mark a distinctly different phase of life, there are no such distinct markers to indicate a cross over into the category of "elderly". This is true of not only of human beings, but of the entire primate world at large<sup>86</sup>. Regarding the human species, it has been declared that "there are no diseases particular to old age"<sup>87</sup> and nothing radical to indicate that one has become old.

Perhaps part of the problem, then, of defining what makes someone "elderly" is the fact that certain social markers of age have changed. When the retirement age was originally set at sixty-five, the life expectancy was still fifty. As the life expectancy began to surpass the retirement age, retirement then became a marker of old age, a time when people are theoretically expected to enjoy their last few years of life<sup>88</sup>, but that is always on the verge of becoming a dreadful and meaningless social limbo, which only preludes death. Today, this limbo tends to expand and there is often a wide gap between retirement, which generally takes place between sixty and sixty-five, and death, which usually occurs

<sup>83</sup> <http://www.trinity.edu/~mkearl/ger-biol.html> Accessed 23 Oct. 2008.

<sup>84</sup> <http://eng.newwelfare.org/?p=314&page=2> Accessed 23 October 2008.

<sup>85</sup> <https://www.cia.gov/library/publications/the-world-factbook/rankorder/2102rank.html> Accessed 23 Oct. 2008.

<sup>86</sup> See Augusto Vitale, "Aging in Monkeys: How Primates View Their Elders" in this book

<sup>87</sup> Worcester, Alfred as quoted in <http://www.trinity.edu/~mkearl/ger-biol.html> Accessed 23 Oct. 2008.

<sup>88</sup> <http://eng.newwelfare.org/?p=314&page=2> Accessed 23 Oct. 2008.

much later. This gap has caused the division of old age into the categories of “young elderly” and “old elderly”.

The concept of age has three different components:

1. *Chronological age*: age measured by the time (years and months) that someone has existed.

2. *Biological age*: measurable changes that take place in us all as we age. They cover a wide variety of measurements. Some are simple, such as the changes in eye-sight, hand grip strength or the thinning of the skin. Others are more complex, such as measuring lung capacity and force, or blood work to see the changes in various hormone levels. These measurements are called biomarkers.

3. *Social age*: a way of grouping people based on particular roles, cultural experience, performances, social networks of belonging, etc. All societies possess some tacit norms for determining social functions.

Chronological age is due only to a social convention, that is the way in which any given society measures time. Biological age results from physiological changes whose internal clockwork remain still largely unknown, although we know that it can be set and altered by quite a number of factors, ranging from genetic influences to diet, exercise, and environmental conditions. Finally, social age depends on a series of age-graded roles that we fulfil both simultaneously and sequentially. Each role has its own social clock for adjudging the age-appropriateness of various role performances, such as the “right” time for getting married, starting a family, “peaking” in one’s career, retiring, and so on.

Chronological, biological, and social ages tend to remain synchronised within the same culture. Yet periods of social changes are always characterised also by a gap between the different definitions of age. Starting from the seminal work of Philippe Ariès, much scholarly work has been devoted to the birth of childhood in the West. Childhood is a very new concept. It did not exist at all in the Medieval period; it grew into existence in the upper classes in the 16th and 17th centuries, solidified itself in the 18th century upper classes, and finally flourished in the 20th century in both the upper and lower classes. To be sure, no one claims that before the birth of the concept of childhood there were no young people. Rather, young humans between the ages of 7 and 15 were not seen as children, but as little adults. European civilization knew only babies and adults. Childhood – say, a period in which the young human learns cultural norms and begins to reflect them – simply did not exist as a social role. The birth of childhood was then a byproduct of the great social, political, philosophical and scientific turmoil, which characterized the passage from Middle Age to Modernity.

Similarly, the invention of adolescence was a result of the late industrial revolution, which required a longer educational and training period before starting working. For centuries, human cultures have celebrated rites of passages into puberty, which also marked the entrance into full and autonomous adulthood. Never before was a sexually mature person was treated as a “growing child” and remained under parental supervision. On the contrary, since the mid-1800s, the advent of sexual maturation has been increasingly followed by a further period living under parental authority, say, a period of time between childhood and adulthood. This period has been conceptualized as an “extended puberty”, as a period of socialization of the youth, in which education should reg-

ulate the lives of the young in carefully organized institutions of formal education. Adolescence was then progressively described as a particular stage of life with precise age parameters, developmental possibilities and social requirements (for instance, juvenile “rebellion” is the obvious consequence of this period of mid autonomy and dependence, in which the youngster feels to be an adult but is still requested to live as a child). More recently, social changes have generated a new gap between chronological, biological and social times, say, a new period of time between adolescence and adulthood, characterized by the fact that young adults tend to prolong endlessly school and training periods, live at home longer, postpone marriage, and, generally speaking, postpone the entrance into traditional adulthood. Researchers, sociologists and psychologists speak of a new phase of life, “youthhood”, or extended adolescence, which starts with the end of traditional adolescence (around eighteen) and tends to last until the thirties. This extended adolescence is increasingly solidified by the economic decline and jobs displaced by technology.

