

DELIVERABLE D4.1

Report on Best Practices and Roadmap towards the Roadmap



SENIOR PROJECT

Project co-funded by the European Commission FP7

Contract: 216820

Co-ordination and Support Action (CSA)

Start date of the project: 1 Jan 2008

Duration 24 months

2009

Deliverable:	D4.1
Title:	Report on Best Practices and Roadmap towards the Roadmap
Due date:	31 December 2009
Actual submission date:	12 November 2009
Lead contractor for this deliverable:	TRILATERAL RESEARCH & CONSULTING LLP
Contact:	david.wright@trilateralresearch.com
Dissemination Level:	PU

WWW.SENIORPROJECT.EU

THE SENIOR PROJECT

Social Ethical and Privacy Needs in ICT for Older People: a Dialogue Roadmap

Report on good practices in e-inclusion, ethical guidance and designing a dialogue roadmap



Senior Deliverable D4.1
November 2009

Prepared by David Wright
Trilateral Research & Consulting LLP, London
Contact: david.wright@trilateralresearch.com

All rights reserved.
© 2009 SENIOR Project
<http://www.seniorproject.eu>

Contents

1	Introduction – Good practices in e-inclusion	6
1.1	What are good practices?	6
1.2	Value of good practices	9
1.3	Selecting good practices	10
1.4	Disseminating good practices	12
1.5	Linking strategies and good practices	14
2	Examples of good practice in e-inclusion.....	15
2.1	SignVideo – a video interpreting service for deaf people.....	15
2.2	Digital story-telling in Sweden as a tool for e-inclusion	18
2.3	Internet Bus & Net Squares - Tampere City Library (Finland)	22
2.4	Creating a digitally and socially inclusive city – Milton Keynes, UK	25
2.5	Seniornett – Training in ICT and e-inclusion for elderly people in Norway	29
2.6	RoboBraille – Danish Centre for Visual Impairment	32
2.7	The Tiger Leap programme, Estonia	35
2.8	Ethical guidance on use of wandering technologies in Scotland.....	38
2.9	Accessible communications for people with disabilities – France Telecom Orange ...	41
2.10	Eldy – free software for senior citizens	43
3	Ethical guidance for e-inclusion	46
3.1	Introductory remarks.....	46
3.2	Ethical principles	49
3.3	Respect for autonomy (right to liberty)	49
3.3.1	Dignity.....	50
3.3.2	Informed consent.....	51
3.4	Nonmaleficence (avoiding harm)	53
3.4.1	Safety.....	53
3.4.2	Social solidarity, inclusion and exclusion	54
3.4.3	Isolation and substitution of human contact.....	55
3.4.4	Discrimination and social sorting.....	55
3.5	Beneficence.....	56
3.5.1	Universal service	56
3.5.2	Accessibility	57
3.5.3	Value sensitive design	58
3.5.4	Sustainability	59
3.6	Justice.....	59
3.6.1	Equality and fairness (social justice).....	60
3.7	Privacy and data protection.....	61

3.7.1	Collection limitation (data minimisation) and retention	61
3.7.2	Data quality	62
3.7.3	Purpose specification.....	62
3.7.4	Use limitation	63
3.7.5	Confidentiality, security and protection of data	64
3.7.6	Transparency (openness).....	64
3.7.7	Individual participation and access to data.....	65
3.7.8	Anonymity.....	66
3.7.9	Privacy of personal communications – monitoring and location tracking ...	67
3.7.10	Privacy of the person.....	68
3.7.11	Privacy of personal behaviour.....	68
3.8	Ethical tools	69
3.8.1	Process.....	69
3.8.2	Stakeholder engagement and consultation	70
3.8.3	Risk assessment, uncertainty and unintended consequences	72
3.8.4	Accountability	73
3.8.5	Third-party ethical review and audit	74
3.8.6	Providing more information and responding to complaints.....	75
3.8.7	Good practice	76
4	Designing an e-inclusion (dialogue) roadmap.....	77
4.1	First stage – Setting objectives and analysing the existing situation.....	77
4.1.1	Social aspects	78
4.1.2	Economic aspects	78
4.1.3	Political aspects	79
4.1.4	Organisational issues.....	79
4.1.5	Ethical issues	81
4.1.6	Stakeholders, including the e-excluded.....	81
4.2	Second stage – Identifying needs and gaps and lessons learned	82
4.2.1	Needs	82
4.2.2	Gaps.....	83
4.2.3	Lessons learned	84
4.3	Third stage – Formulating a strategic research agenda.....	84
4.3.1	Research agenda (market, technological and social policy research)	84
4.3.2	Performing the research.....	86
4.3.3	What’s expected from the research	86
4.3.4	Next steps and scheduling with milestones.....	86
	Annex – Interview Questions	87

1 INTRODUCTION – GOOD PRACTICES IN E-INCLUSION

Member States, the European Commission, industry and NGOs representing users have undertaken several actions to advance e-inclusion. A milestone was the 2006 Ministerial Riga Declaration on ICT for an inclusive Information Society, by means of which Member States committed themselves to concrete targets for Internet usage and availability, digital literacy, and accessibility of ICT by 2010. In the context of the Riga Declaration, the European Commission identified six themes which it uses to foster e-inclusion. The six themes and their overall objectives are the following:

- *E-accessibility*. Make ICT accessible to all, meeting a wide spectrum of people's needs, in particular any special needs.
- *Ageing*. Empower older people to fully participate in the economy and society, continue independent lifestyles and enhance their quality of life.
- *E-competences*. Equip citizens with the knowledge, skills and lifelong learning approach needed to increase social inclusion, employability and enrich their lives.
- *Socio-cultural e-inclusion*. Enable minorities, migrants and marginalised young people to fully integrate into communities and participate in society by using ICT.
- *Geographical e-inclusion*. Increase the social and economic well being of people in rural, remote and economically disadvantaged areas with the help of ICT.
- *Inclusive e-government*. Deliver better, more diverse public services for all using ICT while encouraging increased public participation in democracy.

In 2007, the European Commission launched its i2010 e-Inclusion Initiative to raise political awareness of e-inclusion, encourage replication of e-inclusion success stories throughout the EU, and pave the way for future actions.

An important element in the e-inclusion strategies has been the identification and promotion of good practices.

Good practice e-inclusion awards were a highlight of the European Ministerial Conference on e-Inclusion held in Vienna in late 2008 which was attended by more than 1,000 participants.

In this section, we consider what good practices are, note the increasing emphasis on good practices as a matter of e-inclusion strategy, the perceived value of good practices and the criteria for selecting them. The success in using good practices as a matter of strategy and policy is critically dependent on how they are selected and by whom and how well they are promoted (or disseminated). The next section contains 10 examples of good practices.

1.1 WHAT ARE GOOD PRACTICES?

The term “good practice” suggests something that has worked in a particular situation and that may offer lessons for others. A defining characteristic of good practice is that it must be transferable or applicable to others, at least in part. A good practice implies a practice that can be improved, not one that has finality from which one must not deviate.

There are various definitions of good practice. Often these definitions are contextually based. As our interest is in good practices in e-inclusion, it is instructive to consider the definition of

good practice used in the largest online library of good practices in e-inclusion, that collected by the European Commission on its ePractice.eu portal.¹ ePractice.eu describes itself as “the one stop place for the exchange of advice, experiences and events on practices of eGovernment, eHealth and eInclusion, offering the most complete information and exchange opportunities for these areas in Europe”. As of mid-2009, the portal had more than 1,100 good practice case studies. It describes these cases as

written summaries of real-life projects or business solutions developed by public administrations, entrepreneurs and corporations. Case studies included in our portal are based on actual experiences, and reading them provides a picture of the challenges and dilemmas faced by the professionals working in eGovernment, eHealth and eInclusion... The use of ICT leading towards the reorganisation of eGovernment, eInclusion or eHealth processes must be a basic factor in all the cases published in the portal.”

The Commission goes on to say that “Research projects or events are not considered cases. In order to be included in the database, a case must be a real-life project, already executed and developed in a particular context.”²

This definition seems a bit severe in that one can envisage a good practice that does not necessarily involve a reorganisation of e-government, e-inclusion or e-health processes. Similarly, one can envisage a good practice in a research project that merits being used by other research projects. For example, the MAPPED project, a project funded by the European Commission under its Sixth Framework Programme (FP6), certified on its website that it complied with ethical guidelines. We think this is a good practice which merits replication by other research projects. In our view, even a policy could be a good practice. For example, the Commission’s policy on e-inclusion merits replication by the Member States. So far, e-inclusion is a “soft” policy, i.e., it is not the subject of a directive or regulation which obliges Member States to implement it. Nevertheless, the wisdom and good sense of the Commission’s policy on e-inclusion has found favour with the Member States, as evidenced by the Riga Declaration by means of which Member States committed themselves to introducing various measures to overcome exclusion of digitally disadvantaged persons and bringing them into the mainstream of Europe’s Information Society.

In spite of the rigidity of the ePractice criteria for good practice case studies, one could agree that a good practice should have some measurable results in order to evaluate whether it is good practice or not. Without real-world application, where is the proof of its goodness? A good practice should reach beyond theory to real-world application in some context, where its impact can be observed or measured in some way.

The authors of a report on good practices in e-health (Stroetmann et al., 2009, p. 6) observe that a good practice comes from real life and should offer a learning experience and recognisable benefits. They say that

What is judged as “best” will always depend on the national, cultural, structural context and subjective assessments. What might be judged by some as best in one context may not be applicable at all in another, even similar context or not “work” for other reasons like legal requirements or habits and attitudes of citizens. On the other hand, good practice cases ... – in spite of reflecting unique experiences – can provide useful insights for others, likely to stimulate creativity, self-reflection and the transfer or adaptation of good ideas.

¹ <http://www.epractice.eu/en/einclusion>

² <http://www.epractice.eu/info/cases>

The authors also noted that of the good practice cases they collected “Project managers and users from various backgrounds described the success of their eHealth solutions mostly in ... ‘how’ the respective solution was implemented and did not relate success much to ‘what’ was implemented” (Stroetmann et al., p. 9).

A good practice should not imply that others must follow it rigidly, as one might be expected to do in the case of a standard. A good practice is one that offers lessons from which one can learn and possibly apply in a similar or even different situation or context. But it may not be possible to completely transfer the practice, simply because there are cultural or environmental or other contextual factors that are different. Thus, careful evaluation is needed before adopting any so-called good practice. One person’s good practice is not necessarily the best for another person, company or country. Applying a good practice unquestioningly might have a negative impact in a different context.

The Tavistock Institute in its report on e-inclusion good practices presented some examples of good practice and commented that

What all these examples have in common is that they have chosen an approach which combines the ‘primary task’ of addressing the particular needs of the eInclusion dimension (e.g. providing access to ICTs by making available PCs or high-speed Internet access) with measures that embed these activities within the wider socio-economic context of the target groups that are being addressed. This ensures that some of the inherent barriers to the take-up of ICTs are being addressed and at best overcome. Looking back at the possible strategies for tackling social exclusion, this means that what the selected examples... have in common is an underlying preventative approach / vision for tackling issues of digital exclusion (Cullen et al., 2007, p. 53).

A good practice is inherently a case study. It must be capable of being described and transmitted, or promoted, to others. In some fashion, it must offer guidance for others.

Taking account of the foregoing, but perhaps adopting a more inclusive approach to what constitutes a good practice than the ePractice.eu portal, we envisage good practices in e-inclusion being of three main types, i.e., projects, guidances, and policies and programmes.

Projects

By projects, we include research projects such as those funded by the EC under its Framework Programmes and their equivalent in the Member States which are typically of fixed duration (from a year or so up to several years in the case of Integrated Projects and Networks of Excellence). We also include projects of an operational or ongoing nature.

Guidances

Some projects or organisations or associations, agencies or other entities have published guidances which could be considered as good practices. In some cases, the guidance has been prepared by a consortium for the guidance of its partners. In other cases, the guidance has been prepared for others. For example, the UK Information Commissioner’s Office (ICO) has prepared guidance on good practice in security of personal information.³

³ For this and many other good practice notes from ICO, see

Policies and programmes

The EC and Member States have adopted policies and programmes on e-inclusion which could be considered as good practices. For example, the Commission and various Member States have adopted policies and programmes the aim of which is to make broadband access to the Internet available to all citizens.

1.2 VALUE OF GOOD PRACTICES

Good practice cases have strategic value, i.e., as an element in strategies aimed at overcoming e-exclusion, but they may also have value as examples of ways of responding to ethical challenges. Collecting and disseminating good practices is a way of supporting stakeholders in their efforts to address common challenges, to facilitate implementation of e-inclusion strategies and to promote the benefits that flow from the e-inclusion of all citizens. Good practice cases can be an important resource for decision-makers, who require reliable evidence of the benefits of e-inclusion ethics (Stroetmann et al., 2009, p. 10).

Well disseminated good practices have an economic value too, in avoiding duplication of effort or avoiding the cost of reinventing the wheel. A UK study (SEU, 2005, p. 62) found that “lack of evaluation can lead to a poor appreciation of the benefits of ICT for social inclusion, poor replication of good practice, or duplication of effort where the experience of past initiatives is not drawn upon.”

Good practice cases are intended to influence others engaged in similar activities. The rationale for an e-learning manual is described thusly: “This Manual provides examples of good practice collected from different European countries in the field of e-inclusion and e-learning for people with psychological disabilities. Its purpose is to provide all actors involved in the fight against the digital divide with ideas and successful paths that could be included within their own activities” (e-ability project, p. 8).

Good practices may make the difference between e-excluded groups joining or not joining mainstream digital society, as Mellor et al. (2008, p. 41) found:

Various social pressures were non-conducive to maintaining participants’ engagement with the Internet, with some participants feeling stigmatized when they joined the project. In any residential environment that planned to introduce Internet facilities, a clear and obvious commitment from the management and care staff would be helpful, and an opinion leader could be encouraged to be part of the project. The introduction of computers to groups who already share some common activities, even if not much more than a friendly cooperative arrangement, would improve the chances for success when combined with patient, readily-available support.

Thus, in this case, good practice would ensure a supportive, rather than stigmatising social context, even in a relatively small social context such as that of an individual assisted living facility. The case described by Mellor et al. shows that even bad or poor practice can have value in pointing out what to avoid.

One might assume that good practice cases do influence other practices and policy-making, based on circumstantial evidence. The European Commission (2008), for example, has said

that the EU has to innovate in the way it sets policy frameworks, in its legislation, in bringing people together in the exchange of best practice and in catalysing new approaches. Similarly, the UK government says its recent *Digital Britain* report (2009b, p. 34) “allows the Government to assess the excellent work already achieved, and to suggest a step change in the ways to help the digitally disconnected, *building on the best practice to date*, and on the knowledge and understanding we now have about the barriers and the ways to overcome them.” [Italics added.]

While one might assume that good practice cases do influence other practices and policy-making in e-domains, notably e-inclusion, so far there appears to be limited empirical evidence to support that assumption.

1.3 SELECTING GOOD PRACTICES

Good practices are selected in different ways. They may be designated as a good practice by the organisation that follows the practice or by the authors of a report or by a committee of independent experts.

The European Commission has a good practice portal (ePractice.eu) where individuals can lodge what they take to be a good practice, at least to some extent. The portal does have an Editorial Board which seems to exercise some judgement in what is accepted for publication on the website.⁴ As of mid-2009, the portal has accumulated and published more than 1,100 good practice cases since its launch in June 2007, which, it says, proves “the growing interest of European professionals in sharing practices and being informed about the latest developments in the eGovernment, eInclusion and eHealth domains”.⁵

Under contract to the European Commission, the German consultancy Empirica produced two reports on good practices in e-health and e-inclusion, but in neither case is an explanation offered on how the good practice case studies were selected or by whom they were selected.

Some good practices or the best of good practices are designated as such as a result of their selection by a jury of independent experts. The European Commission invited the submission of e-inclusion good practices in 2008. It received 469 cases from which it selected five for each of seven categories, and of those it selected one from each of the seven categories as the winners of its e-inclusion awards.

The criteria used by the judges in selecting the best of the good practices were the following:

- Impact on the community – What positive impact did the project make on the community it serves and how was that impact measured?
- Innovative use of technology – How was the project innovative? Was it the technology used, route to market, method of engagement or another element?
- Embracing all users – How has the project encouraged greater accessibility or improved the user friendliness of digital technology for the community it serves?
- Working with others – How has the project created partnerships with other organisations to improve the experience for all those involved and what were the benefits?

⁴ The portal says that “ePractice.eu publishes, in good faith, all cases correctly submitted, although in some circumstances the Editorial Board reserves the right to question suitability and remove a contribution. In these occasions, ePractice.eu may contact the author and work with him/her to clarify the situation. Cases are occasionally withdrawn at the request of the author or an institution.” <http://www.epractice.eu/info/cases>

⁵ <http://www.epractice.eu/case1000>

- Sharing the learning and knowledge – How have the lessons learnt and knowledge gained been shared with other organisations to benefit the communities served?
- Long term sustainability – What was the duration of the project, and how did the funding model meet those commitments and obligations?
- WOW factor – Why was the project amazing? Could it be the way it came together, the people involved, the outcomes it achieved, or something else?⁶

In the case of the 2009 e-government awards, the European Commission (n.d.) says the best of good practices will be evaluated and selected by a panel of independent experts. “The experts will be drawn from across Europe from a variety of backgrounds to ensure the widest possible coverage in terms of specialist knowledge and geographical balance. The panel of experts will be suggested by the European eGovernment Awards Consortium and endorsed by the European Commission services. Experts are bound to confidentiality rules and will have to confirm that they are not involved in conflicts of interest regarding their deliberations.”

Selection criteria for the e-government awards are relevance, impact, innovation, potential for sharing good practice, management approach, and communication and dissemination.

Perhaps somewhat more distant from e-inclusion and e-domains, the European Occupational Safety and Health Agency (OSHA), based in Bilbao, has been conducting good practice competitions for several years. Its experience with selecting good practices for awards makes its selection criteria useful as a point of reference. They are as follows:

Relevance	Is the information directly relevant to Good Practice to eliminate or reduce risks at work?
Focus	Is the example from the workplace or involving interventions aimed at work?
Tackling risks at source	How well does the example eliminate or prevent risks at source through good management practice, and the effective use of risk assessment and implementation of its findings? Are interventions such as training part of an overall approach aimed at eliminating or preventing risks at source?
Implementation	How well have these measures been successfully implemented in practice?
Improvements	How well does the example demonstrate real improvement?
Participation	Does the example demonstrate effective participation, including the involvement of employees / workers and their representatives?
Consultation	Where appropriate, how well does the example show evidence of good consultation between management and trade unions / workers?
Sustainability	Will the example be sustainable over time?
Legislation	How far do the measures comply with the relevant legislative requirements of the Member State, and preferably go beyond minimum requirements?
Transferability	How well the information could be used in other situations (e.g. Member States, industry sectors, other workplaces)?
Innovative	Is the example current - i.e. recent and relevant to existing work practices in the EU? Preferably, it should “add value” to existing practices in the Member State providing the example.

⁶ <http://www.citizenonline.org.uk/e-inclusionawards/judging>

Detail of coverage of information	Does the information provided give sufficient detail?
Design and aesthetics (for the Web)	Is the example clearly and simply described?
Consensus	Is the example acceptable to all National Network partners?

From the above examples, we can see there are different ways of selecting good practices (including self-nomination) and different criteria applied in selecting them, which suggests that there might be room for improving the value of good practice case studies through greater harmonisation of selection criteria.

1.4 DISSEMINATING GOOD PRACTICES

The critical success factor for extracting value from good practices is their dissemination, i.e., how they are promoted. A UK study (SEU, 2005) said that evidence suggests that innovations to tackle social exclusion are seldom evaluated, often marginalised and have low visibility. “Few people know about the successful projects already delivering. A focal point is needed to bring together good practice and initiatives worthy of wider roll out. This report proposes an independent unit to consolidate and promote evidence of highly effective and efficient practices, and raise the political profile of the opportunities.”

Good practices in e-inclusion have been and are being promoted in Europe in several different ways, among which are the following (with examples of each):

Good practice awards

The European Commission established the e-Inclusion Awards to raise awareness, encourage participation and recognise excellence and good practice in using ICT and digital technology to tackle social and digital exclusion across Europe. The scheme ran for the first time in 2008 and was open to organisations from Europe from all sectors: government and public, business and private, non-governmental and voluntary. 469 organisations entered in total.⁷ 35 finalists (five per each of the seven categories – see below for details) were invited to exhibit their project at the Ministerial Conference on e-Inclusion in Vienna on 30 November - 2 December 2008 and were presented with a medal for their achievements.

The seven categories and seven winners were the following:

- Ageing Well: London Borough of Newham (United Kingdom)
- Geographic Inclusion: Kyyjarven Mediamyllarit ry (Finland)
- Digital Literacy: Association “Langas i ateiti” (Lithuania)
- Cultural Diversity: Milton Keynes Council (United Kingdom)
- Marginalised Young People: A-Clinic Foundation (Finland)
- e-Accessibility: Synscenter Refsnæs (Denmark)
- Inclusive Public Services: Sotiria Hospital (Greece).

The European Commission’s 2009 call for good practice cases in the field of e-government received a total of 259 submissions which are competing in four categories for the European

⁷ http://ec.europa.eu/information_society/events/e-inclusion/2008/exhibition/awards/index_en.htm

eGovernment Awards title.⁸ Selected finalists will receive invitations to exhibit at the 5th Ministerial eGovernment Conference, to be held from 19 to 20 November 2009 in Malmö, Sweden. According to the Commission, the awards, organised every two years, support the implementation of its e-government policy and action plans. In addition to the four winners selected by the jury, a public prize will be awarded to the case among the 52 short-listed finalists that receives the most votes by ePractice.eu members.

Prosyletising, good practice “missionaries”

Here are two examples of good practice missionaries:

IDABC is the European Commission programme that promotes the delivery of e-government services in the European Union. IDABC stands for Interoperable Delivery of European eGovernment Services to public Administrations, Businesses and Citizens. It promotes the delivery of cross-border public services to citizens and enterprises in Europe. Its mission is to improve efficiency and collaboration between European public administrations.⁹ The IDABC programme is based in the Directorate General Informatics. Among its other activities, it produces and updates twice a year e-government fact sheets for each of the Member States.

In June 2009, the UK government appointed Martha Lane Fox to a two-year assignment as “champion for digital inclusion”. The idea of appointing a champion emerged in 2008 in the UK’s first national strategy for ending the digital divide. The lastminute.com founder, a dotcom pioneer, Lane Fox is supported by a taskforce of experts. As the government’s digital champion, Lane Fox says her main strength will be an ability to “give digital inclusion projects a voice in places where they might not otherwise be heard”. A consultation on the strategy found that the champion “must have the power and authority to enforce any changes that are necessary to ensure digital inclusion of the most vulnerable groups is delivered” (Cross, 2009).

Publications

The European Commission sponsors the *European Journal of e-Practice*, a digital publication which promotes the sharing of good practices in e-government, e-health and e-inclusion.¹⁰

The Commission’s Directorate General for Information Society publishes an e-inclusion newsletter and an e-health newsletter, both of which are delivered via e-mail.

Good practice libraries and portals

A high-level workshop on ethics and e-inclusion, held in Bled, Slovenia, in May 2008, recommended that stakeholders “Develop and maintain a good/bad practice case study library which illustrates the ethical dimension of ICT services and products used to promote social inclusion and improved quality of service to those in most need” (Rogerson, 2008, p. 6).

In fact, there are already libraries of good practice now. The EC’s ePractice.eu has what it describes as a “constantly increasing knowledge base of good practice”, containing hundreds of e-government, e-inclusion and e-health cases submitted by members of its community.

⁸ <http://www.epractice.eu/en/news/292104>

⁹ <http://ec.europa.eu/idabc>

¹⁰ <http://www.epracticejournal.eu>

Registered users of ePractice.eu can submit their own projects to the portal and contact the authors of cases already described there. As of mid-2009, 48 countries were participating in this portal with 15,000 members and more than 1,100 descriptions of various projects.¹¹

Special events

Age Concern England encourages and helps older people to get online.¹² It estimates that more than nine million people over the age of 55 in the UK are excluded from using technologies. It promotes events such as myfriends online week (16-20 March 2009) to highlight the opportunities for older people to make new friends and keep in touch with family at home and abroad.

In June 2009, the European Commission published a call for proposals for the organisation of a major awareness-raising campaign associated with EU e-Skills Week in March 2010.¹³

Conferences and workshops

The Commission and others have organised numerous conferences and workshops devoted to e-inclusion. Several of the most significant have already been mentioned above, namely the Ministerial meeting which led to the Riga Declaration in June 2006, the workshop on ethics and e-inclusion held in Bled, Slovenia, in May 2008, and the Ministerial conference on e-inclusion held in Vienna, 30 Nov – 2 Dec 2008.

1.5 LINKING STRATEGIES AND GOOD PRACTICES

A Belgian project provides a good example of how good practice, e-inclusion strategy, ethics and dissemination activities can be integrated successfully and brought to the attention of policy-makers. The project, entitled “Colourful Flanders turns to Grey”, was designed, initiated and managed by the Flemish Institution for Science and Technology Assessment (viWTA, a parliamentary institution for technology assessment), and conducted by the Centre for Audience Research (Catholic University of Leuven). The ultimate aim of the study was to formulate short-term and long-term policy recommendations with regard to the elderly and ICT (Eggermont, 2006). The project set tough, but realistic measures of success for itself: “The usefulness of the project (and its methodology) will not surface until the framework is reflected in actual policy plans. The project will only be assessable when policy objectives that have been inspired by this study, gradually start to be linked with legislative, policy, service, or budgetary measures.”¹⁴ Among the actions it took was to present the project results directly to the Flemish Parliament.

While individual projects, such as this Belgian example, can link good practice, strategy and policy, higher level co-ordination is also necessary, at the macro level as it were. The European Commission (2009, p. 10) makes this point when it says that action is required across a number of policy areas to deal with Europe’s ageing population and that coordination at European level can facilitate the exchange of best practices, develop synergies and reduce negative spill-overs. Co-ordination is a way of improving the efficiency and effectiveness of social spending. The European Commission collaborates with Member States through the so-

¹¹ <http://www.epractice.eu/en/cases/>

¹² www.ageconcern.org.uk/myfriendsonline.

¹³ http://ec.europa.eu/enterprise/newsroom/cf/itemlongdetail.cfm?item_id=3160&lang=en

¹⁴ Eggermont et al., p. 215.

called open method of coordination (OMC) on social protection and social inclusion. Tangible evidence of this co-ordination on e-inclusion exists beyond the words contained in the Riga Declaration. The i2010 e-Inclusion Subgroup National Reports (Dec 2007) contain a wealth of information, including contact details, examples of e-inclusion good practices and policies.¹⁵

2 EXAMPLES OF GOOD PRACTICE IN E-INCLUSION

The majority of the following examples of good practice achieved recognition at the Ministerial conference on e-inclusion held in Vienna in early December 2009. All but two of the following case studies have been prepared based on interviews. The last two case studies were contributed by France Telecom Orange and the Eldy Association.

2.1 SIGNVIDEO – A VIDEO INTERPRETING SERVICE FOR DEAF PEOPLE

SignVideo is an award-winning e-inclusion service developed by Significan't, a social enterprise based in London, which provides interpretation services for deaf people using remote video links over the Internet connecting them with interpreters. Significan't has expanded quickly, to become the UK leader in sign language video interpreting. By May 2007, it had distributed more than 500 videoconferencing units to customers in the UK and Europe.

Significan't acts as an enabling partner to organisations, businesses and home users who wish to have unrestricted communication with deaf people who use sign language. Whether interpreting is required for a simple everyday enquiry or a complex life-saving situation, the SignVideo service provides the means to instantly break down communication barriers via its video-enabled call centre.

With the introduction of the UK Disability and Discrimination Act of 2005, service providers became obliged to provide and pay for services that are accessible by people with disabilities. Significan't Managing Director Jeff McWhinney said in an interview that he estimates that SignVideo cuts service costs for deaf people by about two-thirds. It is a carbon-friendly solution, he said, because it reduces travel by both the deaf person and the interpreter. The interpreter's time and skills are maximised, because the video service eliminates the interpreter's need to travel to a meeting. Instead of wasting time travelling, the interpreter can provide service to other clients.

McWhinney says Significan't is committed to delivering the highest levels of service and support to its customers. It aims to make the SignVideo interpreting service a widely available feature of all public services. Its declared mission is to empower deaf citizens and to use the latest developments in new technology to tackle barriers to their social inclusion.

Significan't regards itself as a social enterprise, that is, a business with social objectives. It is a profit-making company but it re-invests its profits into developing new services and/or new technologies for deaf people. Charities are not allowed to make a profit, and are restricted to grants (often short term) and not-for-profit donations and this has an effect on how entrepreneurial they can be in developing and/or investing in risky ventures and

¹⁵ http://www.epractice.eu/files/download/i2010_eInclusion_Reports.pdf

developments. Thus, Significan't is an intermediate or hybrid organisation, somewhere on the continuum between a capitalist enterprise and a charity.

McWhinney gave an example of how SignVideo has removed hassles previously experienced by deaf people and those with whom they interact. "If a deaf person wanted to get a parking permit, he would have to go to the Council (the local government authority) and somehow communicate that he wanted a permit. If the deaf person was extremely lucky, there would be an interpreter there who could convey what he wanted. If not as with the majority of cases, the local authority might say come back in two weeks when they could find an interpreter. Two weeks later, the deaf person might not show up, so that the local authority would incur unnecessary expense. With our service, the deaf person would only need to make one journey to the local authority, who could take advantage of the SignVideo at any time."

He characterised SignVideo as a marriage between call centres and interpreters. "It also has great potential for rural areas. In such areas, you might have to wait six weeks to secure the services of an interpreter. With our services, you can have an interpreter within minutes."

Significan't started in 2003 as an international sign language interpreting agency led by Brigitte François. In 2004, McWhinney, former CEO of the British Deaf Association, was recruited to help develop the SignVideo videoconferencing-over-the Internet service. In September 2004, the SignVideo Contact Centre was created.

The SignVideo service was first tested in a London borough in 2004. "The local authority of Islington in London was our test bed. They were a major partner at the outset. The Greater London Authority (GLA) also helped us. They saw there would be problems in complying with the Disability and Discrimination Act. Local authorities had to publish how they were going to provide services on an equal basis for the disabled. The GLA made an application to central government, to the Department of Communities and Local Authorities which gave us some 'pump priming' funding in 2005, which enabled us to start a pilot showing our video service to the deaf. And the following year, we provided a full service. Now the SignVideo service is totally self-sustaining. We achieved that after about 15 months."

From the test bed in Islington, Significan't now has 15 local authorities around London as customers. It provides services for National Health Service Trusts, local and national government agencies, voluntary organisations, deaf businesses and deaf individuals in their workplaces. "We've also had discussions with people in Australia and New Zealand and have an NGO in Brussels as a customer."

Significan't seems to have some good growth possibilities. Currently, the number of video access points in local authorities is limited, and all services are provided from that one point, i.e., that deaf person goes to the video access point, where he or she could be put in touch with the VideoSign interpreter, and the interpreter acts as the go-between with the relevant local authority service. "Now we are dependent on deaf people going to a video access point. However, we are exploring possibilities with a couple of local authorities whereby deaf people could use webcams from their own homes."

The cost of a video call cost is much higher than a normal telephone call, indeed, beyond the means of most deaf people, but that may change. He cited an example of deaf people in Austria calling each other via a 3G mobile phone at a subsidised cost that is not available to deaf people in the UK.

Significan't does not provide services to all. McWhinney said there are some environments where video services are not suitable, for example, in conference calling involving several people, or in situations where there is a high level of "emotional tension", for example, in child abuse cases. It is not always possible for an interpreter to pick up non-verbal cues which may be vital in these situations. Also, sign language interpreters are, of course, only human, and they need regular breaks like the rest of us. "Video interpreting is very demanding of the interpreter, both physically and intellectually. We have clear boundaries on our work. One customer wanted to use our service for a citizenship swearing in, but it was to take place in an open area, so our interpreter couldn't hear well what was being said. There was an issue too about our interpreter having to interpret a specific legal text to which a citizenship applicant would have to swear."

Asked for his views on criteria for good practices, McWhinney said one could make a qualitative response – "For us, what we want to do is to create a win-win situation for service providers and end users. We want a situation where the parties involved can extract the maximum benefit from the service, where end users are entirely satisfied. Customer satisfaction is crucial. And for that, you have to get feedback. Feedback is vital for any good practice. User involvement is important. There are too many projects where users *might* be involved, but their views are overlooked."

On the quantitative side, he said a good practice has to make effective use of available resources, time, costs and skills. An important measure for any prospective good practice is whether the staff implement it. "Some good practices fall down because management can't sell it to staff, or staff aren't convinced." The main stumbling block is how much workload the practice creates. A well planned, good practice should entail an acceptable workload. "Also, a good practice should start from the bottom up. In our case, it was the users who said they wanted a service like ours, and we stepped into the gap." McWhinney said the feedback he has received from local authorities and others has been very positive.

He said the SignVideo service is, of course, replicable. "In fact, we are working with an organisation in the south of France, which has developed a service like ours, which is delightful for us, because we can share experiences. The Swedish government is also funding a similar service, available in people's own homes, but in their case, it is a video relay service connecting deaf people to telephone users."

With regard to ethical issues, he said Significan't was determined that all of its interpreters should follow a code of ethics, a key commitment of being members of the Register of Sign Language Interpreters, a professional registration body, with its own rules, insurance, disciplinary measures and safeguards.

He said ethical issues might arise in some specific contexts. For example, if an interpreter can't see clearly or isn't getting a good sound, an ethical issue might arise whether to turn someone away even though there is a clear need for their service. "We also expect a high standard from local authority service providers, who might otherwise say to a deaf person: here, read this, perhaps not realising that the deaf person struggles to do so." McWhinney, who is deaf himself and who also uses an interpreter, said deaf people are disadvantaged not only by being deaf but also because they are suffering from the assumption that they are able to communicate fluently in English, as research has shown, a lower reading ability than most

other people. Because they don't hear spoken language, it makes the acquisition of English doubly difficult.

Another important ethical issue is privacy and the confidentiality of communications. "We don't record any information about any discussion that goes through our interpreters. In addition, there may be some private or personal details that some interpreters may not want to deal with, e.g., medical appointments. Also, like many call centres, we don't allow people to go into our call centre when it's active."

He said Significant't has produced "a customer handbook, where we have a clear description of what we expect. We also have a graphical description of what situations we can deal with." Significant't has annual training workshops for its interpreters which explore and discusses issues of an ethical nature. "All interpreters have access to a system that enables them to report or discuss specific ethical issues that come up in a call that may impact the service we provide."

With regard to recognition and awards for its service, Significant't was a finalist for the Dell small business of the year award. It was also a finalist for the ACCESS-IT@Learning award in 2008. Significant't founder Brigitte François won the British female inventor and innovator award of 2007. She also got a merit award at the EUWINN's Female inventor and innovator award in Berlin. In 2006, the company won the best government to citizen IT project award. It was also a finalist for the European Commission's e-inclusion awards at the Ministerial conference in Vienna in early December 2008. The Greater London Authority advisor on disability learned of the competition for the e-inclusion awards, and informed Significant't and the Islington Council about it. The latter collaborated in making the application to the European Commission. The EC recognised Significant't's service as a good practice in e-inclusion and specifically for turning access to local services into a reality for deaf people.

For more information:

Jeff McWhinney

Louise Vickers

+44 208 463 1122

louise@significant-online.co.uk

<http://www.signvideo.co.uk/aboutus.php>

2.2 DIGITAL STORY-TELLING IN SWEDEN AS A TOOL FOR E-INCLUSION

A challenge for e-inclusion is getting media attention focused on the e-excluded. Fair media portrayal should increase the possibilities for people with disabilities to be included in society and to find employment. A Swedish project, called MediAbility, found a novel way of meeting this challenge – it empowered the e-excluded by giving them the tools to make their own digital video stories which generated sufficient interest that they were used by leading media companies.

"Our project was about people with disabilities not being present in mainstream media. We wanted to change that," said project spokesperson Mia Ahlgren in an interview. "We worked with public service TV, to make them aware of this injustice. We wanted people to take control of communications tools in their own right."

The MediAbility project collaborated with mainstream media companies for more and fairer portrayal of people with disabilities. The project was initiated by the Swedish Disability Federation, a Swedish umbrella organisation, representing 43 national disability organisations and 460,000 individual members. The Federation obtained funding for the project from the Swedish Inheritance Fund. The project started in February 2006 and concluded with a final report in June 2009.

The idea of digital storytelling was developed in California about 15 years ago, but the MediAbility project took it a step further by making it easy and inexpensive for the e-excluded to make short videos which were published on the website of UR, the Swedish Educational Broadcasting Company, one of the project partners.¹⁶ The project has also been an active partner in a European networking project.¹⁷

“We co-operated with Swedish public broadcasting companies. We worked with the educational broadcasting company. They had a Web project, where they were already working with digital TV story-telling, so we grafted our project on to theirs. They helped us with the first workshop. They provided a distribution medium. We also co-operated with the Swedish public TV broadcaster on the study. We collaborated with different educational institutions, which were doing work on the digital divide, and we had some conferences with them.”

“Our project had two parallel actions, a research study on how people with disabilities were portrayed and workshops on what people wanted to convey. The workshops grew. We conducted them in different parts of Sweden. We had small groups of eight people in each workshop. We adapted a method developed in California, using simple technologies. The main thing would be the story. In our project, we started at quite a high level, telling people they should make a video. We had people who didn’t know about computers. In a way, we ‘tricked’ them into using technologies. Developing a story was the motive for using computers. Once people got used to the technology, they became curious and some participants went on to use computers for other purposes.”

“We asked journalists with disabilities to do some stories on what we were doing. Our first workshops were at a school for people with disabilities. Then we ran an advert across our 43 member organisations. We did workshops for them. We also did workshops with educational institutions. Most of the workshops were held where there were already groups. The only criterion was: do you have a story to tell? We didn’t say anything about computer skills. I wouldn’t say it was easy, but the reward was great.

“For young people, the MediAbility project was just another way of telling story. For some older people, it really changed their lives. But regardless of age, they all felt proud of themselves. They produced a film in two days that would be put on the website of a public broadcaster. We’ve done our best to show people how easy it is to get going. It’s not expensive. You just need a tutor. You also need proselytisers, somebody who can champion and promote this method.

“Our method can be used for different groups of people. We had very mixed groups. We had both young and old people. We had people with cognitive disabilities and mental illnesses,

¹⁶ <http://www.ur.se/rfb/index.php?t=1&tt=9>

¹⁷ <http://www.mediaanddisability.org>

such as schizophrenia, participating in our workshops. We only had one person who was totally blind.

The workshops were two days long. “Our workshops started with a short introduction where we showed participants some examples of digital stories as a way to build enthusiasm and to stimulate their own ideas. We asked them to think a bit before the workshop, for example, about a place that meant a lot to them. We asked participants not to talk about their disabilities. Instead, we encouraged them to prepare stories about something that interested them. It makes people really happy to do a video on what interests them.

“Some workshop leaders used a theme, for example, on human rights, to stimulate ideas, but the participants always decided themselves what story to tell. Their videos were based on their own ideas. For example, the theme of human rights was translated to ‘What makes you feel good?’ in a group with participants with intellectual disabilities. But one of the participants made a story about the war in Kosovo.

“We started workshops with oral story-telling. We put people in small groups, where there would be some peer-to-peer discussion. People could see they have some things in common. We told them their stories should end with something they have learned.

“In logical and structured steps, and with coaching in story-telling and technology, the participants first worked out a story-line and then made storyboards to determine what kind of images they would need. Then they were given a digital camera. The participants would ‘act’ to make a good picture. Workshop leaders helped them to use software programs such as MovieMaker for PCs or iMovie for Macs to make their videos. The workshop leaders served as intermediaries to participants to remove barriers in digital communication. The participants’ videos were typically two minutes long. The participants’ showed each other the videos they made. People could continue to explore digital communication without any extra cost, and sometimes they invented their own ways to make content accessible.

“It’s been quite eye-opening, asking people what they wanted to do. Everyone has a story to tell. Their stories are so different. A challenge for some participants was to make a short story. One of the older participants had a brain damage 40 years ago. He wanted to tell a story about how he had recovered. He made a six-minute video. After the workshop, he sent us an e-mail with a one-minute video about how he appreciated the workshop.”

The MediAbility website gives an example of empowerment digital video story-telling as follows:

Barbara is 59 years old and lives in a small community in the countryside. She had hardly used computers when she took part in a MediAbility digital storytelling workshop in August 2006.

She was not really interested in digital communication but she felt she had “a story to tell”. She made her first two-minute film and made new friends in the workshop. A few weeks later, she decided to join a course to learn how to produce documentary films. Barbara made a digitally edited documentary about a person she had met in the workshop.

Barbara joined another MediAbility workshop on how to start your own blog. Recently, she passed our course for training future workshop leaders. Two years after entering the digital

society, she initiated a course on digital storytelling in her local community, where she will be the tutor. Today, she uses a computer for information search and e-mails and she pays her bills electronically. For Barbara, learning about digital storytelling has become a story of empowerment by narration.

“We had about 160 participants in total,” said Ahlgren. “We thought it would be expensive to do these workshops, but it wasn’t. We used other people’s computers and meeting places, so we could do a lot more workshops. We did about 25 workshops in different places in Sweden. We had an organising person, who would help identify what was needed. We were facilitators. We made the best solution for each workshop. In some workshops, we used the educational broadcasters.”

Of lessons learned from the project, Ahlgren said, “When you work with people with disabilities, many people think you need special preparations, but we learned that you could mix different people. You can use the same method even if you have people with different disabilities. The mixed groups were the biggest value. With this method, you learn about things you have in common with other people.” She said their method should work anywhere for people who haven’t been heard very much.

She also expressed the hope that technologies and software for people with disabilities will improve. As it was, her project used software that was relatively simple and easy to use.

In response to a question about what makes a good practice, she said “Good practice depends on the purpose. It should be out of the box, sustainable, inquiring. Sometimes you need to find new ideas, to do something in a different way. It’s important that you start from the user point of view. That’s been very strong in our project. Good practices should be user-oriented. You need to bring in users from the beginning. You start with users, not the technology. Presentation is an important issue in good practice. Also important is how questions are asked, especially of elderly people. When you talk about elderly people, people with disabilities, there are often prejudices, but they are like the rest of us.”

On ethical issues, she said, “We talked a lot at the beginning about the difference between private and personal. We tried to discourage workshop participants from talking about their disabilities. If they wanted to do a private story, we would ask them not to show it on the Internet. We had one woman do a beautiful film about the two sons who were taken away from her. We always tried, especially with people with mental illness, to have someone present who knew them. If you are working in these areas, it’s important to have contacts with people who know the participants. Another ethical issue for us was to let people be free to do their own stories.