These radical changes in the social construction of younger ages have been mirrored by similar changes in the social construction of older ages. For centuries, one entered into the elderly role when his body was too weak to put up with daily working. The elder was by definition someone who was hardly able to make his living alone and should rely on the family, the tribe, or the enlarged community, to survive. In his turn the elder could contribute to social life through knowledge and practical wisdom accumulated during his life. This scheme was increasingly challenged by industrialization, by the general change in working conditions, and automatisations. Two events characterise the current ageing processes: the naissance of an extended middle age applying to the post-65 age group (which could be called the “third age”) and the creation of a “fourth age” (older senior citizens).

The term “middle age” was a concept popularised in the 1960s to indicate a grey area between adulthood (30-40 years old) and retirement (affecting those 60 years and older). “Extended middle age” is now the term commonly used to indicate a continuation of this period but a change in circumstances (e.g., retirement). During extended middle age, the main physical and mental abilities remain almost unaltered though the person is gradually forced into the role of the senior citizen. For many in this group, who have often been referred to as the “young elderly”, ICT could play a substantial role in their every-day lives. Many of them are using the internet to make travel arrangements, shop, or keep in touch with loved ones. They are talking on mobile phones, and using a vast array of everyday electronic devices. Progress in the field of ICT has allowed many young elderly to remain in the workforce longer, to participate in social and political life, and to overcome barriers, which tend to force them into the elderly role. Yet, paradoxically, among these barriers one could find ICT itself. ICT has become an essential instrument in conducting business, communicating, and interacting in today’s world. More than 250 million Europeans regularly use the Internet<sup>89</sup> and more than 2 billion people worldwide use mobile

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<sup>89</sup> <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/605&format=HTML&aged=0&language=EN&guiLanguage=en> Accessed 24 Oct. 2008.



phones<sup>90</sup>. It can easily be said that computers and the world wide web are a major part of today's work environment. If people are computer illiterate, if they are unable to use a keyboard, or unable to see a monitor, if they cannot access the Internet, or are confused by things like flashing banners, pop-up windows and small font sizes, their business perspectives may be limited. If the buttons on a mobile phone are too small for people with dexterity problems, their communication options are limited. If people do not know how to surf the net, they are limited in terms of their ability to access goods and services available solely on line. These limitations are disabilities in today's world. As such, we can say that as much as technology can help the elderly overcome disabilities, it can also create them. Thus, technology presents us with a conundrum. On the one hand it can extend the lifecycle and allow people to participate in society for a greater period of time than ever before. On the other hand, it can also be a barrier to participation within society.

The "fourth age" applies to older senior citizens, people in their eighties and nineties. In this period, practically all people show substantial losses in physical mobility and cognitive functioning. Gerontologists often refer to these changes as increasing frailty<sup>91</sup>. Frailty is a crucial concept in late ageing<sup>92</sup>. Those who live to an advanced age will probably face it soon or later. Frailty is not really a disease but rather a combination of the natural ageing process and a variety of medical and social problems. ICT may address frailty in many ways. Memory assistance, robotics, neuro-ICT interfacing, navigation systems, speech, sign and movement recognition, ICT for social networking, alternative communication environments and virtual worlds, are all example of ICT which can effectively contrast frailty. Technology allows people to live longer and longer, although it cannot revert the arrow of time. This could remind us of the Greek myth of Tithonus, a handsome shepherd who became the lover of Eos, the dawn. Eos kidnapped him and asked Zeus, the kings of all gods, for Tithonus to be immortal, yet she forgot to ask for him eternal youth. Tithonus indeed lived forever "*but when loathsome old age pressed full upon him, and he could not move nor lift his limbs, this seemed to her in her heart the best counsel: she laid him in a room and put to the shining doors*" (Homeric Hymn to Aphrodite). Out of metaphor, we see that the great ethical challenge that ICT for ageing poses in this class of senior citizens concerns their visibility. In this case

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<sup>90</sup> <http://www.umsl.edu/services/govdocs/wofact2007/geos/xx.html#Comm> Accessed 23 Oct. 2008.