“We also had a contract. Anyone who wanted to spread their films had to sign a contract to allow their films to be shown. We contacted people to ask them if it was okay for their films to be reused in educational broadcasting. We had a couple of girls who put their videos on the Internet, and then wanted them back. We took the film off our website, where we controlled the film, but they understood that people could have downloaded their video. We also didn’t want to do films with children.”

The MediAbility project was a finalist in the e-inclusion good practice awards at the Ministerial e-inclusion conference in Vienna in early December 2008. Other recognition came

when Ahlgren was asked by the Swedish broadcasting company to be a juror in a competition organised by NHK, the Japanese broadcaster, called the Japan Prize. “I was probably asked because of our work. The competition was about selecting educational content from TV and the Web. There were a lot of people from different countries. We even met the Crown Prince!”

Digital storytelling was one part of the Mediability project, but the project also included other activities to encourage participation in digital media. In addition to digital story-telling, the MediAbility project organised workshops about blogging and networking on the Web to encourage people to use free-of-charge blog tools. “All workshop participants started their own blogs, and some have continued blogging regularly.”

For more information:
<http://mediability.wordpress.com/>
Mia Ahlgren
tel: + 46 8 546 40 452
e-mail: Mia.Ahlgren@hso.se

2.3 INTERNET BUS & NET SQUARES - TAMPERE CITY LIBRARY (FINLAND)

Libraries in many countries have been playing an important role in e-inclusion by providing people with access to computers and the Internet. Tampere City Library in Finland has gone further than most. In addition to providing free Internet access and free training in basic computer skills at its local branches, the library has literally gone further – it takes a bus equipped with computers and Internet access into local communities to teach the e-excluded about using the Internet.

Elina Harju, co-ordinator of the Internet bus service, said its “Netti-Nysse”¹⁸ service (as it’s called) “put the Web on wheels and took it to the people. Our goal is to serve the people and to encourage Tampere residents to start using the computer and the Internet and to give them the initial guidance to be able to do that. Basic instruction is free of charge.”

Clubs, societies, groups of neighbours or any group of people who want to learn to use the computer and how to surf the Internet can book the Netti-Nysse for their use and have it come to their neighbourhood. “We structure our training so that a group meets five times for two hours at a time. First, we get the group acquainted with the mouse. When the mouse has been tamed, it’s time to start working on search engines. Free e-mail accounts are opened for everyone and people are helped with web banking and other services.”

She said the birth and history of the Internet bus Netti-Nysse is a story of co-operation Harju, a teacher-trainer by background, had the idea for the Netti-Nysse initiative in 2000. She and her colleagues went to the city council with the proposal, which they liked and agreed to fund. The service is regarded as part of the mobile library service. They were supported in bringing the idea into reality by the city’s IT department and some business partners, who gave them some computers and a bit of money. They also secured some funding from the Ministry of Education and regional government. An old city bus was turned into an Internet bus by local

¹⁸ It is somewhat difficult to translate “Netti-Nysse” into English. Netti comes from InterNet. Local buses are called Nysse and a direct translation might be something like “Now it comes”. Netti-Nysse is a local way to the Internet bus.

vocational schools, the City of Tampere, local companies and the eTampere project. The bus service started in June 2001. In September 2005, the old Netti-Nysse bus was retired and replaced by brand new a successor Internet bus (Netti-Nysse II). The service is mostly provided in Tampere, although they sometimes go outside the city.

The Netti-Nysse service has only five people working full time, none of whom come from the library. The trainers all have a background in computers and experience with customers. “Our tutors, the people who help the customers, are a very important part of the idea. With each group, there are two tutors available. Individual support, having someone to question, is essential for people who are entering the world of computers and Internet for the first time. Our tutors are experienced customer service professionals with a good sense of humour. Clear, understandable language and a spirit of encouragement play an important role in our service. Tutors must be easily approachable by anyone. For us, there is no such thing as a silly question.

“Extra attention is paid to creating a relaxed atmosphere and ensuring our guidance material is written in clear language. We normally offer a package of instruction including five sessions of two hours each. We fix the schedule to suit the groups as best we can. Normally our first group starts at 9 am and the last one is out by 8 pm.

“In our groups, we focus on the Internet, but to get there we normally need to practise with the mouse first. To help with that, we have produced a ‘Catch the mouse’ tutorial on the Internet. The tutorial can be downloaded for free and is available in six different languages – Finnish, Swedish, Spanish, Portuguese, Polish and English – at our homepage. After the mouse has been ‘caught’, we start surfing on the Internet, making use of search engines, opening free e-mail accounts and studying web-banking systems. People get excited very quickly about what is on the Internet and they forget about the actual computer.

“After they gain basic knowledge, we encourage people to take next step, from surfing to doing. At Netti-Nysse, we have had digital story workshops, where we combine still photos with the voice of the storyteller. Everyone has stories. In Internet expeditions, the participants do not need to have particular skills at all. There, we surf together on our map. The destinations have been chosen so that they prompt memories and stories. That is our version of social media.

“After our sessions, we encourage people to carry on practising. We tell them about the free Internet access points in town (of which there are more than 140) and inform them about other elementary computer courses. The ‘Net Square’ is the newest service of the Tampere city library. It offers an excellent continuation to our customers with good support and free access computers. At Net Squares, there are also basic courses, but the most important is that there is always help available.” Net Squares are physical locations in branch libraries. Net Squares have their own staff to help and support people with computer problems.

The Netti-Nysse service is open and available to anyone. Groups typically comprise 10 people. “During the first two years, about 200 different groups attended the elementary courses. There has been a wide range of different groups; many senior citizens, but also groups of mothers, truck drivers, home aids, young unemployed people, people with hearing problems and Parkinson’s disease, immigrants, entrepreneurs, extended families and many different associations.” She said it is obvious that a group familiar to the individual supports the learning experience and creates a relaxed atmosphere as well as social capital.

Many people taking the training are “old ladies”, but there is a lot of variety within the classes. Nowadays, about 65 per cent of the course participants are over 56 years old and two-thirds are women. More than 80 per cent of those who take the training say they are going to use computers after the course. Less than 20 per cent say they might use a computer if support and free access were available and about one per cent have doubts that they will use a computer. “We try to encourage our students to think about how they can benefit from the Internet. Loneliness is a problem for all age groups. It’s a big problem in Finland. Internet access can help overcome that problem and build social capital at the same time.”

According to Harju, the feedback and demand shows they are succeeding in their endeavours. “People learn, enjoy learning and tell their neighbours and friends about it too.” She said they receive many favourable comments about the bus service, of which this one is an example: “I’m going to tell all of my friends about this opportunity. It’s good to get such professional instruction from one’s taxes. The tutors were really patient in guiding those of us who have never had anything to do with computers before.” As a result, said Harju, “Our customers take care of our marketing.” The bus is fully booked for three months in advance.

The Netti-Nysse also has taken part in various events, exhibitions and regularly arranges open house days. “Through different themes and events, we also try to lower the threshold of the Information Society and bring it closer to everyday life,” she said.

The Netti-Nysse has done a European tour. “We went to a five-day conference on library services in Milan where we performed a demonstration of our service. We stopped at five cities on the way back and talked to other librarians about our work. We had an open house type of demonstration in the city centres. Citizens could visit and see what we were doing. We also visited some schools.” She thinks their city bus is easier to approach, less formidable for many people than a conventional classroom. “Our customers are mostly older people, who feel uncomfortable about not knowing about computers. Our outreach draws people in a way that a normal classroom might not. Many have had poor learning experiences, so we give them lots of support. People can train at their own pace.”

Among the lessons learned, she said a name for the Internet bus has been important in attracting people. “The bus has a funny name and is brightly coloured. It is accessible. It has a PR value.” She also said pedagogical issues are important. “A good sense of humour and patience are vital. The service has to serve everyday life. People have to see the benefit and joy that Internet access can give to everyday life. Training has to be practical and has to help people to get to know each other. Tutors need to be very patient. They need to understand that people can feel scared. The setting has to be relaxed so people will be stimulated to learn.”

Supporting people’s computer literacy plays an essential part in building the Information Society but it is still not enough, she said. Giving people meaningful content and the opportunities to use computers are also needed. In Tampere, the Information Society is being developed through wide and good co-operation thanks to the eTampere project.

The eTampere and Netti-Nysse services aim at evoking discussion, creating co-operation and showing the need for novel practices in an inclusive Information Society. “Our goal is to help people to see the possibilities and then make their own choices concerning their role in the Information Society.”

From her perspective, among the criteria a good practice should meet is easy access. Technology has to be user-friendly, especially for older people, and learning materials and instructions have to be clear. Cultural issues must not be overlooked. “From our conversations with people in different countries, we can see huge cultural differences. In Nordic countries, adult education is something very natural. We benefit from this culture.” She added that a good practice should be replicable and that they are always happy to share their experience.

On the issue of ethical considerations, she said they do collect some information from the people using the service, about their age and profession, for statistical purposes. “We do not collect personally identifiable information, and we tell people that we can’t help them with their own bank accounts. People sometimes ask us to solve a personal problem, but we can’t do that. We do, however, encourage people to learn from e-banking, to search for help from banks. We can help them to find information and use demos, for example, from older people’s service centres.”

The Netti-Nysse has been recognised as a good practice. In November 2001, the European Commission presented the Netti-Nysse and the city of Tampere with an award for “Best eGovernment Practice”. Another award came from the Ministry of Education as Netti-Nysse won a national prize for its “innovative adult education practices”. The Millennium Technology Prize Foundation gave Netti-Nysse a Special Recognition Award for a people-centred application that exploits the World Wide Web and Internet Technology in 2004. At the European Commission e-Inclusion Awards in December 2008, Netti-Nysse and Internet Squares were among the five finalists in the e-learning category.

Netti-Nysse was part of the eTampere project (2001-2005), details of which can be found at www.etampere.fi. Netti-Nysse grew out of the eTampere project. “eTampere was kind of strategic framework for us,” said Harju.

For more information:

Elina Harju
Internet bus Netti-Nysse
Tampere City Library
Finland
tel: +35 840 590 8496
e-mail: elina.harju@tampere.fi

2.4 CREATING A DIGITALLY AND SOCIALLY INCLUSIVE CITY – MILTON KEYNES, UK

Milton Keynes in the UK has more than 10,000 disadvantaged citizens within its population of approximately 250,000 people. Milton Keynes Council wanted to provide these citizens with affordable access to technology, help them develop computer skills, enhance their employment prospects and give them the opportunity of reaping the economic benefits from being online, including engaging electronically with the Council.

Milton Keynes has attacked e-exclusion on several fronts. It introduced a scheme to extend broadband throughout the city. It has loaned hundreds of refurbished computers to needy families. It set up a training scheme to show them how to use the technology. It has promulgated some specific applications, such as telehealth, and introduced an avatar on its own website to make it easier for people to interact with the local authority. Milton Keynes

Council recognised that infrastructure is necessary, but that in itself is not enough. People need affordable computers and training on how to use them.

The Council created ConnectMK Ltd as its vehicle for providing low cost Internet connections without 12-month contracts and renting out computers. ConnectMK is a private limited company wholly owned by the Milton Keynes Council. It supports the Council's social inclusion policy. One of its key trading partners is Freedom4, which is a joint venture between Freedom4 PLC and Intel Capital (Intel Corp's technology investment fund). Freedom4 is building a wireless broadband (WiMAX) network in Milton Keynes.

ConnectMK refurbishes old Council computers and installs Windows XP and Microsoft Office on them and then rents them to disadvantaged citizens for just £1.50 per week. The scheme has been a great success with about 1,000 PCs already on loan and with a waiting list of citizens who would like to join the scheme, limited only by the number of computers available from the Council.¹⁹

Milton Keynes Council is the first local authority in Europe to be authorised by Microsoft to provide computers preloaded with the XP operating system and Microsoft Office under a social licensing agreement (Community MAR, Microsoft Authorised Refurbisher).

Government and other studies have shown that there is a strong link between home access to a PC and economic prosperity, employment prospects and educational attainment. The snag is that many people cannot afford to buy or cannot afford the support that might be needed to use a PC or laptop at home.

In 2008, ConnectMK loaned more than 680 computers to people in the city who could not afford to buy a PC. It also opened a network of 15 drop-in centres called Digital Service Centres which provide free computer access and training.

Milton Keynes was the first local authority to bring a human face in the form of virtual assistants (avatars) to improve customer care and ease of searching on its own Council website.

Among the principal stakeholders who have collaborated with the Council to bring all these ideas to fruition are the following:

- Freedom4, which provides wireless broadband access to the Internet for home users and businesses in the UK. Access is provided through WiMAX, a fourth generation wireless technology.
- Adepteq, a commercial systems and solutions company, is a key stakeholder which has worked with many local authorities across the UK. The company drove the talks with Microsoft.
- Microsoft, which gave the city licences for community use at a tiny fraction of the usual cost of the software.

Milton Keynes Council's creation of a subsidiary company was an innovative measure, according to Lisa Bailey, its operations manager. "It combines a local authority ethic with a

¹⁹ Digital Britain, Final Report, Department for Culture, Media and Sport and Department for Business, Innovation and Skills, June 2009, p. 36.
http://www.culture.gov.uk/what_we_do/broadcasting/6216.aspx

commercial ethic. The company was set up with funding from the local authority. The operation is run on a very tight budget.”

The Milton Keynes initiative even has good green credentials. Instead of pitching out hundreds of PCs from the desks of local authority employees or sending them back to a supplier for disposition, the city has refurbished and recycled the PCs, which, it says, is 30 to 50 times more economic and green than disposing of them.

The project started four years ago (in 2006) with drop-in centres, where Lisa Bailey started working as a volunteer. She says her roots are in the community she aims to benefit.

She said the city has about 1,000 PCs on loan (as of October 2009). While the charge of £1.50 a week is nominal, using some research the Council felt that charging people for use of the computers would elicit more social responsibility. “If you give people something for free, they are less likely to take care of the equipment.” As the low charge suggests, there was no intention to make a profit.

She said they have about 300 people on the waiting list for computers, but that figure is being reduced as new kit becomes available. “We would like to double or treble the number of computers available in our program.”

Milton Keynes does not provide training on computers. “It has a social responsibility not to duplicate services provided by others. We have had to network with others in the municipality to fully understand the services already on offer. We signpost our users to where they can get training. We work with about 20 agencies (non-governmental organisations) from the third sector on a daily basis for training. There are so many agencies out there. Many residents don’t know about them. We advise residents about what training is available in their area. Most residents aren’t immediately ready for traditional classroom teaching. They don’t like to step out of their estate. We have 15 areas of deprivation in Milton Keynes. Networking at the grassroots level is really important. We need to have a good support network to implement our e-inclusion vision.”

“There’s no one model for digital inclusion. You don’t have to create a digital company, as Milton Keynes did. However, we think our public private partnership is proving its worth. In the long run, if you have local authorities trying to improve efficiency and performance and do well by the community, you need to provide home access. As a result of our experience, we built a toolkit or guidelines for local authorities which covers the legalities and discusses how we went about forming a partnership. The toolkit includes operational guidelines, including templates.”

Not only did ConnectMK/DigitalMK win an award at the European Ministerial conference on e-inclusion in Vienna in early December 2008, but it also did well in responding to the UK government’s Digital Challenge. The UK government issued a Digital Challenge to local authorities in 2007. The competition, sponsored by the Department for Communities and Local Government (DCLG), aimed to identify a national showcase for ICT innovation and set a vision of creating a truly digitally enabled society. Milton Keynes was one of the 10 short-listed “winners”. The 10 local authorities formed a novel entity called DC10plus as a way of implementing their shared agenda.

“The Digital Challenge programme was a call to local authorities to find innovative ways to overcome the digital divide,” explained Lisa Bailey. “If some people are socially excluded, they are likely to be digitally excluded. There were about 75 local authorities who responded to the Digital Challenge over two years. The 10 finalists got a small pot of money to pilot their ideas for overcoming digital exclusion. There was a panel of independent judges who picked the finalists. Responding to the Digital Challenge competition was a long, but worthwhile process. The competition was a good incentive. There is a DC10 website now. Many other local authorities have become members because they want to learn how to deal with digital exclusion.”

DC10plus is a collaborative network of more than 1,000 local authorities and their partners dedicated to creating partnerships, sharing best practice and developing new initiatives to promote social and digital inclusion through the use of technology. Its vision is to be a network for change, to help local authorities and their service delivery partners to empower people and connect communities through technology and innovation. “The DC10 idea has really driven the idea of local authorities disseminating results and sharing experience,” said Lisa Bailey.

“We also have accreditation as a European open living lab. We collaborate with other countries in doing some scientific research.”

Lisa Bailey said Milton Keynes’ e-inclusion initiative was the brainchild of Steven Jewell, who is in charge of information technology and e-government at the Council. “He knew what the wastage cost was on old computers. He knew they would just go to waste. He could also see the cost of the Council’s providing services to residents. If a resident comes in to talk to local authority staff, the cost works out at about £14 on average. If the resident discusses his problems over the phone with local authority officials, the cost is about £12. But if the resident can go online and sort out what he or she needs, the cost drops to £1, so to get these costs down, people need the tools (i.e., computers with Internet access). They need to know how to use computers and to access the Internet. They also need attractive websites. That’s why we created an avatar for the Milton Keynes website, an avatar which could answer residents’ questions. An avatar encourages interactivity.”

Lisa Bailey said they had learned many lessons as a result of their experience. “If you are going to do something like this, you have to work with others, you have to make sure residents want it. We have an ethnically diverse community. We work with community leaders. Other organisations have their own agenda, so you have to find a way to work together and to support each other economically, socially and in terms of sustainability and addressing educational needs.

“We have a unique situation. We are learning commercial expertise. We have a strong partnership with Adepteq. Even if you don’t run your e-inclusion initiative as a commercial company, you still need a commercial mindset. You also have to understand your community mix. Our approach won’t work for all.”

There is a need for additional funding. “We have people working on marketing and sales. Our initiative isn’t breaking even yet, but we will get there. Our main source of revenues is the rental of the computers. The broadband service is a commercial service provided by Freedom4 which wholesales the broadband service to Milton Keynes.”

The Milton Keynes initiative is regarded as an e-inclusion good practice “because we have products and services which are meeting real e-inclusion needs in a cost-effective, innovative, environmentally friendly way and they are scalable.

“Being one of the 10 finalists was a huge morale booster, so was our winning an award at the e-inclusion Ministerial conference in Vienna. People do recognise our achievement. That recognition has also helped in our applying for European funding. The Ministerial conference was a good opportunity to explore what others are doing and why.”

With regard to what criteria good practices should meet, Lisa Bailey said any good practice has to show that residents have been consulted and can show that the practice is needed. The practice has to be something that residents want.

With regard to ethical issues, Lisa Bailey said there were two key ethical issues. One was the issue of data sharing. “We have personal data, so we have had to comply with data protection law, which means we can’t give details of our clients to others. The other ethical issue was about the PCs we offer. We had to ensure that we empowered people, but we wanted to avoid access to the Internet for inappropriate use. If a client breaks our contract or does something contrary to the law then we will take action.

“We are frequently questioned about creating a commercial entity and whether that creates any conflicts. The Tool kit addresses the complexities in a way that others can explore whether this is an option for them”

Milton Keynes won its award at the e-inclusion conference in Vienna for bringing the benefits of better health-care and new technology to the people of the city. The award recognised the excellence of its work in connecting the community of Milton Keynes to the advantages of new technology.

For more information:

www.digitalmk.org (for information about the Council's work)

www.e-inclusionawards.eu (for information about the e-inclusion awards)

www.connectmk (for information about ConnectMK)

www.dc10plus.net (for information about the DC10plus network)

Lisa Bailey

Operations Manager

ConnectMK Ltd

Lisa.bailey@milton-keynes.gov.uk

+44 1908 310589

+44 1908 252288

+44 7933 794532

2.5 SENIORNETT – TRAINING IN ICT AND E-INCLUSION FOR ELDERLY PEOPLE IN NORWAY

Seniornett Norge is a non-government organisation working towards e-inclusion for elderly people. The organisation has two tiers: the first is the annual ‘Senior-surf day’, an open house event held at libraries and community centres nationwide for the elderly to learn about ICT.

The second tier is a 'club' or training centre established at a local site where senior citizens can continue their learning and become proficient ICT users.

Seniornett Norway is 12 years old, and has grown "stone by stone", said Seniornett managing director Tore Langemyr Larsen in an interview. "Its aim is to get all senior citizens over 55 to use computers and use the Internet. There are 1.2 million inhabitants in Norway over 55, about 25 per cent of the total population. Only half of those are using the Internet or have used a computer. Norway is a high-cost country. The government and private enterprise need to reduce costs, so, for example, they are concentrating on net-banking and delivering tax returns via the Internet. It's a big problem if those over 55 can't use the Internet."

In addition to the economic incentives, familiarity with the Internet has social benefits, for example, in one's being able to contact friends and family whenever one wants. "Facebook is popular for a reason," said Larsen. "Some seniors are beginning to use social networks, but they are behind young people. We started with the motivation phase, to explain that the Internet is not just for youngsters. It's why we started the senior surf day where seniors could get their first taste, to whet their appetite. We have had more than 50,000 seniors going to their libraries to get their first taste of the Internet. We publish adverts encouraging them to try the Internet, but this is not enough. Seniors need training, as in clubs, where they can learn from each other, share experience, genealogy research, photos. We started these clubs and now have about 100 all over Norway. We train the instructors for these training centres. To reach out to 600,000 seniors not on the Internet, our strategy is to train the trainers who can train more instructors which creates a pyramid effect. It's been quite successful. It's why we were a finalist for the EC e-inclusion awards.

"We have had contact with other countries, such as the UK, Japan and the US, but they don't train the trainers and don't have clubs like we do. Our approach is different because we train the trainers. We think we are more efficient. We rely on the pyramid effect. We are proud of it. In Norway last year [2008], more than 100,000 seniors over 65 went on the Internet for first time. We'd like to take some of the credit for that."

Seniornett has a small core of permanent employees, but it has about 1,000 volunteer instructors who work in the senior citizen clubs providing training and guidance. Seniornett helps the clubs with broadband lines and some equipment.

Seniornett Norway gets funding from government grants and private donations. "Telenor, the Norwegian telecoms carrier, and the Bill and Melinda Gates Foundation have given us free licences. We get support from banks because they want seniors to use their net-banking services. About 50 per cent of our funding comes from government grants, with the rest coming from the private sector."

Volunteers can in principle be anybody, but they are mostly senior citizens from all walks of life, said Larsen "Some are retired, some are not, some are from the IT industry and others not. We have a wide spectrum of volunteers, and most stay with us for a long time. It's a labour of love. It's very inspiring to get seniors on the Internet. Once they get over the fear of the mouse and keyboard or doing something that they think might break it, they become like children in their enthusiasm."

Oslo is the hub of the network, but the clubs are spread all over Norway. "Seniors don't want to travel long distances to get to a club. That's why we need clubs as close to the senior

citizens as possible We have a very good geographic distribution. Our aim is to have about 300 clubs in the next three or four years, and after that our concentration will shift to the running of the clubs, to make them more efficient and training people to use new software. For example, seniors have had a big problem in going from XP to Vista. We talk to Microsoft quite often about the usability of its software, its user-friendliness, to make it easier to use.”

Telenor was the first mid-wife of Seniornett when it gave a computer to a library about 12 years ago. The library asked what they could do with it. It became obvious that training was needed if the computer was going to be used. “Telenor has a commercial interest in what we do because it will help them sell more broadband service. Our program is sustainable because it is a win-win situation, everyone benefits from getting seniors on the Net.”

Regarding lessons learned, Larsen cited several. He said that “to get seniors on the Internet, they need to understand why they should spend the time and money to do so. The biggest obstacle is motivation, is responding to their question: ‘Why should I?’ We emphasise the new life they can have on the Internet. We concentrate not on the technology, but on the uses. A lot of repetition is needed in training. Also, the train-the-trainer model is quite successful. Even so, getting funding is not easy, even when everybody thinks it’s a good idea. I spend about 75 per cent of my time looking for donors. I would tell anyone planning to do what we do not to underestimate the effort needed to get funding.

“Our model of training the trainers is valid for other countries. So is the concept of the club. Our trainers give senior citizens a course of about 24 hours, but the seniors need to practise after that. Their new skills will disappear very quickly if they don’t practise. A lot of practice is very important. Clubs are better than training centres or traditional classrooms. The clubs are in libraries, in senior citizen centres, some in social organisations like the Kiwanis and Rotary clubs, some are in volunteer centres. The clubs don’t have to pay rent, they get free space. Sometimes they get free broadband connections. Costs are low. I think it’s a sustainable project. Once we get up to 300 clubs, we might need to double the number of people we have in the NGO (from four to eight).”

Regarding criteria for good practice in e-inclusion, Larsen said “a good practice should tailor the training around seniors. They are good learners, but they need a different training from that given to an 18-year-old. There’s a long list of things important for seniors, but not for 18-year-olds. Practices and exercises are very important in training. If you use too many technical terms, they get hazy-eyed. It’s important to use non-technological terms. Most software and hardware developers have a long way to go to address senior citizen needs. As just one example, the comma and full-stop on a keyboard could be made bigger. We work with government as they develop software and applications for citizens to use. We tell them not to make fonts too small, to make functions appear at the same place from one webpage to the next, to be consistent in the use of terms. Seniors need to understand what happens if they strike a key. There are many things that go into a good practice. It is helpful to have trainers from the same age group, so there is the prospect of good rapport with those to be trained. Senior citizens also need to have a lot of breaks. It’s important to accept that there are no stupid questions.”

Larsen said Seniornett has not really encountered any serious ethical issues so far. “We have, however, prepared some brief guidelines for seniors. For example, if you go on Facebook, remember that the things you post there will be there forever. We tell seniors to be careful

with their private information. When it comes to banking, they have to be careful with their PIN codes, never give to give them out.

“Our last senior surf day was in early October, and we received a lot of media attention. We have had many interviews, talking about our work. We are interested in meeting others in Europe to tell them what we are doing. We think we have a good model, perhaps the best in Europe, in getting senior citizens on to the Internet.”

When asked how he learned about the European e-inclusion good practice competition, he said Seniornett’s sponsors in the Norwegian government, the people working on e-inclusion, suggested that they should apply for one of the European e-inclusion awards. “So we did.” It was not the first time Seniornett was in a good practice competition. Before Seniornett was recognised as an e-inclusion good practice at the Ministerial conference in Vienna, “We won the Rosing prize, an ICT prize, the biggest in Norway, two years ago, for good practice. We were proud of that.”

For more information:

<http://www.seniornett.no/> [in Norwegian]

Tore Langemyr Larsen
+47 9598 5167
tore.langemyr.larsen@seniornett.no

2.6 ROBOBRAILLE – DANISH CENTRE FOR VISUAL IMPAIRMENT

More visually impaired people are being e-included these days thanks to an e-mail-based translation service that converts electronic documents into Braille or audio files in different languages on demand. The service, called RoboBraille, was developed by a public-private partnership of the Danish company Sensus ApS and Synscenter Refsnæs (the Danish Centre for Visually Impaired Children and Youth). Launched in 2004, the service makes textual information accessible to people who would otherwise find it inaccessible due to visual impairments or reading difficulties.

In an interview, Lars Ballieu Christensen, proponent of the RoboBraille service, said his aim was to create a simple, easy to use, centralised solution, where users can e-mail a document which is automatically translated and returned to the user, usually within a matter of minutes. He said he had been working with Braille software since the mid-1980s, and was wondering how the RoboBraille service could be made more widely available. The number of Braille readers is very low in Denmark, perhaps only 500, and he knew he needed to get something easy to use beyond the borders of Denmark and to add other capabilities, for example, for dyslexic people, and adding speech to files, talking books, MP3 files, etc.

Braille comes in a vast number of varieties which creates challenges in learning, producing and obtaining Braille. Not only does Braille differ from country to country and from language to language, Braille also varies according to domain (e.g., literary Braille, scientific Braille, Braille music, Braille poetry and pharmaceutical Braille) and even character sets. RoboBraille has overcome these challenges. The service is now available in Danish, British English, Italian, Portuguese, Greek and a growing number of other languages. The input is always a document whereas the output can be Braille, simple audio files, structured audio books and

graphical Braille artwork. The software works with existing technology. No new add-ons are needed. The user only needs an e-mail account.

The National Centre for Visually Impaired Children and Youth (Sensus' biggest customer) obtained €100,000 in funding from the Danish regional government of Zealand for development of the first prototype of the software. The service was further developed with other European partners and user organisations through a project which received a grant from the European Commission under the eTEN programme.²⁰ The National Centre for Visually Impaired Children and Youth was the project coordinator, while Sensus acted as a subcontractor. From July 2006 to December 2007, the RoboBraille service was tested in Cyprus, Ireland, Italy, Portugal and the United Kingdom in order to see if it could serve diverse cultures and markets across Europe.

Sensus and the National Centre for Visually Impaired Children and Youth have successfully orchestrated partnerships with the private sector and governments in projects aimed at improving the service by adding new functionalities, increasing the number of supported languages and supporting the service with media production capabilities and electronic libraries. The ultimate objective is to create an unlimited supply of material in Braille and other formats to anyone with a need anywhere in the world.

The service is promoted to a wide range of user groups: visually impaired, dyslexic, poor readers and illiterates as well as the general public. The service is available now world-wide. Christensen said the service gets between 1,000 and 2,000 user requests a day. The RoboBraille service is free of charge to non-commercial users. Institutions need to have a service agreement with Sensus.

The National Centre for Visually Impaired Children continues to get funding from the Danish government as well as support from other countries for additional development. The Danish Ministry of Education has provided one-off financial support in order to develop the service for the dyslexic and people with poor reading skills. In addition to dissemination, these funds are being used to support:

- the creation of structured talking books in the standardised DAISY format,
- complex document formats such as Adobe PDF,
- scanned images in formats such as GIF and TIFF.

The National Centre for Visually Impaired Children and Youth has also received funding from a private Danish foundation to develop a Polish version of RoboBraille. Sensus is in negotiations with the Danish Development Agency (DANIDA) to develop an Arabic version of RoboBraille. Both partners are discussing a Spanish version with an organisation in Santiago. The RoboBraille business model is based on attracting development funding for projects in different countries. The service is not yet self-sustaining, but may be in two or three years. "There's no hurry," said Christensen. "We have lots of ideas. We prefer to grow through a range of development projects." He said he spends a lot of time seeking funding from governments (the Danish government continues to be the most important source) but also from some major private foundations. He said the pharmaceutical industry is interested in

²⁰ Other partners in the consortium included the Associazione Nazionale Subvedenti, ONLUS (Italy), the National Council for the Blind of Ireland, the National Association of Housing of the Visually Impaired (Ireland), the Royal National College for the Blind (UK), the Pagkypria Organozi Tyflon (Cyprus) and Centro de Inovacao para Deficientes (Portugal).

being able to put correct Braille on their boxes and in providing the patient information leaflets in alternative, more accessible formats. RoboBraille addresses both issues.

Queried about the main lessons learned since developing the RoboBraille service, Christensen said, “There’s no easy answer. Things don’t need to be the way they always were. The RoboBraille business model does not need to be the way of most commercial enterprises.” He said the external validators of their EC project didn’t seem to get the idea of a free service. They pushed models for charging people or developing an advertising-based service. “We have proven it’s possible to create a totally different business model. It’s possible to make things happen even if at the outset it might have appeared impossible. For example, it’s possible to go to Egypt to find partners to create an Arabic version, as we have done.”

He said the RoboBraille was a good practice because it’s a real service for real users, and has good scalability. It started in Denmark, but now is a global service with different language versions.

With regard to selection criteria for good practice cases, he said that it was difficult to generalise, that selection probably comes down to each case.

On the issue of ethical considerations, he said the most important for the RoboBraille service is that “we don’t want to make money on people’s deficiencies. That’s why the service is free of charge. Nor did we want to include advertising.” These considerations were resolved by adopting a business model that also “ensures that we retain our ability to innovate”.

The RoboBraille service has won several awards, most recently the ACCESS-IT@Learning award 2009 (in September), the UK National e-wellbeing award (in the category “Reaching the Digitally Excluded”) in June 2009, a Well-Tech award for innovation and accessibility in Italy in 2008, and the social contribution award from the British Computer Society in 2007. In addition, it won an e-inclusion award at the Ministerial Conference on e-inclusion held in Vienna in December 2008.

Synscenter Refsnaes (www.synref.dk), founded in 1898, provides services for some 2,000 blind and partially sighted pupils aged 6-15 throughout Denmark. It operates the RoboBraille service.

Sensus ApS (www.sensus.dk) is a research-based consultancy organisation specialising in accessibility, inclusion, information technology and disability. Founded in 1987, Sensus employs some 10 highly skilled advisers and a number of freelancers. To conduct user evaluations, Sensus maintains a large network of people with special needs, including blind and partially sighted, deaf-blind, dyslexic, poor readers, deaf and motor impaired.

For more information:

Lars Ballieu Christensen

RoboBraille co-ordinator

tel: +45 40 32 68 23 or +45 48 22 10 03

e-mail: lbc@robobraille.org or lbc@sensus.dk

See also

<http://www.robobraille.org/frontpage>

and

Christensen, Lars Ballieu, “RoboBraille – An unlimited supply of educational material in alternative formats”, *The Educator*, Vol. XXI, Issue 2, ICEVI 2009, pp. 32-37.

2.7 THE TIGER LEAP PROGRAMME, ESTONIA

The objective of e-inclusion is to ensure everyone has access to computers and the Internet. Estonia has taken ambitious steps to make e-inclusion a part of daily life, starting with its children. In 1996, it launched the so-called Tiger Leap programme, as a consequence of which all schools in Estonia were given computers and connected to the Internet. Today, all students in the country receive training in ICTs from primary school onwards.

The allusion to the East Asian Tigers, the countries whose economies boomed in part as a result of information technology use, is not accidental. It symbolises perfectly what Estonia has attempted to replicate.

“If we say Tiger Leap in Estonia, everyone knows about it: It’s about schools, computers and being connected with the Internet,” said Triin Kangur, public relations manager of the Tiger Leap Foundation, in an interview. “We are working with schools and teachers to develop education using ICT all through school from first year to last year, and even pre-school.”

The Tiger Leap programme was first proposed in 1996 by Toomas Hendrik Ilves, then ambassador of Estonia to USA and later President of Estonia, and Jaak Aaviksoo, then Minister of Education. The project was announced by Lennart Meri, the President of Estonia in 1996, and the programme got underway the following year when funds were allocated to the programme from the national budget.

“The programme is funded by the Ministry of Education, but we had many other partners from industry and other ministries who have also contributed their ideas to the programme, so the programme is well rooted in Estonian society,” said Kangur. “All public schools were connected pretty quickly. They all have broadband connections now, and many of those have Wi-Fi as well as wired connections. The programme continues to enjoy high level political support.”

To implement the programme, the government created the Tiger Leap Foundation, which is mostly funded by the Ministry of Education. Industry made some contributions for a short period at the beginning, and the Foundation also participates in European projects. The reason for creating the Tiger Leap Foundation was so that it would have more flexibility than a government department, so that the programme could be implemented more quickly. Surprisingly, it is a small foundation, with only 12 employees, plus 45 trainers who train teachers. “Estonia has a population of only 1.3 million people, and there are only 16,000 teachers and 570 public schools, including primary schools and high schools, so we don’t need many people to carry out the activities,” explained Kangur.

Tiger Leap is a continuing programme. “After four years, we created a development plan for new projects. We are on our third development plan,” she said. Now that all the schools have computers and Internet access, the Tiger Leap Foundation is focusing more on educating teachers about e-learning. “We have different projects, all of which have names like Science Tiger, Techno Tiger and Tiger Robot. Through Tiger Leap, we try to introduce new technology so that children and teachers find it interesting.”

The Learning Tiger development plan for 2006-2009 has mainly focused on e-learning and related content. According to the Foundation's website, teachers' in-service training is a priority. It states that ICT opportunities in Estonian schools have achieved a very good level over the last 10 years with a constantly broadening variety of courseware to diversify the learning process.

"The Ministry keeps its finger on the pulse of the programme, so they know how Tiger Leap programme has changed daily work," said Kangur. "After every project, we carry out surveys of teachers, so we know how the project has affected their work, and so that we know what to do better. We also get feedback from parents and children."

Tiger Leap Foundation training is free of charge to all teachers. Teachers who have passed the training have to fill in a feedback questionnaire and will receive a Tiger Leap Foundation certificate. In order to evaluate training needs, the Foundation has developed a set of teachers' educational technology competency requirements.

"Last year, we had a project where we gave 4,000 laptops to teachers who were the most active in e-learning or integrating new methods in teaching. A quarter of teachers now have their own laptops which they can use at school and home."

Estonia's teacher training programmes have gained financial assistance from Intel (in 2003) and Microsoft (in 2005 and 2006).

Regarding the main lessons learned, "With years of experience, we have learned that teachers are interested in using different methods and technologies in their work. Pupils also find it interesting to work in different ways rather than just sitting behind a desk. Thanks to our teacher training programme, where teachers have the possibility to learn different ways of teaching and how to connect e-learning and daily work, we have seen great progression and willingness to use ICT in lessons. Teachers have started to use and create e-materials. In more advanced teachers initiative, several web-based communities have started to work, to assist their colleagues online, discuss and get new ideas for carrying out their activities.

"We definitely need to continue with teacher training, and teachers need to have the possibility to create and download materials from the Net. Therefore, Tiger Leap has a 'School-life' portal (www.koolielu.ee) for teachers where they can communicate through forums. It is connected to our online repository of e-learning materials, which teachers are welcome to use and improve.

"We think our programme can be replicated by other countries. We have transferred it to Georgia and we have contacts with other countries. There is an interest from other countries in what we are doing.

"Although Tiger Leap has never had an international marketing campaign, our programme is well known in Europe. We spread the information about our activities at various European conferences. Here I must thank also our Ministry of Foreign Relations and the e-Governance Academy (eGA). eGA is a non-governmental, non-profit organisation, founded for the creation and transfer of knowledge concerning e-governance, e-democracy and the development of civil society, which is also spreading information about us to other countries."

The Tiger Leap Foundation has been participating in other European projects, such as Schoolnet, Calibrate and eMapps.com. According to the Foundation's website, information exchange and collaboration enriches both sides and establishes premises for the effective use of ICT opportunities in education administration and direct tutorial work.

“We believe Tiger Leap to be a good practice. A good practice should have high level management support, and the programme or project management should be well carried out, and well communicated. The idea itself must be a good one, and must sell well,” said Kangur.

She said that they have not had to deal with many ethical issues. “Internet safety is, however, an issue. Almost 90 per cent of children have access to a computer at home as well at school. This is an advantage but also a problem. The problem here is that most families, most homes, have WiFi access, not only in the living room, but in the kitchen and bedrooms. Children find it more convenient to work in their own bedrooms, so they have little parental supervision over where they are surfing and what they are doing on the Net. The Ministry of Social Affairs and many others in Estonia feel that parents should be more responsible for seeing what children are doing on the Internet. This November, the Tiger Leap Foundation in partnership with the Estonian Union for Children Welfare and the Ministry of Social Affairs will deliver their proposal to European Commission, to join the international INSAFE programme.²¹ “It's time for us to start a larger Internet safety programme in Estonia. We intend to create an awareness centre at the Tiger Leap Foundation (our partners will become responsible for a helpline and hotline) for children and parents, so that those who encounter objectionable content on the Internet can report it to us.

“We are not saying e-learning is the only way to learn. It's something that supports the traditional way of teaching and learning. We see some parents who say we shouldn't include e-learning as part of daily teaching and learning. We also see that there are still some teachers who find the Internet and ICT not useful, not interesting. They are mostly older teachers. A second group of teachers have an open mind, and learn how to combine e-learning and traditional learning. And a third group are keen to use e-learning. People are different. We are not trying to make e-learning compulsory.

“It's up to each school to address parental concerns. Children like using computers and the Internet. It is fun for them. They are using the Internet every day anyway, so why not combine it with schooling?”

For more information:

<http://www.tiigrihype.ee/?setlang=eng>

Triin Kangur
Tiger Leap Foundation
triin@tiigrihype.ee
Skype: triin.kangur
+372 655 0290

²¹ <http://www.saferinternet.org/ww/en/pub/insafe/index.htm>

2.8 ETHICAL GUIDANCE ON USE OF WANDERING TECHNOLOGIES IN SCOTLAND

Restraints are still a common way to deal with wandering. In order to prevent their residents from getting lost, many care establishments lock doors or use barriers such as keypads or handle arrangements that require skills to open. Not only do these arrangements prevent the free movement of those who are at risk of wandering but also that of all the other residents. Coming up against a locked door can cause frustration or anger for a person with dementia.

To help determine those cases in which wandering technologies can be appropriate, the Mental Welfare Commission of Scotland produced a document, entitled *Safe to wander?*. It sets out ethical principles and guidance on good practice in the use of wandering technologies in support of individuals with dementia who are residents in care homes or hospitals. The technologies include tagging and tracking devices used to alert a care-giver when a person leaves a given area and to help locate a person who has gotten lost. Wandering technology involves the attachment of an electronic device to a person or their clothing, so that if they pass across a particular boundary, an alarm goes off, and staff are alerted. Wandering technology can also involve tracking devices which can locate the wearer if he or she becomes lost or fails to return.

The Mental Welfare Commission has provided both general principles and a checklist. Regarding the use of new technologies, it recommends that

- an intervention must provide a benefit that cannot otherwise be achieved;
- the intervention must be the least restrictive in relation to the person's freedom in order to achieve the desired benefit;
- the past and present wishes of the person must be taken into account;
- the views of relevant others should be taken into account; and
- the intervention should encourage the person to use existing skills and develop new ones.

Those considering the use of wandering technologies should take into account the causes of the individual's behaviour, risks to the individual, alternatives to the technology, ethical implications of the system, the views of the individual, relatives, care team, etc. as well as the legal implications. The use of wandering technology devices must be enabling to the wearer, not limiting. If not, the technology could be seen as an unwarranted invasion of personal liberty. If wandering technology is found to be necessary for certain individuals, it should be discreetly applied, so that the resident is not "labelled". Furthermore, to be effective, the device should be small, comfortable and unobtrusive for the benefit of the person themselves. A visible, uncomfortable device is likely to be undignified, stigmatising and rejected.

Because individuals with dementia are particularly vulnerable, not in a good position to defend their rights and at risk of getting lost (and being hurt) if left without adequate care, it is important that those who make decisions about their well-being are well aware of the ethical dimensions that are at play in using wandering technologies.

The *Safe to Wander?* guidance says, "The use of technology, including wandering technology, in care homes and hospitals is not in itself a good or a bad thing. Where technology is used, this should be as a tailored and appropriate response to the identified risks faced by an individual. How technology is applied can make the difference between providing restrictive and inflexible care, or a freedom-enhancing setting."