<sup>91</sup> According to gerontologists, a person should be considered frail when at least three of these factors are met:

- unintentional weight loss (five kg or more in a year),
- general feeling of exhaustion,
- weakness (as measured by grip strength),
- slow walking speed,
- low levels of physical activity.

<sup>92</sup> Fried, Linda P., Catherine M. Tangen, Jeremy Walston et al., "Frailty in Older Adults: Evidence for a Phenotype", *Journal of Gerontology: Medical Sciences*, Vol. 56a, No. 3, March 2001, pp. 146-157.

[http://biomed.gerontologyjournals.org/content/vol56/issue3/#JOURNAL\\_OF\\_GERONTOLOGY\\_\\_MEDICAL\\_SCIENCES](http://biomed.gerontologyjournals.org/content/vol56/issue3/#JOURNAL_OF_GERONTOLOGY__MEDICAL_SCIENCES)

visibility and inclusion largely overlap. Out of sight, out of mind tells an old saying, which is particularly true in this case, where technology can be used to hide the elderly. There is indeed something obscene, or psychologically unbearable, in the sight of an older person, who is becoming increasingly frail, who is losing his mental and physical abilities, until the point of not being able to take care of himself any longer. Only a compassionate gaze, which is able to take on itself the weakness of the other, can put up with the view of human frailty, when it becomes so extreme. But is our society still able to withstand such a gaze?

As Adam Greenfield puts it in this book “there are many tasks in the context of elder care that are either too dirty, too dangerous, or too dull for many people to want to do”. Here technology plays a pivotal role and finds its scope, but also may become the sophisticated equivalent of the room where the Goddess of the Greek myth buried the old Tithonus. In other words, technology could create a dispersed, decentralized, system of “individual nursing homes” where the older oldest are destined to spend their last years of life, segregated by the human community, isolated into a technological prison made up by electronic bracelets, wireless sensors, networked communication, automatic supervisors, and robotic companions. This would not be acceptable. It is imperative, if we are to maintain an inclusive society, that ICT cannot be used to replace human contact and human relationships, to hide those people that we prefer not to see because of their physical or mental conditions. We cannot abandon the elderly – no matter how much older they are – to technology. Older senior citizens are facing the last years of their lives. New technologies may offer a way to extend their lives in a more comfortable, more dignified condition. Yet it should be clear that there are some questions concerning life and death that do not admit a technical fix: do we intend to address the needs of senior citizens or do we use technologies for making the elderly, and with them some basic questions about life and death, disappear from our horizon?

The challenges posed by including the elderly in the Digital Society require a multidisciplinary and pluralistic approach. This book has been a contribution in that direction. We would like to thank the European Commission for having given us the opportunity to write it. In particular we thank the Directorate General Information Society and Media, and Commissioner Viviane Reding, who had the kindness to write the preface of this book, Paul Timmers, Head of the ICT for Inclusion Unit, who has believed in the importance of investing time and resources on the ethical, social and policy issues of e-Inclusion, and the project officer, Silvia Bojinova, who is daily supporting our efforts.

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## **SENIOR**

### **THE SOCIAL, ETHICAL AND PRIVACY NEEDS IN ICT FOR OLDER PEOPLE: DIALOGUE FOR A ROADMAP**

**A project funded by the European Commission FP 7 - Research area: ICT-2007.7.1 ICT and ageing**

Website: <http://www.seniorproject.eu>

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- Vrije Universiteit Brussel, Belgium

**SOCIAL, ETHICAL AND PRIVACY NEEDS IN ICT FOR OLDER PEOPLE: DIALOGUE for a ROADMAP (SENIOR)** is a 24-month support action which aims to provide a systematic assessment of the social, ethical and privacy issues involved in ICT and Ageing, to understand what lessons should be learned from current technological trends, and to plan strategies for governing future trends.

*The SENIOR contribution to policy implementation is twofold. First, SENIOR will describe the ethical and privacy impacts of ICT for inclusion. This objective will be achieved through a series of thematic expert meetings. Each meeting will (i) define ICT systemic solutions and technology trends, (ii) discuss relevant ethical and privacy issues and (iii) weigh the trade-offs between privacy, ethics and technological innovation. Second, the project will identify ICT services and solutions that avoid exclusion and promote inclusion of senior citizens and will develop a roadmap showing how ethics and privacy principles could be incorporated in technology design. The roadmap will set out key actions, investment strategies, resource requirements, risks and milestones.*

*The main outcome of the project will be a Roadmap (to 2020) that is expected to drive future development and deployment of ICT for ageing in Europe.*