Dr Donald Lyons, director of the Mental Welfare Commission (MWC) and co-author of the guidance, said the guidelines were produced in response to the queries the MWC was receiving in response to concerns expressed by stakeholders about practical or ethical difficulties in the application of recent mental health and incapacity legislation. He and co-author Alison Thomson sent the draft guidance for comment to stakeholders including carers, professional and charitable organisations, hospitals, government and care homes as well as specific groups such as the Dementia and Development Centre at the University of Stirling, Alzheimer's Scotland, the Association of Directors of Social Work, the Care Commission, the Royal College of Psychiatrists, the Royal College of Nursing and West Lothian Council. He singled out valuable input received from the Glasgow Dementia Working Group (which has evolved into the Scotland Dementia Working Group), which is composed of people with dementia.

Wandering is not necessarily the best word, he said in an interview. Some people with dementia have a desire to walk, to go somewhere. They are not necessarily wandering aimlessly. He and Ms Thomson contributed a chapter based on the guidance to a book entitled *Walking not Wandering*²², which makes exactly this point.

The principal technologies used in dementia cases are passive sensors, which transmit an alarm to alert carers or the police if someone is exiting an assisted living facility or their own home. Other technologies include sensor pads (beds, chair, floor), nurse/carer call systems, panic buttons, fall and movement sensors, electronic tagging and tracking systems, CCTV or video surveillance and intruder alerts. So far, GPS-embedded bracelets or necklaces are not in use for tracking people with dementia. Although tracking devices are not much used in UK care homes, the technology is becoming increasingly easily available and financially affordable. Tracking devices with GPS are being used in Spain for some patients with Alzheimer's disease. Even if such devices are used, there will still be a need to ensure the person's safety once he or she has left an assisted living facility.

Dr Lyons cited Scotland's West Lothian Council as an example of an authority implementing passive sensors. He said using such technologies is safer than locking a person in the house, which could expose them to significant risks such as fire. In a care home, some people are able to come and go safely, others are not. If doors are locked, all residents may be deprived of their liberty. It is also demeaning of a person's dignity if they have to ask permission to go out. There are ways of stopping people from accidentally going out and coming to harm, for example, by making the assisted living facility more interesting. Care homes with enclosed gardens, allow people to walk around to their heart's content. However, many care homes are badly designed and not designed with dementia in mind. If someone with dementia does go out, it is very demeaning and inappropriate if a carer has to go out after them and pull them back into the home. Before thinking about technology, said Dr Lyons, one has to think about the circumstances in which it is used. Scottish legislation requires that interventions be the least restrictive to individuals' freedom. Indeed, the legislation was a driver in the production of the guidance, which is intended to increase personal freedom.

The *Safe to Wander?* guidance was produced in early 2007 and is used throughout Scotland. Some entities in England have expressed interest in the guidelines too, but Dr Lyons said that although they reference Scottish legislation, they could be used virtually anywhere.

²² Mary Marshall and Kate Allan (eds.), *Dementia: Walking Not Wandering - Fresh Approaches to Understanding and Practice*, Hawker Publications, London, 2006.

As an example of a lesson learned since production of the guidelines, Dr Lyons said the MWC is engaging stakeholders at an even earlier stage in the production of other guidance documents. Calls for advice and discussions with stakeholders help the MWC to identify those areas of practice where people are finding it difficult to understand how to work within the law and associated ethical principles. Now when the MWC decides to produce a set of guidelines, it invites experienced representatives from all relevant stakeholder groups to form a group to discuss key issues and to share ideas and examples of good practice. The MWC brings stakeholders together and gives them some anonymised scenarios drawn from real cases and asks them what they would do in the depicted situations. “We get stakeholders to think through the ethical implications, so that in this way they become more involved in the actual drafting of guidelines.”

The guidelines produced by the MWC represent good practice, in his view, because they involve stakeholders from the outset, including people who have used MWC services, advocates, lawyers, mental health service managers, occupational therapists and others. The MWC, he says, is very well rooted in the community and consults widely. Guidelines are seen as practical, rather something produced in an ivory tower.

Among criteria for good practices, he said compatibility with legislation was paramount. Relevant Scottish legislation includes the Mental Health and Care and Treatment Act, the Adults with Incapacity Act and the Human Rights Act. Good practice has to be based on principles, but applicable to real-life situations that practitioners encounter on a daily basis. MWC guidance documents use anonymised case examples to show how the guidelines can be implemented. Good practice also must have stakeholder buy-in to ensure their relevance and utility; indeed, all key stakeholders should be involved in the production of such guidelines.

In addition to the production of ethical guidelines, the MWC also contributes to professional development activities and gives general advice aimed at helping care providers to incorporate awareness of rights and the law into training and education programmes. It also supports the Principles into Practice Network, which acts as a forum for anyone in Scotland with an interest in discussing and developing good practices based on ethical principles.

The Mental Welfare Commission is funded by the Scottish government, but is an independent organisation working to safeguard the rights and welfare of everyone with a mental illness, learning disability or other mental disorder.

This case study has been prepared using information from the MWC’s website, the two publications mentioned below and an interview with Dr Donald Lyons.

For more information:

Mental Welfare Commission for Scotland, *Safe to Wander? Principles and guidance on good practice when considering the use of wandering technologies for people with dementia and related disorders*, 2007.

http://www.mwscot.org.uk/web/FILES/Publications/Safe_to_Wander.pdf

Mental Welfare Commission for Scotland, *Rights, Risks and Limits to Freedom*, Edinburgh, 2006. http://www.mwscot.org.uk/newpublications/good_practice_guidance.asp

or

Dr Donald Lyons
Director
Mental Welfare Commission for Scotland
tel: +44 131 313 8777
e-mail: donald.lyons@mwscot.org.uk

2.9 ACCESSIBLE COMMUNICATIONS FOR PEOPLE WITH DISABILITIES – FRANCE TELECOM ORANGE

Communications, especially telecommunications, have never been easy for the deaf and hearing-impaired. France Telecom Orange, however, has taken an initiative to improve access to the telephone and other digital media by people with disabilities, notably the deaf and hearing-impaired. It has established a dedicated customer centre for them. The service was launched in 2009 following an eight-month trial and demonstration. The service enables such customers to contact the telesales department directly by means of a plug-in on the Orange website.

According to France Telecom Orange, this good practice illustrates how innovation makes contact easier for people with various impairments by using technology and online services. The company aims to be closer to all of its disabled customers by designing services that take hearing and speaking impairments into account.

The principal stakeholders involved in developing the new customer service offer were the deaf and hearing-impaired people supported by FTO's Accessibility Group Department, which undertook the trial and demonstration and launched the service.

The experimentation and demonstration in French sign language and in text format began in November 2007 and finished in June 2008. One year later, the real-time written communication interface was launched and is now available on Tuesdays. Customers could use the French sign language format, via a webcamvideo, by the end of 2009.

Funding for this service came from France Telecom Orange itself (no government subsidies). The company has also improved access to its "Autonomy offers", which is a dedicated range of products and services for disabled and elderly people. The Accessibility Group has a direct distribution channel with 184 special "independence stores", an Autonomy section on the orange.fr website and a free-phone customer centre (0 800 11 22 33). The customer care centre, developed especially for the disabled, will be fully operational by the end of 2009 and is the first of its kind in France.

The customer service centre, located in Nancy, is managed by the Accessibility Group Department in a collaboration with the distribution team.

The service was initiated in response to the needs of the disabled and people close to them. The Accessibility Group wanted to make contact with customer services easier for people with various kinds of hearing impairments by using technology and online services. It was also an effort to develop another customer relationship and to improve access to the distribution channel (free toll number, free fax number and e-mail) for France Telecom Orange's products and services for deaf people. The company believes its range of products helps disabled people to be better integrated in civil society by using online services as others

can do. The hearing-impaired thus have an opportunity to get answers to their needs, to choose the most appropriate communications solution to meet their needs and to get assistance if needed for after-sales service.

For France Telecom Orange, the service reconciles the ethics of sustainable corporate social responsibility with marketing and commercial performance, which is one of the main preoccupations of any company. In fact, the company views this service as a real achievement in customer satisfaction and brand valuation. With its accessibility strategy of dedicated offers and adapted distribution channels, the Accessibility Group shows that it has affirmed its aim to take into account all customers' needs and to overcome the digital divide.

The company regards the service as a good practice, because it illustrates that this market segment with special needs can reach a customer care centre anytime they wish. More generally, France Telecom Orange thinks a good practice should meet several important criteria, of which the following are the most important: customer satisfaction, accessibility innovation, ethics, security, governance, human resource diversity and training, social responsiveness and sensitivity to local communities and the environment.

On the issue of how good practices should be selected, FTO uses a multi-criteria analysis method, analyses the different difficulties that any disabled people can face and offers adapted answers to their needs.

With regard to ethical considerations, FTO's stated commitment to accessibility means developing ethical actions to contribute to building an ethical brand image among customers, reducing the digital divide and increasing access to its products and services. It has been estimated that up to 10 per cent of the European population is disabled and 10 per cent are elderly. France Telecom Orange Group recognises the need to cope with this societal challenge.

More specifically, FTO's Accessibility Group has dealt with ethical issues in the field of the accessibility by launching four main changes:

- from a technology push culture to a customer centric approach,
- from a vertical Group way of working to a transversal method of operating (that is to avoid a pure player and chimney approach compared to mutualised management)
- taking benefits from forward-looking technologies,
- integrating accessibility in all FTO group processes (innovation, conception, merchandising, distribution, after-sales services, etc.).

In June 2008, France Telecom Orange received the "Exemplary Corporate Citizenship" award from APAJH (Fédération des Associations pour adultes et jeunes handicaps), which is an advocacy group for people with disabilities. The award recognises the FTO Accessibility Group's initiatives to support people with diminished capabilities and people with disabilities. The broad FTO program includes special access signage for retail outlets with the "Autonomy" label, a special website and a trial free phone service for people with hearing disabilities.

For more information:

- www.orange.fr, log on "autonomy section"

- See also the press release published in 2007 when the accessibility trial and demonstration were launched, available at:
http://www.orange.com/en_EN/press/press_releases/cp071126en.jsp

2.10 ELDY – FREE SOFTWARE FOR SENIOR CITIZENS



More than 20 per cent of the Italian population is over 65 but only a small percentage of it uses the Internet, statistics that are broadly similar across Europe. There are various reasons for this, one of which is that Internet access is not user-friendly for senior citizens.

Launched in 2006, Eldy is freely available software aimed at senior citizens which facilitates computer use and navigation on the Internet. Its graphical user interface (GUI) has been designed to help them in accomplishing the most common tasks. Eldy has been developed by an Italian non-profit organisation, the Eldy Association. The software facilitates the usage of the Internet for communication and data management, provides an e-mail and chat service, a web-browser with easy-to-use functionalities, word-processing and an image management application, and some other services, such as weather forecasts. In Eldy, letters and buttons are bigger than usual. The software has an evident colour contrast between text and background. Unnecessary buttons have been removed to make it easier to use the software interface.

Eldy is the first software to allow those over 55 to enjoy the Internet and the computer. The number of Eldy users has grown to more than 200,000 since January 2007. Most of these users (more than 95 per cent) are over 55 and most of them (more than 70 per cent) did not use a computer before installing Eldy. The Eldy software is supported by an army of volunteers.

Eldy is both easy to use and user friendly, so the experience is effective and entertaining. Eldy is also a fast-growing community with the backing of public administrations in Italy, which

are helping the diffusion of the software with the distribution of more than 1.4 million CDs and provision of training.

The project aims to reduce the digital divide which separates the elderly from use of the Internet. Since launch of the software, the elderly are now more included in our society. The Eldy Association has created a community based on ethical values such as friendship and mutual support. It has provided the software and organised many training courses, but the biggest contribution to the creation of the Eldy community has come from volunteers, who have spent a huge amount of time helping each other and teaching other seniors how to use the software.

The key stakeholders have been the Eldy Association, regional administrations and thousands of volunteers as well as the users themselves.

The initial funding for the project, about 1 million euro, came from private sources. Subsequently, the regional governments of Lombardia and Friuli Venezia Giulia (FVG), several provinces in Italy and private partners have provided the financial and moral support to enable the project to grow and thrive.

The project started in the city of Vicenza in Italy. Eldy soon attracted the attention of many public administrations which spread the software in their territories. The regional government of Lombardia made a big contribution to diffusion of the software by printing it on CDs and distributing them. Eldy is now well known throughout Italy, and beyond. Eldy is now being used in France, the UK, Spain, Mexico, Israel and African countries. Translations are available in Catalan, Dutch, English, French, German, Hungarian, Mexican, Serbian and Spanish, as well as Italian.

The project started because the Eldy Association felt the need to fill the gap between old and young, which grows day by day. In Italy, more than 80 per cent of people over 60 don't even know how to switch on a computer and are excluded from all of the services and new communications available through the Internet. The Eldy Association wanted to find a solution to this social problem.

The Eldy project was deemed necessary because most senior citizens don't have access to the information and communications services and tools offered by the Internet, including, for example, public administration services.

Since its inception, the Eldy Association has learned many lessons: First of all, if we provide senior and illiterate users with easy-to-use software, they fall in love with technology. Second, technology is empty without a community and friends to be found just a click away. We learned also that software is a good starting point, but without training, motivational support and marketing, it is completely useless.

It is possible to download the Eldy software at any time. Not only is it freely available to senior citizens, but also it does not contain any form of advertising. For these reasons, it needs ongoing financing. Until now, the sustainability of Eldy has been guaranteed by the commitment from the regions of Lombardia and Friuli.

The European population is growing older, and a big proportion of senior citizens cannot access many fundamental services that younger people take for granted. Eldy is a good

practice because it helps many people to be connected and offers them the opportunity to socialise and communicate in new ways. The Eldy community is based on friendship and support which reduces the isolation of senior citizens.

Not many ethical issues have arisen, but an important one arose early on, and that was: how to manage a business versus a mission? We have ruled that the mission comes first, and always, which is why Eldy has no adverts, no commercial content. This was a hard issue to discuss and define, but since 2006, it has been crystal clear! The Eldy is not only software, and not simply a project – it is a strange mixture of values, the good things that ethics should be about.

Recently, the Eldy Association has started a new project in Monopoli, in the very south of Italy, where children 9-11 years old will teach Eldy to their seniors. In Bassano, in the north of Italy, young people (17-18 years old) will teach Eldy to their seniors. In Rome, the Association is supporting a priest who is introducing Eldy to senior citizens and those who are seriously ill, so that they can share their last moments online instead of alone. Eldy's latest project involves 40 volunteers who are supporting 100 blind people – with coffee and training – using a text-to-speech enabled version of the software.

Eldy received an honourable mention at the Ministerial conference on e-inclusion in Vienna in December 2008.

For more information:

www.eldy.eu.

<http://www.epractice.eu/en/cases/eldy>

Enrico Neri
enrico.neri@eldy.eu

3 ETHICAL GUIDANCE FOR E-INCLUSION

3.1 INTRODUCTORY REMARKS

Is it possible to prepare an ethical guidance for e-inclusion, one that holds true in all contexts for all stakeholders at all times?

It seems unlikely. Many experts would agree that “It is difficult if not impossible to make a complete checklist of ethical issues that is valid for researchers in all technological research. New research might bring forth new ethical issues that are not foreseeable. A checklist can therefore never guarantee that all ethical issues will be identified. The checklist, can however, make sure that ethical issues that are foreseeable are being identified.”²³

Ethical guidelines could be prescriptive (“Thou shalt not...”), but such an approach seems fraught with dangers and risks since what is ethically correct in one context or situation may not be ethically correct in another. A society might abhor murder, but if agents of the society had the chance of eliminating Hitler at the mid-point of the Holocaust, should they have done so? A society can proscribe testing on animals, but if some testing on animals is necessary (but cruel) in order to test a promising vaccine that can overcome HIV, should that testing be permitted?

In the LOCOMOTION project, funded under the European Commission’s Fifth Framework Programme, Dr Ken Boddy argued in favour of “situated ethics” as the most appropriate theory from which to analyse the issues associated with the application of technologies. Situated ethics evolved from the work of the Christian theologian Joseph Fletcher (1966), who stressed that ethical decisions always occur in concrete social space (real people in real situations) and that the morality of their decisions must involve contextual appreciation. This realist approach to ethics rejects both absolutism and relativism in favour of groundedness.²⁴

This approach is in keeping with the classic 1985 essay, “What is Computer Ethics?”, in which its author James H. Moor said, “Understanding logical malleability is also important in setting policies for the use of computers.”²⁵ He explained “logical malleability” by saying that “Computers are logically malleable in that they can be shaped and molded to do any activity that can be characterized in terms of inputs, outputs, and connecting logical operations.” This power of computers means that “A typical problem in computer ethics arises because there is a policy vacuum about how computer technology should be used... A central task of computer ethics is to determine what we should do in such cases, i.e., to formulate policies to guide our actions.” In other words, given the logical malleability of information technology, it

²³ Van Gorp, Anke, “Ethics in and During Technological Research; An Addition to IT Ethics and Science Ethics”, in Paul Sollie and Marcus Düwell, *Evaluating New Technologies*, Springer Science, Dordrecht, 2009, pp. 39-40.

²⁴ Boddy, Dr Ken, LOCOMOTION Ethical Study Report, Deliverable D 3.3, Final Version, September 2004, p. 15. Others have made similar observations. “The evaluation and the practical consequences of a particular technological application depend on where it is introduced. A fully objective evaluation is difficult, and it becomes impossible without considering the social and cultural context in which it will be received.” Basart Munoz, Josep M., “Ethics Applied to Technologies – Is All Well?”, *IEEE Technology and Society Magazine*, Winter 2008, pp. 45-49.

²⁵ Moor, James H., “What is Computer Ethics?”, in Terrell Ward Bynum (ed.), *Computers & Ethics*, Blackwell, 1985, pp.266-275.

appears highly problematic to write a set of ethical prescriptions applicable to all contexts, as Moor explicitly opined: “Computer ethics is not a fixed set of rules which one shellacs and hangs on the wall. Nor is computer ethics the rote application of ethical principles to a value-free technology. Computer ethics requires us to think anew about the nature of computer technology and our values.”

Helen Nissenbaum, author of the influential essay “Privacy as contextual integrity”, argued along somewhat the same lines. She presented a model of informational privacy in terms of contextual integrity, namely, that in determining privacy threats, one needs to take into account the nature of a situation or context: what is appropriate in one context can be a violation of privacy in another context.²⁶

If a proscriptive ethical guidance is problematic, then a better approach would be to ask questions, which is what the European Commission itself does.²⁷ Those making proposals for funding under the Commission’s Framework Programmes of research and technological development must respond to a set of ethical questions (e.g., “Does the proposal involve tracking the location or observation of people?”). Questions aimed at identifying issues also feature in the privacy impact assessment models in countries such as Canada²⁸ and the UK²⁹. Scholars such as Gary Marx have also formulated sets of questions aimed at uncovering ethical issues.³⁰ Not all experts or ethicists favour a checklist of questions because they fear that responding to such questions will become routinised or that somehow they will lead to a “dumbing down” of thoughtful consideration of the issues at stake. While that is a risk, nevertheless questions do seem a useful way of provoking consideration of the issues at stake by those undertaking new projects or designing new technologies or services. In any event, other measures such as privacy audits or reviews by a committee of independent ethicists will surely spot a too-casual response to the questions.

While agnostics can express their doubts about a guidance set in stone, surely they must accept that a set of shared values is necessary for a society to function well. Shared values are an integral part of the vision of what the European Union is all about. The EU, before being a geo-political entity, is a community of values:

European identity is founded on the values contained in its Declaration for Europe, adopted at the extraordinary CoR plenary session held in Rome on 23 March 2007; these values include respect for human beings, their freedoms, rights and dignity; the principles of solidarity and responsibility; the rule of law and equality before the law; cultural diversity; the consolidation of the European social model; and the development of local and regional autonomy and civil society. These values, which are non-negotiable and valid for all who reside in the Union, lay the foundations for a bond of trust between the Union, its different levels of governance and its citizens, and establish the key features of a common European identity.³¹

²⁶ Nissenbaum, H., “Privacy as Contextual Integrity”, *Washington Law Review*, Vol. 79, No. 1, 2004, pp. 101-139.

²⁷ http://cordis.europa.eu/fp7/ethics_en.html#ethics_cl

²⁸ Treasury Board of Canada Secretariat, *Privacy Impact Assessment Guidelines: A framework to Manage Privacy Risks*, Ottawa, 31 Aug 2002.

²⁹ [UK] Information Commissioner’s Office (ICO), *Privacy Impact Assessment Handbook*, Version 2.0, June 2009. http://www.ico.gov.uk/for_organisations/topic_specific_guides/pia_handbook.aspx

³⁰ Van Gorp, op. cit., p. 35, also proposed a list of questions “that helps researchers doing research in technological fields to identify ethical aspects of their research”.

³¹ EU Committee of the Regions, Conclusions of the Conference-debate of the Commission for Constitutional Affairs, European Governance and the Area of Freedom, Security and Justice, Münster, 2 May 2007.

The EU Reform Treaty, signed by Heads of State and Government at the European Council in Lisbon on 13 December 2007, 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.³² These values are also stated in the Charter of Fundamental Rights of the European Union³³, and constitute the key frame for design and implementation of all EU policies. The presupposition that all EU policies have to be consistent with the fundamental rights means that EU policies – beyond their obvious and explicit targets – also have a general goal to promote and pursue European ethical principles.³⁴

The European Charter of Fundamental Rights sets out certain shared values, which could serve as an ethical guidance. In fact, it has been adopted here as the baseline for identifying the key values or ethical principles or issues that must be taken into account in the development of new projects, etc. Other important policies dealing with ethical issues or touching upon such issues are also mentioned.

Palm and Hansson are of the view that the primary task of an ethical technology assessment should be to identify potential ethical issues associated with a new technology. Even if new technology often gives rise to new moral issues, historical experience can help to identify common problem areas. They offer a preliminary check-list of ethical issues, i.e., including:

- Dissemination and use of information
- Control, influence and power
- Impact on social contact patterns
- Privacy
- Sustainability
- Human reproduction
- Gender, minorities and justice
- International relations
- Impact on human values.³⁵

Most of these issues are to be found in the pages that follow. Human reproduction is not considered here as it is not an information technology. Some of the issues listed in Palm and Hansson are found in the pages that follow under different headings, e.g., “Impact on social contact patterns” is here subsumed under the heading “Isolation and substitution of human contact”; “Control, influence and power”, which mentions the digital divide, is subsumed under the heading “Social solidarity, inclusion & exclusion”; “Gender, minorities and justice” is subsumed under the heading “Discrimination and social sorting”. Rather than a simple list, the issues considered in this paper are grouped according to the framework of the four broad principles set out by Beauchamp and Childress, namely respect for autonomy, nonmaleficence, beneficence and justice,³⁶ but privacy and data protection principles and

³² <http://eurlex.europa.eu/JOHtml.do?uri=OJ:C:2007:306:SOM:EN:HTML>

³³ http://www.europarl.europa.eu/charter/pdf/text_en.pdf

³⁴ COM(2007) 161 final, Brussels, 4 Apr 2007.

³⁵ Palm, Elin, and Sven Ove Hansson, “The case for ethical technology assessment (eTA)”, *Technological Forecasting & Social Change*, Vol. 73, 2006, pp. 543-558. An extensive set of criteria, some of which are ethical, for assessing emerging technologies can be found in Kuzma, Jennifer, et al., “An Integrated Approach to Oversight Assessment for Emerging Technologies”, *Risk Analysis*, Vol. 28, No. 5, 2008, pp. 1197-1219. Kuzma et al. also use a question approach for assessing emerging technologies.

³⁶ Beauchamp, Tom L., and James F. Childress, *Principles of biomedical ethics* (5th ed.), Oxford University Press, New York, 2001.

issues have been separately grouped, in view of their preponderant role in ethical considerations of information technologies in general and e-inclusion in particular.

The approach followed here aims to help stakeholders to determine whether their actions involve ethical issues. This guidance does that by means of questions. Recognising that contexts and circumstances can vary and that ethics must take those into account, a guidance that consists of a series of questions can still implicitly recognise the fundamentality of shared values as well as the importance of stakeholders' taking context into account. Thus, while the Charter can forcefully say there is an obligation to respect human dignity, a guidance could frame a question, e.g., does this ICT project respect human dignity?

Ethical questions can be asked at any point during research, development, deployment, application and use of ICTs.³⁷ The sooner they are asked, the greater are the chances that a project can avoid subsequent criticism or costly retrofits. Ethical questions can be posed to and considered by different stakeholders, e.g., those who develop the technology, deploy it and use it, as well as those who authorise and audit its use and those who use it or might be affected by it. Generally, the questions on the pages that follow are asked of those who are developing a new technology or planning to develop a new project or service or considering a new policy, rather than of those who might be affected by the technology or project.

Ethical questions can also be asked about the *process* of assessing the use of technologies or a new project. Thus, in addition to questions framed around various ethical issues, this guidance also raises questions about process. We offer a set of ethical “tools”, with a particular focus on process, which can be used to ensure that ethical issues are properly and adequately considered from the time the development of a new project, policy, service or technology is initiated.

In this text, the term “project” is frequently used. The term should be interpreted in its widest sense, i.e., here it can be taken to mean a new policy, programme, technology, system, service, etc.

3.2 ETHICAL PRINCIPLES

Each section that follows has some brief explanatory text and then a set of questions relating to the given issue. We have drawn on various sources in compiling these questions. No doubt more issues and questions could be added and some of the questions could be framed differently, and that's fine. To some extent, the issues and questions set out here should be regarded as indicative, rather than comprehensive.

3.3 RESPECT FOR AUTONOMY (RIGHT TO LIBERTY)

According to Beauchamp and Childress, “Personal autonomy is, at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice. The autonomous individual acts freely in accordance with a self-chosen plan... A person of diminished autonomy, by contrast, is in some respects controlled by others or incapable of deliberating or acting on the basis of his or her desire and plans... Virtually all theories of autonomy agree that two conditions are

³⁷ Vedder, Anton, and Bart Custers, “Whose Responsibility Is It Anyway? Dealing with the Consequences of New Technologies”, in Paul Sollie and Marcus Düwell (eds.), *Evaluating New Technologies*, Springer Science, Dordrecht, 2009.

essential for autonomy (1) *liberty* (independence from controlling influences) and (2) *agency* (capacity for intentional action).”³⁸

Autonomy, equated with liberty, is a right enshrined in Article 6 of the European Charter of Fundamental Rights as well as Article 3 of the UN’s Universal Declaration of Human Rights of 10 December 1948³⁹.

Questions

Does the project curtail a person’s right to liberty and security in any way?

Does the project recognise and respect the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community?

Will the project use a technology to constrain a person or curtail their freedom of movement or association?

Does the person have a meaningful choice, i.e., are some alternatives so costly that they are not really viable alternatives?

3.3.1 Dignity

Dignity is a key value, as evidenced by its being the subject of Article 1 (“Human dignity is inviolable. It must be respected and protected.”) of the Charter of Fundamental Rights as well Article 25 which specifically refers to the rights of the elderly (“The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.”)

Dignity also features in Article 1 of the UN’s Universal Declaration of Human Rights, which states that “All human beings are born free and equal in dignity and rights.” Article 1 of the Charter of Fundamental Rights provides that dignity is to be not only “respected”, but also “protected”. This means that public authorities are required not only to refrain from tampering or interfering with an individual’s private sphere, but also to take steps in order to bring about the conditions allowing individuals to live with dignity.

Dr Ken Boddy (from the FP5 LOCOMOTION project) has opined that dignity means that citizens should be enabled to live in dignity and security and be free of exploitation and physical or mental abuse. Citizens should be able to participate actively in the formulation and implementation of policies that directly affect their well-being. They should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.⁴⁰

The fact that some citizens need to be in assisted living residences does not mean that they have lost their entitlement to their fundamental rights and dignity. The LOCOMOTION report rightly makes this point: “Clients should be enabled to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect

³⁸ Beauchamp and Childress, 2001, p. 58.

³⁹ www.un.org/Overview/rights.html

⁴⁰ Boddy, p. 39.

for their dignity, beliefs, needs and privacy and for the right to make decisions about their continuing care and the quality of their lives.”⁴¹

Respect for the dignity of senior citizens can be manifested in different ways, including in the use of devices by or for senior citizens – i.e., as far as possible devices “should not make users feel different from others or make them appear to be something ‘less’ than the rest of us”.⁴²

“It is clear that many people do not want to stand out in a crowd and anything that ‘makes them’ (forces them to) do so, is an intrusion on their privacy and a demeaning of their dignity.”⁴³

Questions

Does the project recognise and respect the right of citizens to lead a life of dignity and independence and to participate in social and cultural life?

Is such a recognition explicitly articulated in statements to those involved in or affected by the project?

Does the project comprise or violate human dignity? For example, does the project involve body scanners?

Does the project require citizens to use a technology that marks them in some way as cognitively or physically disabled?

Does the project or service or application involve implants?⁴⁴

3.3.2 Informed consent

It has been said that consent must be meaningful: “Give us your data or we won’t serve you” is not meaningful consent.⁴⁵

The EU Directive on clinical trials (2001/20/EC) provides good guidance on informed consent. It says that a person gives informed consent to take part in a trial only if his decision:

- is given freely after that person is informed of the nature, significance, implications and risks of the trial and either:
- is evidenced in writing, dated and signed, or otherwise marked, by that person so as to indicate his consent, or
- if the person is unable to sign or to mark a document, his consent is given orally in the presence of at least one witness and recorded in writing.

The Directive says the following conditions apply to the giving of informed consent by a capable adult:

⁴¹ Boddy, p. 40.

⁴² Boddy, p. 48.

⁴³ Boddy, p. 47.

⁴⁴ For ethical considerations re implants, see the European Group on Ethics in Science and New Technologies (EGE), Opinion No. 20 on Ethical Aspects of ICT Implants in the Human Body, Adopted on 16 March 2005.

⁴⁵ Goldberg, Ian, Austin Hill and Adam Shostack, “Trust, Ethics, and Privacy”, *Boston University Law Review*, Vol. 81, 2001, pp. 101-116.

- The subject (end user) has had an interview with the investigator, or another member of the investigating team, in which he has been given the opportunity to understand the objectives, risks and inconveniences of the trial (research activity) and the conditions under which it is to be conducted.
- The subject has been informed of his right to withdraw from the trial at any time.
- The subject has given his informed consent to taking part in the trial.
- The subject may, without being subject to any resulting detriment, withdraw from the trial at any time.
- The subject has been provided with a contact point where he may obtain further information about the trial.

The Directive says that in the case of other persons incapable of giving their consent, such as persons with dementia, psychiatric patients, etc., inclusion in clinical trials in such cases should be on an even more restrictive basis. Medicinal products for trial may be administered to all such individuals only when there are grounds for assuming that the direct benefit to the patient outweighs the risks. Moreover, in such cases the written consent of the patient's legal representative, given in cooperation with the treating doctor, is necessary before participation in any such clinical trial.

The posture of the Directive toward informed consent is not only relevant in clinical trials, but also in trials and applications of information technology too, in instances where persons might use a particular technology of their own free will or might be obliged to use it in a situation where they cannot give informed consent (for example, because they suffer from dementia). Many online services should also obtain informed consent with regard to the collection and use of personal data. Informed consent is also addressed in Article 7 of the EU Data Protection Directive: “Member States shall provide that personal data may be processed only if: (a) the data subject has unambiguously given his consent”.

Questions

Has the project obtained the free and informed consent of those persons involved in or affected by the project?

Has the person been informed of the nature, significance, implications and risks of the project (or trial)?

Has such consent been evidenced in writing, dated and signed, or otherwise marked, by that person so as to indicate his consent?

If the person is unable to sign or to mark a document so as to indicate his consent, has his consent been given orally in the presence of at least one witness and recorded in writing?

Are people aware that personal data may be collected? Are they aware of who is collecting it and why?

Has the person consented to collection of his personal data?

Does the consent outline the use for which data are to be collected, how the data are to be collected, instructions on how to obtain a copy of the data, a description of the mechanism to correct any erroneous data, and details of who will have access to the data?

If the individual is not able to give informed consent (because, for example, the person suffers from dementia) to participate in a project or to use of a technology, have the project representatives consulted with close relatives, a guardian with powers over the person's welfare or professional carers? Has written consent been obtained from the patient's legal representative and his doctor?

Has the person had an interview with a project representative in which he has been given the opportunity to understand the objectives, risks and inconveniences of the project or research activity and the conditions under which it is to be conducted?

Has the person been informed of his right to withdraw from the project or trial at any time, without being subject to any resulting detriment or the foreseeable consequences of declining to participate or withdrawing?

Has the project ensured that persons involved in the project have given their informed consent, not only in relation to the aims of the project, but also in relation to the *process* of the research, i.e., how data will be collected and by whom, where it will be collected, and what happens to the results?

Are persons involved in or affected by the project able to withdraw from the project *and* to withdraw their data at any time right up until publication?

Does the project or service collect information from children?

Is consent given truly voluntary? For example, does the person need to give consent in order to get a service to which there is no alternative?

Does the person have to deliberately and consciously opt out in order *not* to receive the "service"?

3.4 NONMALEFICENCE (AVOIDING HARM)

Beauchamp and Childress say that "The principle of nonmaleficence asserts an obligation not to inflict harm on others" and that "Nonmaleficence only requires intentionally refraining from actions that cause harm. Rules of nonmaleficence, therefore, take the form of 'Do not do X'"⁴⁶.

3.4.1 Safety

Article 38 of the Charter of Fundamental Rights deals with consumer protection: "Union policies shall ensure a high level of consumer protection." It is the subject of Article 153 of the EC Treaty: "In order to promote the interests of consumers and to ensure a high level of consumer protection, the Community shall contribute to protecting the health, safety and economic interests of consumers, as well as to promoting their right to information, education and to organise themselves in order to safeguard their interests." Consumer protection at European level is also provided by (amongst others) Directive 93/13 on unfair terms in consumer contracts, Directive 97/7 on consumer protection in respect of distance contracts

⁴⁶ Beauchamp and Childress, 2001, p. 113 and p. 115.

and the Directive on liability for defective products (85/374/EEC).

Questions

Will the project cause any physical or psychological harm to consumers?

Have any independent studies already been carried out or, if not, are any planned which will address the safety of the technology or service or trials? If so, have they been made public?

To what extent is scientific or other objective evidence used in making decisions about specific products, processes or trials?

Does the project affect consumer protection?

Will the project take any measures to ensure that persons involved in or affected by the project will be protected from harm in the sense that they will not be exposed to any risks other than those they might meet in normal everyday life?

Can the information be used in such a way as to cause unwarranted harm or disadvantage to a person or a group?

Does the project comply with the spirit of consumer legislation (e.g., Directive 93/13 on unfair terms in consumer contracts, Directive 97/7 on consumer protection in respect of distance contracts and the Directive on liability for defective products (85/374/EEC)?

3.4.2 Social solidarity, inclusion and exclusion

The European Council's Lisbon Strategy adopted the notion of e-inclusion which "refers to the actions to realise an inclusive information society, that is, an information society for all".⁴⁷ To achieve this objective, which is a manifestation of the value of social solidarity, Europe must tackle the root causes of exclusion and e-exclusion. There are various reasons why some people are excluded from the Information Society, but cost and knowledge are among the principal ones.⁴⁸

Questions

Has the project taken any steps to reach out to the e-excluded?

Does the project or policy have any effects on the inclusion or exclusion of any groups?

Are there offline alternatives to online services?

Is there a wide range of perspectives and expertise involved in decision-making for the project?

⁴⁷ Council resolution e-Inclusion, exploiting the opportunities of the information society for social inclusion, 2001/C 292/02, OJ 18 October 2001.

⁴⁸ Wright, David, and Kush Wadhwa, "Mainstreaming the e-excluded in Europe", *Ethics and Information Technology*, 2010 [forthcoming].

How many and what kinds of opportunities do stakeholders and citizens have to bring up value concerns?

3.4.3 Isolation and substitution of human contact

Isolation is the objective condition of having too few and too poor social ties, of not being in any relevant social network. New forms of communication – from phone calls to e-mails, instant messaging, Web meetings, social networking, wireless personal area networks and so on – help to alleviate, if not overcome, isolation. By the same token, however, new communication tools may become a substitution for face-to-face contact and could, thereby, make social isolation worse. Palm and Hansson rightly observe that “even if communication is facilitated, it is not self-evident that this will bring people together. There is a tendency for electronically mediated contacts to substitute face-to-face contacts.”⁴⁹ Moreover, many senior citizens and the disabled are already isolated because the new technologies and services are not affordable or are otherwise inaccessible. In any event, the availability of new communication technologies may diminish the interest in going outside the home, which would only compound the reduction in face-to-face contacts.

Questions

Will the project use a technology which could replace or substitute for human contact?

Is there a risk that a technology or service may lead to greater social isolation of individuals?

Is there a risk that use of the technology will be seen as stigmatising, e.g., in distinguishing the user from other people?

3.4.4 Discrimination and social sorting

Article 21 of the European Charter of Fundamental Rights prohibits “Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation”.

Discrimination occurs, not only in employment but also in access to goods and services such as banking, education, transport and health. Aiming to guarantee equal treatment in these areas, the European Commission proposed legislation on anti-discrimination outside the field of employment in the summer of 2008. The European Parliament adopted the Directive on 2 April 2009.

Profiling technologies have raised a host of ethical, legal and other issues including privacy, equality, due process, security and liability. Profiling technologies make possible a far-reaching monitoring of an individual’s behaviour and preferences. Profiling technologies are by their very nature discriminatory tools. They allow unparalleled kinds of social sorting⁵⁰ and segmentation which could have unfair effects. The people profiled may have to pay higher prices, could miss out on important offers or opportunities, and may run increased risks

⁴⁹ Palm and Hansson, p. 552.

⁵⁰ Social sorting is a process of classifying people and populations according to varying criteria, to determine who should be targeted for special treatment, suspicion, eligibility, inclusion, access and so on. See Lyon, David, *Surveillance as Social Sorting: Privacy, Risk, and Digital Discrimination*, Routledge, London, 2003, p. 20.

because catering to their needs is less profitable. In most cases, they will not be aware of this, since profiling practices are mostly invisible and the profiles themselves protected by intellectual property or trade secret. This poses a threat to the equality of and solidarity of citizens.⁵¹

Questions

Could the project be perceived as discriminating against any groups?

Does the project or service use profiling technologies?

Does the project or service facilitate social sorting?

3.5 BENEFICENCE

Beauchamp and Childress say “Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare. Such beneficial actions fall under the heading of ‘beneficence’... principles of beneficence potentially demand more than the principle of nonmaleficence because agents must take positive steps to help others, not merely refrain from harmful acts.” They cite two principles of beneficence: “*Positive beneficence* requires agents to provide benefits. *Utility* requires that agents balance benefits and drawbacks to produce the best overall results.”⁵²

Questions

Will the project provide a benefit to individuals? If so, how will individuals benefit from the project (or use of the technology or service)?

Who benefits from the project and in what way?

Will the project improve personal safety, increase dignity, independence or a sense of freedom?

Does the project serve broad community goals and/or values or only the goals of the data collector?

Are there alternative, less privacy intrusive or less costly means of achieving the objectives of the project?

What are the consequences of not proceeding with development of the project?

Does the project or technology or service facilitate the self-expression of users?

3.5.1 Universal service

Universal service means an obligation imposed on one or more operators of electronic communications networks and/or services to provide a minimum set of services to all users,

⁵¹ For more on profiling and social sorting, see Hildebrant, Mireille, and Serge Gutwirth, *Profiling the European Citizen*, Springer Science, Dordrecht, 2008 as well Lyon, op. cit.

⁵² Beauchamp and Childress, p. 165

regardless of their geographical location within the national territory, at an affordable price.⁵³ Universal service is broader than basic telephony service. Now the notion of universal service in Europe encompasses broadband and Internet access for all. The European Commission and various Member States have recognised that it makes economic and social sense to extend broadband Internet access to all citizens. It is also the ethically correct thing to do. They have made commitments with specific deadlines to achieving this objective.⁵⁴ Finland has recently made broadband access to the Internet a basic right.⁵⁵

Questions

Will the project or service be made available to all citizens?

Will training be provided to those who do not (yet) have computer skills or knowledge of the Internet?

Will the service cost the same for users who live in remote or rural areas as for users who live in urban areas?

3.5.2 Accessibility

With some exceptions, industry is reluctant to factor the needs of the disabled and senior citizens in their design of technologies and services and to adopt a design-for-all approach. The accessibility (user-friendliness) of devices and services are prerequisites for the e-inclusion of senior citizens in the Information Society. Markets tend to overlook senior citizens' needs: there are few guidelines, voluntary or mandatory standards and related regulatory frameworks.⁵⁶

Others have said commitment to accessibility is widespread throughout the ICT industry, that there is a strong willingness on the part of software and hardware vendors to create accessible products; however, vendors' ability to develop and deploy accessible products is held back by the need to comply with multiple standards. Thus, there needs to be greater convergence between the accessibility standards in force in different areas – such as Europe and the US – so that vendors can develop products that can be marketed and sold worldwide.⁵⁷

⁵³ Directive 2002/22/EC of the European Parliament and of the Council of 7 March 2002 on universal service and users' rights relating to electronic communications networks and services (Universal Service Directive), Official Journal L 108 of 24 April 2002.

⁵⁴ On 28 January 2009, the European Commission announced its aim to achieve 100 per cent high-speed Internet coverage for all citizens by 2010. See European Commission, "Commission earmarks €1bn for investment in broadband – Frequently Asked Questions", Press release, MEMO/09/35, Brussels, 28 January 2009 <http://europa.eu/rapid/pressReleasesAction.do?reference=MEMO/09/35>

⁵⁵ Johnson, Bobbie, "Finland makes broadband access a legal right", *The Guardian*, 14 Oct 2009. <http://www.guardian.co.uk/technology/2009/oct/14/finland-broadband>

⁵⁶ European Commission, *Ageing well in the Information Society, Action Plan on Information and Communication Technologies and Ageing*, An i2010 Initiative, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2007) 332 final, Brussels, 14 June 2007.

⁵⁷ See the statement by Oracle: "Oracle Welcomes New EU Policy on e-Inclusion". <http://www.oracle.com/global/eu/public-policy/fs/new-e-inclusion-policy.html>

Although the initiatives of some in the private sector to improve accessibility are welcome, overall, there is still a far from adequate supply of affordable, accessible ICTs.⁵⁸ According to the European Commission, a lack of accessibility persists in many areas, including websites, digital television, phones, emergency services and public information terminals. New barriers to accessibility are appearing, often because of market failures, even though the markets for accessible products and services are worth many billions of euros. With 15 per cent of the EU population suffering some form of disability, they represent a mass market.

Questions

Does the new technology or service or application expect a certain level of knowledge of computers and the Internet that some people may not have?

Is the project or technology or service being designed to be accessible and easy to use for senior citizens and/or citizens with disabilities?

Are some services being transferred to the Internet only, so that a service is effectively no longer available to people who do not (know how to) use computers or the Internet?

3.5.3 Value sensitive design

Some experts have argued that technology is not neutral with respect to values. Among those that argue in favour of Value Sensitive Design, Flanagan, Howe and Nissenbaum say that the design of technologies bears directly and systematically on the realisation, or suppression, of particular configurations of social, ethical, and political values.⁵⁹ They also observe that “the values of members of a design team, even those who have not had a say in top level decisions, often shape a project in significant ways as it moves through the design process. Beliefs and commitments, and ethnic, economic, and disciplinary training and education, may frame their perspectives, preferences, and design tendencies, resulting eventually in features that affect the values embodied in particular systems.”⁶⁰

Questions

Is the project or technology or service being designed taking into account values such as human well being, dignity, justice, welfare, human rights, trust, autonomy and privacy?

Have the technologists and engineers discussed their project with ethicists and other experts from the social sciences to ensure value sensitive design?

Does the new technology, service or application empower users?

⁵⁸ European Commission, European i2010 initiative on e-Inclusion: “To be part of the information society”, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2007) 694 final, Brussels, 8 Nov 2007, p. 4.

⁵⁹ Flanagan, Mary, Daniel C. Howe and Helen Nissenbaum, “Embodying Values in Technology: Theory and Practice”, in Jeroen van den Hoven and John Weckert (eds.), *Information Technology and Moral Philosophy*, Cambridge University Press, Cambridge, 2008, pp. 322-353.

⁶⁰ Flanagan, et al., p. 335.

3.5.4 Sustainability

Sustainability, as used here, refers to a condition whereby a project or service can be sustained, can continue into the future, either because it can generate the financial return necessary for doing so or that it has external support (e.g., government funding) which is not likely to go away in the foreseeable future. In addition to economic and social sustainability, more conventional understandings of sustainability should also be considered, i.e., decisions made today should be defensible in relation to coming generations and the depletion of natural resources. Often new technological products can be improved for instance through the use of more recyclable materials.⁶¹

Questions

Is the project, technology or service economically or socially sustainable?

Will a service provided by means of a research project continue once the research funding comes to an end?

Does the technology have obsolescence built in?

3.6 JUSTICE

Beauchamp and Childress draw a distinction between the terms *justice* and *distributive justice* as follows:

The terms *fairness*, *desert* (what is deserved), and *entitlement* have been used by various philosophers in attempts to explicate *justice*. These accounts interpret justice as fair, equitable, and appropriate treatment in light of what is due or owed to persons. Standards of justice are needed whenever persons are due benefits or burdens because of their particular properties or circumstances, such as being productive or having been harmed by another person's acts. A holder of a valid claim based in justice has a right, and therefore is due something. An injustice thus involves a wrongful act or omission that denies people benefits to which they have a right or distributes burdens unfairly.

The terms distributive justice refers to fair, equitable, and appropriate distributions determined by justified norms that structure the terms of social cooperation. Its scope includes policies that allot diverse benefits and burdens, such as property, resources, taxation, privileges, and opportunities. Distributive justice refers broadly to the distribution of all rights and responsibilities in society, including, for example, civil and political rights.⁶²

Questions

Has the project identified all vulnerable groups that may be affected by its undertaking?

Is the project equitable? Can it be made more equitable?

Does the project confer benefits on some groups but not on others?

Do some groups have to pay more than other groups for the same service?

⁶¹ Palm and Hansson, p. 553.

⁶² Beauchamp and Childress, 2001, p. 226.

3.6.1 Equality and fairness (social justice)

One commentator has distinguished between equality and fairness, thusly:

The terms “justice” and “fairness” are often used interchangeably. Taken in its broader sense, justice is action in accordance with the requirements of some law. Some maintain that justice consists of rules common to all humanity that emerge out of some sort of consensus. This sort of justice is often thought of as something higher than a society’s legal system. It is in those cases where an action seems to violate some universal rule of conduct that we are likely to call it “unjust”. In its narrower sense, justice is fairness. It is action that pays due regard to the proper interests, property and safety of one’s fellows. While justice in the broader sense is often thought of as transcendental, justice as fairness is more context-bound. Parties concerned with fairness typically strive to work out something comfortable and adopt procedures that resemble rules of a game. They work to ensure that people receive their “fair share” of benefits and burdens and adhere to a system of “fair play”.

The principles of justice and fairness can be thought of as rules of “fair play” for issues of social justice. Whether they turn out to be grounded in universal laws or ones that are more context-bound, these principles determine the way in which the various types of justice are carried out...

The principles of equity, equality, and need are most relevant in the context of distributive justice, but might play a role in a variety of social justice issues. These principles all appeal to the notion of desert, the idea that fair treatment is a matter of giving people what they deserve.⁶³

Questions

Will the service or technology be made widely available or will it be restricted to only the wealthy, powerful or technologically sophisticated?⁶⁴

Does the project or policy apply to all people or only to those less powerful or unable to resist?

If there are means of resisting the provision of personal information, are these means equally available or are they restricted to the most privileged?⁶⁵

Are there negative effects on those beyond the person involved in the project or trials and, if so, can they be adequately mediated?

If persons are treated differently, is there a rationale for differential applications, which are clear and justifiable?

Will any information gained be used in a way that could cause harm or disadvantage to the person to whom it pertains? For example, could an insurance company use the information to increase the premiums charged or to refuse cover?

⁶³ Maiese, Michelle, “Principles of Justice and Fairness”, Beyond Intractability.org, July 2003.

http://www.beyondintractability.org/essay/principles_of_justice/

⁶⁴ Marx, p. 174.

⁶⁵ Marx, p. 174.

3.7 PRIVACY AND DATA PROTECTION

Privacy is guaranteed as a right in the European Charter of Fundamental Rights, the European Convention of Human Rights, the UN's Universal Declaration of Rights as well as the EU's Data Protection Directive (95/46/EC), the e-Privacy Directive (2000/58/EC), etc.

Article 12 of the Universal Declaration of Human Rights says "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence."

Article 8 of the Council of Europe's Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocol No. 11, Rome, 4.XI.1950, addresses the right to respect for private and family life.⁶⁶

The 1980 OECD Guidelines on the Transborder Flows of Personal Data and the EU's Data Protection Directive (95/46/EC) identify a set of fair information practices or principles which are important in any consideration of ethical issues that might arise in matters affecting privacy and data protection.

The complexities and intricacies of issues relating to privacy and data protection have received huge attention from policy-makers, regulators, academia, the mass media and many other stakeholders, including ethicists. "Privacy... is now recognized by many computer ethicists as requiring more attention than it has previously received in moral theory. In part this is due to reconceptualizations of the private and public sphere brought about by the use of computer technology, which has resulted in inadequacies in existing moral theory about privacy."⁶⁷

Some years ago, Roger Clarke identified four dimensions of privacy:

- privacy of the person;
- privacy of personal behaviour;
- privacy of personal communications; and
- privacy of personal data.⁶⁸

All four of these dimensions are referenced in the pages that follow.

3.7.1 Collection limitation (data minimisation) and retention

The OECD guidelines say there should be limits to the collection of personal data and any such data should be obtained by lawful and fair means and, where appropriate, with the knowledge or consent of the data subject.⁶⁹

⁶⁶ <http://conventions.coe.int/treaty/en/Treaties/Html/005.htm>

⁶⁷ Brey, Philip, "Method in computer ethics: Towards a multi-level interdisciplinary approach", *Ethics and Information Technology*, Vol. 2, No. 2, June 2000, pp. 125-129. Previous to this, Moor commented that "From the point of view of ethical theory, privacy is a curious value. On the one hand, it seems to be something of very great importance and something vital to defend, and, on the other hand, privacy seems to be a matter of individual preference, culturally relative, and difficult to justify in general." He goes on to argue that privacy has both instrumental value (that which is good because it leads to something else which is good) and intrinsic value (that which is good in itself). Moor, James H., "Towards a Theory of Privacy in the Information Age", *Computers and Society*, Sept. 1997, pp. 27-32.

⁶⁸ Clarke, Roger, "Introduction to Dataveillance and Information Privacy, and Definitions of Terms", Aug 2007. <http://www.rogerclarke.com/DV/Intro.html>

⁶⁹ The Guidelines don't specify or define what "where appropriate" means.

Data retention concerns the storage of call detail records of telephony and Internet traffic and transaction data, the phone calls made and received, e-mails sent and received and websites visited. These data provide an idea of who stays in contact with whom, when and how frequently. Further identifying information could be added as well as location data. The content of calls or e-mail is not (supposed to be) retained indefinitely. The Data Retention Directive (2006/24/EC) obliges service providers to retain call data for at least six months and up to two years. Such data may be viewed by law enforcement authorities.⁷⁰

Questions

How will the project determine what constitutes the minimum amount of personal data to be collected?

Who will determine what constitutes the minimum amount of personal data to be collected?

Will any data be collected which is not necessary for fulfilling the stated purpose of the project?

Is information collected in ways of which the data subject is unaware?

Is information collected against the wishes of the person?

For how long will the information be retained?

Will the information be deleted when it is no longer needed for the purpose for which it was collected?

3.7.2 Data quality

The OECD guidelines say that personal data should be accurate, complete and kept up-to-date. Similarly, Article 6 of the EU's Data Protection Directive says that personal data must be accurate and, where necessary, kept up to date.

Questions

What measures will be put in place to ensure the quality of the information gathered?

What assurances exist that the information collected is true and accurate?

Has the information been collected from others than the person to whom it pertains?

If the information collected is not accurate, what consequences might ensue?

3.7.3 Purpose specification

The OECD guidelines say that the purposes for which personal data are collected should be specified not later than at the time of data collection. Similarly, Article 6 of the EU's Data

⁷⁰ European Parliament and Council, Directive 2006/24/EC on the retention of data generated or processed in connection with the provision of publicly available electronic communications services or of public communications networks and amending Directive 2002/58/EC, 15 March 2006.

Protection Directive say that personal data must be collected for specified, explicit and legitimate purposes and not further processed in a way incompatible with those purposes.

Questions

Regarding the project, technology or service, are individuals aware that personal information is being (is to be) collected, who seeks it, and why?

Has the purpose of collecting personal data been clearly specified?

Has the project given individuals a full explanation of the purpose of the project or technology in a way that is clear and understandable by individuals?

Has the person been informed of the purpose of the research, its expected duration and the procedures by means of which the data is being (will be) collected?

Is there an appropriate balance between the importance of the project's objectives and the cost of the means?

How have the goals of the data collection been legitimated?

Is there a clear link between the information collected and the goal sought?⁷¹

3.7.4 Use limitation

The OECD guidelines state that personal data should not be disclosed, made available or otherwise used for purposes other than those specified except with the consent of the data subject; or by the authority of law. Similarly, Article 6 of the EU's Data Protection Directive says that personal data must be adequate, relevant and not excessive in relation to the purposes for which they are collected and/or further processed.

Questions

Is the personal information used for the reasons offered for its collection for which consent may have been given, and do the data stay with the original collector, or do they migrate elsewhere?

Is the personal data collected used for profit without permission from or benefit to the person who provided it?⁷²

Who will have access to or use of the data collected?

Will the data be transferred to or shared with others?

⁷¹ Marx, Gary T., "Ethics for the New Surveillance", *The Information Society*, Vol. 14, 1998, pp. 171-185 [p. 174].

⁷² Marx, p. 174.

3.7.5 Confidentiality, security and protection of data

One of the principles in the OECD guidelines deals with security safeguards and states that “Personal data should be protected by reasonable security safeguards against such risks as loss or unauthorised access, destruction, use, modification or disclosure of data.” Similarly, Article 17 of the Data Protection Directive provides that “the controller must implement appropriate technical and organizational measures to protect personal data against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access, in particular where the processing involves the transmission of data over a network, and against all other unlawful forms of processing.”

Questions

Has the project taken measures to ensure protection of personal data, e.g., by means of encryption and/or access control? If so, what are they?

Who will have access to any personal data collected for the project or service?

What safeguards will be put in place to ensure that those who have access to the information treat the information in confidence?

Many service providers who provide service via the telephone say that conversations are monitored for training or quality control purposes. Will that happen in this project or service? What happens (will happen) to such recorded conversations?

3.7.6 Transparency (openness)

Transparency is a precondition to public trust and confidence.

The OECD guidelines contain an openness principle which states that “There should be a general policy of openness about developments, practices and policies with respect to personal data. Means should be readily available for establishing the existence and nature of personal data, and the main purposes of their use, as well as the identity and usual residence of the data controller.”

While the Data Protection Directive does not explicitly mention openness in this way, recital 63 does say that data protection supervisory authorities “must help to ensure transparency of processing in the Member States within whose jurisdiction they fall”.

Vedder and Custers have opined that “With the growing speed of the information and communication networks, two characteristics of the Internet are further enlarged. First, as the number of content providers and the ease of uploading information further increases, assessing the true nature of sources and intermediaries of information becomes more difficult. Second, as the technologies involved become more sophisticated and complicated, the processes of interaction become less transparent.”⁷³

⁷³ Vedder, Anton, and Bart Custers, “Whose Responsibility Is It Anyway? Dealing with the Consequences of New Technologies”, in Paul Sollie and Marcus Düwell (eds.), *Evaluating New Technologies*, Springer Science, Dordrecht, 2009, p. 25.

Philip Brey comments that “It is part of the job of computer ethics to make computer technology and its uses transparent, in a way that reveals its morally relevant features.”⁷⁴ He proposed an approach which he called disclosive computer ethics, which are concerned with disclosing and evaluating embedded normativity in computer systems, applications and practices.

Questions

If a new database is to be created or an existing database extended, has the data controller informed the data protection supervisory authority?

Has the data controller made known publicly that he has or intends to develop a new database, the purpose of the database, how the database will be used and what opportunities exist for persons to rectify inaccurate personal information?

If a database is breached or if the data controller has lost any data, has he informed the persons whose data have been compromised and/or the data protection authority?

What activities will be carried out in order to promote awareness of the project, technology or service?

Will such activities be targeted at those interested in or affected by the project, technology or service?

Has an analysis been made of who are the relevant stakeholders?

Are studies about the pros and cons of the project or technology available to the public?

3.7.7 Individual participation and access to data

The OECD guidelines contain an individual participation principle which states that “An individual should have the right (a) to obtain from a data controller, or otherwise, confirmation of whether or not the data controller has data relating to him; (b) to have communicated to him, data relating to him within a reasonable time, at a charge, if any, that is not excessive, in a reasonable manner, and in a form that is readily intelligible to him; (c) to be given reasons if a request is denied, and to be able to challenge such denial; and (d) to challenge data relating to him and, if the challenge is successful to have the data erased, rectified, completed or amended.”

Similarly, Article 12 (Right of access) of the Data Protection Directive says that

- Member States shall guarantee every data subject the right to obtain from the controller:
- (a) without constraint at reasonable intervals and without excessive delay or expense:
 - confirmation as to whether or not data relating to him are being processed and information at least as to the purposes of the processing, the categories of data concerned, and the recipients or categories of recipients to whom the data are disclosed,
 - communication to him in an intelligible form of the data undergoing processing and of any available information as to their source,

⁷⁴ Brey, op. cit., p. 126.

- knowledge of the logic involved in any automatic processing of data concerning him at least in the case of the automated decisions referred to in Article 15 (1);
- (b) as appropriate the rectification, erasure or blocking of data the processing of which does not comply with the provisions of this Directive, in particular because of the incomplete or inaccurate nature of the data;
- (c) notification to third parties to whom the data have been disclosed of any rectification, erasure or blocking carried out in compliance with (b), unless this proves impossible or involves a disproportionate effort.

Questions

Have measures been put in place to facilitate the person's access to his or her personal data?

Is there a charge for access to data and, if so, how has that charge been determined?

Is the charge stated on the project or service's website?

Will the charge be perceived as reasonable by those whose data are collected and by the data protection supervisory authority?

How long should it usually take to respond to requests for access to personal data and to provide such data?

Can the person whose data are collected rectify easily errors in personal data? What procedures are in place for doing so?

3.7.8 Anonymity

According to the ISO/IEC 15408 standard on evaluation criteria for IT security, anonymity ensures that a subject may use a resource or service without disclosing its user identity.⁷⁵

The OECD guidelines note that "The precise dividing line between personal data in the sense of information relating to identified or identifiable individuals and anonymous data may be difficult to draw and must be left to the regulation of each Member country."

Article 6 of the e-Privacy Directive (2002/58/EC) says that traffic data relating to subscribers and users processed and stored by the provider of a public communications network or publicly available electronic communications service must be erased or made anonymous when they are no longer needed for the purpose of the transmission of a communication. This also applies to all location data processed for the purpose of the conveyance of a communication on an electronic communications network.

The Article 29 Working Party has considered anonymity as an important safeguard for the right to privacy and recommended:

- (a) The ability to choose to remain anonymous is essential if individuals are to preserve the same protection for their privacy online as they currently enjoy offline.
- (b) Anonymity is not appropriate in all circumstances.

⁷⁵ ISO/IEC 15408, Information technology – Security techniques – Evaluation criteria for IT security, First edition, International Organization for Standardization, Geneva, 1999.

(c) Legal restrictions which may be imposed by governments on the right to remain anonymous, or on the technical means of doing so (e.g., availability of encryption products) should always be proportionate and limited to what is necessary to protect a specific public interest in a democratic society.

(d) The sending of e-mail, the passive browsing of World Wide Web sites, and the purchase of most goods and services over the Internet should all be possible anonymously.

(e) Some controls over individuals contributing content to online public fora are needed, but a requirement for individuals to identify themselves is in many cases disproportionate and impractical. Other solutions are to be preferred.

(f) Anonymous means to access the Internet (e.g., public Internet kiosks, prepaid access cards) and anonymous means of payment are two essential elements for true online anonymity.⁷⁶

In its later opinion on search engines, the Article 29 Working Party said that “search engine providers must delete or anonymise (in an irreversible and efficient way) personal data once they are no longer necessary for the purpose for which they were collected.” It called upon search engines to develop appropriate anonymisation schemes. It also said it did “not see a basis for a retention period beyond 6 months.”⁷⁷

Questions

Has the project taken steps to ensure that persons cannot be identified from the data to be collected?

Have pseudonyms or codes been used to replace any data that could identify the individual?

Is there a possibility that data from different sources could be aggregated or matched in a way that undermines the person’s anonymity?

3.7.9 Privacy of personal communications – monitoring and location tracking

Clarke (op. cit.) explains privacy of personal communications by saying that “Individuals claim an interest in being able to communicate among themselves, using various media, without routine monitoring of their communications by other persons or organisations. This includes what is sometimes referred to as “interception privacy”.

For many decades, technology has existed for intercepting and monitoring communications and tracking an individual’s movement. The technology has become increasingly sophisticated, and even the user’s technology (e.g., mobile phones) makes it easy to pinpoint where someone is making a call. There are laws, of course, against monitoring communications without the consent of the user unless it is legally authorised, e.g., by a court-authorized warrant.

Article 5 of the EU’s e-Privacy Directive states that

Member States shall ensure the confidentiality of communications and the related traffic data by means of a public communications network and publicly available electronic

⁷⁶ Article 29 Data Protection Working Party, Recommendation 3/97: Anonymity on the Internet (WP 6), adopted on 3 December 1997. http://ec.europa.eu/justice_home/fsj/privacy/

⁷⁷ Article 29 Working Party, Opinion on data protection issues related to search engines, 00737/EN, WP 148, Adopted on 4 April 2008. http://ec.europa.eu/justice_home/fsj/privacy/workinggroup/wpdocs/2008_en.htm

communications services, through national legislation. In particular, they shall prohibit listening, tapping, storage or other kinds of interception or surveillance of communications and the related traffic data by persons other than users, without the consent of the users concerned, except when legally authorised to do so in accordance with Article 15(1). This paragraph shall not prevent technical storage which is necessary for the conveyance of a communication without prejudice to the principle of confidentiality.

In essence, it means that interception or surveillance of communications can only take place when legally authorised.

The same Directive also addresses location data, defined as “any data processed in an electronic communications network, indicating the geographic position of the terminal equipment of a user of a publicly available electronic communications service”. Article 9 prohibits the processing of location data unless it is made anonymous, or with the consent of the users. The service provider must inform the users, prior to obtaining their consent, of the type of location data which will be processed, of the purposes and duration of the processing.

Questions

Does the project monitor or record a person’s communications?

Does the project involve observation or monitoring of individuals or tracking their movements or whereabouts?

If the project or other action involves interception of private communications, has such interception been properly authorised (e.g., has a warrant been obtained from a judge)?

3.7.10 Privacy of the person

According to Clarke (op. cit.), privacy of the person, sometimes referred to as “bodily privacy”, is concerned with the integrity of the individual’s body. As examples of issues, he cites compulsory immunisation, blood transfusion without consent, compulsory provision of samples of body fluids and body tissue and compulsory sterilisation. We could add examples such as body searches (e.g., at customs and immigration), body scanning at airports, requirements to provide fingerprints or eye scans upon entering countries such as the United States, and so on.

Questions

Does the project or the service or policy or program involve body searches or body scanning?

Does the project involve biometrics, e.g., taking fingerprints or eye scans?

3.7.11 Privacy of personal behaviour

Privacy of personal behaviour, explains Clarke (op. cit.), “relates to all aspects of behaviour, but especially to sensitive matters, such as sexual preferences and habits, political activities and religious practices, both in private and in public places. It includes what is sometimes referred to as ‘media privacy’.”

In the UK (especially), it's been said (by former Information Commissioner Richard Thomas) that we are "sleep-walking into a surveillance society", and there can be no doubt about it in view of the thousands of CCTV cameras that festoon our streets, shopping malls, subways, airports and so on. CCTV cameras and other surveillance and dataveillance technologies record our behaviour and activity.

Surveillance is not only about catching terrorists or criminals or owners who allow their dogs to foul the pavement, but it is also about monitoring senior citizens afflicted with dementia or the disabled to ensure they do not harm themselves or others.

Questions

Does the project involve surveillance of individuals or groups of people?

Have any signs or other notifications been made to alert people to the presence of CCTV cameras or other surveillance devices?

How long will images or data be retained?

How will such images or data be used or erased?

Who will authorise the surveillance practice, whether in public places such as city streets or banks or in assisted living residences?

What measures will be put in place to avoid abuses where, for example, surveillants watch others engaged in behaviour that generally accepted social norms would regard as intimate or private?

3.8 ETHICAL TOOLS

Various tools exist to help determine whether a project raises ethical issues. A set of questions such as those given in previous sections is one such tool. Other tools are given in the following pages.

3.8.1 Process

An ethical guidance should not consist of questions only. A process for engaging and consulting with stakeholders should be put in place to help project managers and data controllers in ensuring that ethical issues are identified, discussed and dealt with, preferably as early in the project development as possible. The process of identifying, discussing and dealing with ethical issues should be ongoing throughout the project and perhaps even after it has been implemented, if only because new ethical issues may arise that were not evident from the outset of the project development. James H. Moor has made this point: "Because new technology allows us to perform activities in new ways, situations may arise in which we do not have adequate policies in place to guide us." Ethical problems can be generated at any point, says Moor, "but the number of ethical problems will be greater as the revolution progresses".⁷⁸

⁷⁸ Moor, James H., "Why we need better ethics for emerging technologies", *Ethics and Information Technology*, Vol. 7, 2005, pp. 111-119. In his paper, Moor proposes the following hypothesis, which he calls "Moor's Law: As technological revolutions increase their social impact, ethical problems increase."

Questions

Has the project manager or data controller developed a process for identifying and considering ethical issues?

Has the project been validated with and/or by relevant stakeholders?

Is the process by means of which decisions are made clearly articulated to stakeholders?

3.8.2 Stakeholder engagement and consultation

There are various reasons why project managers should engage stakeholders and undertake a consultation when developing new technologies or projects. For one thing, Article 41 of the Charter of Fundamental Rights of the European Union, entitled the Right to good administration, makes clear that this right includes “the right of every person to be heard, before any individual measure which would affect him or her adversely is taken...”, which suggests that consultation with stakeholders is not only desirable but necessary.

But there are other reasons too. Stakeholders may bring new information which the project manager might not have considered and may have some good suggestions for resolving complex issues.⁷⁹ Also, technology development is often too complex to be fully understood by a single agent, as Sollie and others have pointed out.⁸⁰ Palm and Hansson state that “It would be delusive to believe that technology developers are conscious of all the effects of their products. In many cases, negative side effects come as a surprise to technology developers themselves. If they could have anticipated the negative consequences, they would, in the vast majority of the cases, have done their best to avoid them out of social concern or for commercial reasons, or both. In our view, a common reason for failures is the lack of adequate training to identify and address ethical issues in technology development. Engineers are seldom trained to discuss ethical issues in a pre-emptive perspective. The training needed would be that of identifying consequences for different stakeholders at an early stage.”⁸¹ Furthermore, by engaging stakeholders, project managers may avoid subsequent criticism about a lack of consultation. Engaging stakeholders before the project is implemented may be a useful way of testing the waters, of gauging the public’s reaction to the project. In any event, “A central premise of democratic government – the existence of an informed electorate – implies a free flow of information.”⁸² Even if participation does not increase support for a decision, it may clear up misunderstandings about the nature of a controversy and the views of various participants. And it may contribute generally to building trust in the process, with benefits for dealing with similar issues in the future.⁸³

⁷⁹ Stern, Paul C., and Harvey V Fineberg (eds.), *Understanding Risk: Informing Decisions in a Democratic Society*, Committee on Risk Characterization, National Research Council, National Academy Press, Washington, D.C., 1996.

⁸⁰ Sollie, Paul, “Ethics, technology development and uncertainty: an outline for any future ethics of technology”, *Journal of Information, Communications & Ethics in Society*, Vol. 5, No. 4, 2007, pp. 293-306 [p. 302]. Moor, op. cit., p. 118, also supports better collaboration among ethicists, scientists, social scientists and technologists.

⁸¹ Palm, Elin, and Sven Ove Hansson, “The case for ethical technology assessment (eTA)”, *Technological Forecasting & Social Change*, Vol. 73, 2006, pp. 543-558 [p. 547].

⁸² US National Research Council, Committee on Risk Perception and Communications, *Improving Risk Communication*, National Academy Press, Washington, D.C., 1989, p. 9.

http://www.nap.edu/openbook.php?record_id=1189&page=R1

⁸³ Stern and Fineberg, op. cit., pp. 23-4.

Palm and Hansson caution that “the search for consensus in controversial issues should not be overemphasized since it may lead to the closure of issues at a too early stage. In ethical TA, conflicts and different opinions should be highlighted rather than evened out.” They also urge that the assessment “should seek to identify all relevant stakeholders, i.e., a broad spectrum of agents and therefore also a broad spectrum of responsibilities”. They see the task of an ethical assessment as being “to delineate and analyze the issues and point out the alternative approaches for the final analysis that are available”.⁸⁴

Questions

Has the project engaged in consultations with stakeholders or does it intend to do so? If so, when?

Have all relevant stakeholders (i.e., those affected by or with an interest in the technology or project) been identified?

Have they been invited to participate in a consultation and/or to provide their views on the project or technology?

Was the decision to use a technology arrived at through some public discussion and decision-making process?

Are the proposed measures likely to be supported by or not likely to meet objections from stakeholders?

How many and what kinds of opportunities do stakeholders and citizens have to bring up concerns about values or non-technical impacts?

Has the project manager made known to the public the options – and the pros and cons of each option – available with regard to the development or deployment of the project, technology, service, etc.?

How long will the consultation last? Will there be sufficient time for stakeholders to conduct any research which they may need to do in order to represent their views to the project manager?

How will conflicting views of stakeholders be taken into account or resolved? Are some stakeholders (e.g., industry) given more weight than others (e.g., civil society organisations)?

Have stakeholders indicated their support (as a result of a consultation)?

Do the proposed measures affect stakeholder participation in decision-making and, if so, how?

⁸⁴ Palm and Hansson, pp. 550-551.

3.8.3 Risk assessment, uncertainty and unintended consequences

Much has been written about risk assessment over the last few decades. One of the best guidances is Ortwin Renn's recent book on *Risk Governance*.⁸⁵ While risk experts, such as Renn, have considered how to deal with uncertainty, "uncertainty is a concept scarcely scrutinised in ethics in general and ethics of technology in particular", according to Paul Sollie.⁸⁶ He says the uncertainty arising from the unpredictable, unforeseen and unanticipated nature of technology development has many reasons, one of which is that technology designed for specific purposes often ends up being used for completely different activities. He notes that uncertainty is not simply the absence of knowledge. Uncertainty can prevail even in situations where a lot of information is available. New information does not necessarily increase certainty, but might also augment uncertainty by revealing the presence of uncertainties that were previously unknown or understated.

The European Commission's Communication on the precautionary principle⁸⁷ aims to build a common understanding of how to assess, appraise, manage and communicate risks that science is not yet able to evaluate adequately. It says the precautionary principle should be considered within a structured approach of risk assessment, management and communication. Decision-makers need to be aware of the scientific uncertainties, but judging what is an "acceptable" level of risk for society is an eminently political responsibility.

The Commission says the decision-making procedure should be transparent and involve all interested parties at the earliest possible stage in the study of various risk management options once the results of the scientific evaluation and/or risk assessment are available. Where action is deemed necessary, measures based on the precautionary principle should be, *inter alia*:

- proportional to the chosen level of protection,
- non-discriminatory in their application,
- consistent with similar measures already taken,
- based on an examination of the potential benefits and costs of action or lack of action (including, where appropriate and feasible, an economic cost/benefit analysis),
- subject to review, in the light of new scientific data, and
- capable of assigning responsibility for producing the scientific evidence necessary for a more comprehensive risk assessment.

Questions

Has the project performed a risk assessment of the technology to be used or service supplied?

Has the project considered less privacy-intrusive alternatives?

Has the project considered the possibility of unintended consequences of a technology or service? For example, a revolving door may keep out the cold, but may make it impossible for a person in a wheelchair to enter a building.

Has the project identified ways of eliminating or mitigating those risks?

⁸⁵ Renn, Ortwin, *Risk Governance: Coping with Uncertainty in a Complex World*, Earthscan, London, 2008.

⁸⁶ Sollie, 2007, *op. cit.*, p. 295.

⁸⁷ European Commission, Communication on the precautionary principle, COM(2000)1, Brussels, 2 Feb 2000.

Is there a human review of machine-generated results?

Can the technology or service be used for purposes other than that for which they have been designed?

Is there a risk that the project or service or application will create an unwanted precedent?

Is there a risk that the project may have a negative effect on those who are implementing the service or application as well as on those who subject to the application?

Have different types of risks been considered, i.e., political, social, economic, technological, environmental, as well as risks to individuals?

Are some risks foreseen, but difficult to quantify?

Are there uncertainties about use of the technology and its long-term consequences?

How will the project distribute any costs or risks? Will some stakeholders bear greater risks than others?

Who are the agents that are involved in a particular technology development?

What are the consequences of particular decisions during the R&D trajectories?

What are possible applications and consequences of new technologies?

Who is affected and to what extent?

What status do stakeholder values and opinions have and how are these integrated in ethical analysis?⁸⁸

3.8.4 Accountability

The Data Protection Directive says the data controller should be accountable for complying with the principles stated in the Directive.

In the development of new technologies and services, however, “many of the actors and stakeholders involved [in their development]... only have a very restricted insight into the opportunities and risks involved. Moreover, many of them have restricted means to respond. For instance, engineers are involved in the first phases [of research and development], but have limited influence on the introduction of new technologies into the market/society. End users may have effect on how the new technologies are introduced into society and how the new technologies are actually used. However, end users have restricted means to influence research, development and production of new technologies.”⁸⁹ Vedder and Custers argue that it is undesirable to assign all responsibilities to just one group of stakeholders. Instead, they argue in favour of “joint responsibilities”. “Instead of creating gaps in the responsibilities, i.e.,

⁸⁸ The last five questions come from Sollie, 2007, op. cit., p. 298.

⁸⁹ Vedder, Anton, and Bart Custers, “Whose Responsibility Is It Anyway? Dealing with the Consequences of New Technologies”, in Paul Sollie and Marcus Düwell (eds.), *Evaluating New Technologies*, Springer Science, Dordrecht, 2009, p. 30.

parts of the research and development process where nobody is responsible, this may create joint responsibilities. We consider overlapping responsibilities an advantage rather than a drawback in these cases.”⁹⁰

René von Schomberg also argues along these lines. He claims that the idea of role responsibility cannot be used any longer in the complex society in which we live. No one person has an overview of all consequences of a technological development and therefore he argues for an ethics of knowledge policy and knowledge assessment and says that citizens should be involved in the assessment and policy-making.⁹¹

Questions

Does the project make clear who will be responsible for any consequences of the project?

Who is responsible for identifying and addressing positive and negative consequences of the project or technology or service?

Does the project make clear where responsibility lies for liability, equality, property, privacy, autonomy, accountability, etc.?

Are there means for discovering violations and penalties to encourage responsible behaviour by those promoting or undertaking the project?

If the data are transferred outside the European Union, what measures will be put in place to ensure accountability to the requirements of the Data Protection Directive?

Is there a fair and just system for addressing project or technology failures with appropriate compensation to affected stakeholders?

3.8.5 Third-party ethical review and audit

The final phase of the Privacy Impact Assessment (PIA) methodology recommended by the UK’s Information Commissioner’s Office (ICO) is the review and audit phase, the purpose of which is to ensure that the design features arising from the PIA are implemented, and are effective. Implementation of an ethical guidance for e-inclusion could take a leaf out of the ICO PIA manual in this regard. An ethical review and audit by a third party would ensure that an e-inclusion ethical guidance has been effectively carried out. As mentioned in the introduction, an audit is a way of ensuring that responses to the questions are not merely perfunctory.

Unless an organisation appoints an independent ethical review panel, there is a lacuna in ethical assessments and, in particular, a review of the adequacy of such assessments. Although the European Commission has established the European Group on Ethics in Science and New Technologies (EGE)⁹² and Member States have similarly independent ethics

⁹⁰ Ibid., p. 32.

http://ec.europa.eu/research/science-society/pdf/ethicsofknowledgepolicy_en.pdf

⁹¹ von Schomberg, René, “From the ethics of technology towards an ethics of knowledge policy & knowledge assessment”, Working document from the European Commission Services, Jan. 2007.

⁹² Article 2 of the mandate given to the EGE states: “The task of the EGE shall be to advise the Commission on ethical questions relating to sciences and new technologies, either at the request of the Commission or on its own

committees⁹³, these committees do not have a mandate to perform an ethical audit of an individual organisations. Rather they are appointed to provide advice on issues of ethical importance, which are either referred to them (by the Commission, for example) or that they initiate themselves. Nevertheless, a review and audit of ethical assessments by an independent third-party would obviously confer considerable credibility on any reviews undertaken by individual projects.

Questions

Has the project, its objectives and procedures in regard to treatment of ethical issues been reviewed by independent evaluators to ensure that ethical issues have been adequately considered?

If the project involves the development and deployment of complex technologies, an ethical impact assessment may need to be ongoing or, at least, conducted again (perhaps several times again). When does the project manager envisage submitting its ethical impact assessment to a review by an independent third party?

3.8.6 Providing more information and responding to complaints

An important consideration in undertaking ethical reviews is to provide (proactively) information to stakeholders. The results of an ethical technology assessment should be communicated as widely as possible. The choice and design of future technologies should not be restricted to a well-educated and articulated elite.⁹⁴ It is also important that the project manager respond to complaints about either the way the ethical assessment has been conducted or the way in which a particular ethical issue has been considered. The name and contact details for a specific purpose should be made publicly available (for example, on the project manager's website).

Questions

Has the project taken steps to provide information about the project to the public, not simply in response to requests, but proactively?

What steps will the project manager take to make relevant information available to relevant stakeholders as soon as possible?

Are relevant stakeholders aware of the findings of ethical assessments and how they were generated?

Has the project instituted a procedure whereby persons can lodge their complaints if they feel that they have been mistreated by the project?

initiative. The Parliament and the Council may draw the Commission's attention to questions which they consider to be of major ethical importance. The Commission shall, when seeking the opinion of the EGE, set a time limit within which an opinion shall be given."

http://ec.europa.eu/european_group_ethics/mandate/index_en.htm. EU Member States have also established independent ethics committees

⁹³ http://ec.europa.eu/european_group_ethics/link/index_en.htm#4

⁹⁴ Palm and Hansson, p. 550.

Are there procedures for challenging the results, or for entering alternative data or interpretations into the record?

If the individual has been treated unfairly and procedures violated, are there appropriate means of redress?

If anyone objects to the project, does the project make clear whom they can contact to make known their objection?

Has the person been provided with a contact point where he may obtain further information about the trial?

3.8.7 Good practice

Examples of good practice in ethical assessments may be strategically important from a policy point of view in the sense that they might encourage other organisations to undertake similar assessments, which might also be an objective of policy-makers. Examples of good practice are also practically important in the sense they provide guidance on how to undertake ethical assessments. The utility of good practices depends on how well information about such good practices is disseminated and how easy it is for project managers to find relevant good practices.

Questions

Would the project, technology or service be generally regarded as an example of ethical good practice?

Will the technology or project inspire public trust and confidence?

Have the designers or proponents of the project examined other relevant good practices?

4 DESIGNING AN E-INCLUSION (DIALOGUE) ROADMAP

This chapter proposes an e-inclusion roadmap constructed in three stages. The first stage is to analyse the existing situation, the second stage is to identify the needs and gaps and lessons learned, and the third stage is a strategic research agenda.

This chapter should be considered as an outline for a roadmap. More detail and consensus are needed before it could be regarded as operational.

4.1 FIRST STAGE – SETTING OBJECTIVES AND ANALYSING THE EXISTING SITUATION

The first stage in constructing the roadmap is to analyse the existing situation, which consists of a number of elements or dimensions or aspects, i.e., social, economic, political, organisational and ethical. In addition, it is necessary to identify who are the stakeholders, including especially the e-excluded.

As with any planning exercise, it is important to be clear from the outset what the objectives of the roadmap should be. The objectives can be refined as one goes through the three stages outlined here. It is better to abandon one or more existing objectives than to adhere rigidly to objectives which are no longer appropriate.

Our broad objective is to institute a dialogue roadmap aimed at addressing ethical issues arising from the use of ICTs in helping to overcome digital exclusion. By a dialogue roadmap, we mean one constructed through interaction with e-inclusion experts and other stakeholders. As a more specific sub-objective, we aim to promulgate the use of good practice case studies in fulfilling the primary objective.

In analysing the existing situation, one should also consider other related roadmaps, and in the e-inclusion there are several others, including the following:

- European Commission DG Information Society and Media eGovernment Unit and the Inclusive eGovernment ad hoc group, *A roadmap for Inclusive eGovernment: towards making all citizens, and especially disadvantaged groups major beneficiaries of eGovernment*, Brussels, 27 Nov 2006.⁹⁵
- The FP7 CAPSIL project has developed a roadmap for EU research to achieve effective and sustainable solutions to independent living,⁹⁶
- The FP7 EPAL project has produced a roadmap for extending professional active life.⁹⁷
- The FP6 eABILITIES project set out to map current and possible future technological developments in ICT accessibility, and to identify needs, breakthroughs and bottlenecks.⁹⁸
- The FP6 eInclusion@EU project produced e-inclusion policy roadmaps.⁹⁹
- Also of interest is the “Assisted Living Roadmapping exercise” prepared for the UK

95

http://ec.europa.eu/information_society/activities/egovernment/docs/inclusive_egovernment_roadmap.pdf

⁹⁶ <http://www.capsil.org>

⁹⁷ <http://www.uninova.pt/~epal>

⁹⁸ <http://www.eabilities-eu.org/>

⁹⁹ <http://www.einclusion-eu.org>

government.¹⁰⁰

4.1.1 Social aspects

From a social or societal point of view, e-inclusion is driven by the exigencies of demographic change as well as other pressures where certain significant groups of people are excluded from the Information Society. These include senior citizens, disadvantaged young people, immigrants and people with disabilities.

E-exclusion is closely related to social exclusion. Social exclusion is felt at both the individual and societal levels. For the excluded individual, exclusion may give rise to feelings of rejection, low self-esteem, loss of self-confidence, despair and possibly actions that are invidious and harmful to his or her own interests and well-being. For society, the reality of digital and social exclusion inevitably creates certain societal tensions between the haves and have-nots, between the included and excluded, and risks creating a dysfunctional society.

Quite apart from these risks, most people in modern European society would agree that as a matter of social equity, social solidarity and putting into practice the spirit and values of the European Union, we must overcome digital and social exclusion.

4.1.2 Economic aspects

Large numbers of e-excluded citizens have deleterious economic consequences in at least two different ways. One is that the e-excluded create a drag on the economy, where the included must bear the costs of supporting the e-excluded. Such costs include health care, unemployment insurance and other social security benefits as well as the costs involved in combating crime and terrorism which arise when some of the e-excluded resort to socially unacceptable behaviour and actions to compensate for their exclusion. The second is the opportunity cost, where the economy is under-achieving its potential, i.e., if no one is e-excluded, then the economy will gain from the additional tax revenues generated from the productivity of all citizens.

In analysing the economic aspects of the existing situation as it relates to e-inclusion, we can observe the role that industry has been playing in furthering the e-inclusion agenda. Not only have some companies been producing e-accessible products and services, but also they have been collaborating with local authorities and civil society organisations in providing some of those products and services at no or reduced cost and in providing training to disadvantaged groups.

The European Commission and Member States have produced numerous e-inclusion-related policy documents that refer to the economic imperative of addressing digital and social exclusion, perhaps especially of the ageing population.¹⁰¹

¹⁰⁰ Barlow, James, and Richard Curry, "Assisted Living Roadmapping exercise", Workshop report prepared for the UK Department of Trade & Industry, Imperial College, London, 8 Jan 2007.

<http://www.technologyprogramme.org.uk/site/IP/ALIP/default.cfm>

¹⁰¹ Many of the EU-level documents are referenced in the Environmental Scanning Report, SENIOR Deliverable 1.1.

4.1.3 Political aspects

From a political point of view, we can see that policy-makers recognise the existing situation with regard to the exclusion of some people from the Information Society, that they have shown a willingness to overcome this exclusion (the digital divides) and, indeed, have already taken measures to that end.

The European Commission and Member States have adopted e-inclusion policies and programmes, and have been working collaboratively, e.g., through the Open Method of Co-ordination (OMC) and as demonstrated by, for example, the Riga Declaration and the country profiles on the Commission's ePractice.eu portal.¹⁰²

A key policy measure to enable e-inclusion of all citizens is to ensure the necessary infrastructure is in place. To this end, the Commission and many Member States have adopted policies and programmes relating to the provision of broadband to all citizens. They also recognise that the infrastructure alone is not sufficient. Other measures, for example, relating to the accessibility and affordability of the necessary products and services, and providing training to the e-excluded are also necessary, and they have been taking these steps too (in fact, at all levels of government, including local and regional authorities). Also necessary is an awareness campaign and other measures to promote the Information Society, the value and benefits of e-inclusion, good practice case studies and so on. To this end, the Commission and Member States have undertaken various initiatives such as the i2010 e-inclusion "Be part of it" campaign, good practice awards, publications, prosyletising¹⁰³, good practice libraries, websites and portals, special events, conferences and workshops, and so on.

The fact that many case studies have been compiled by many different entities suggests there is a widespread belief in the efficacy of good practice case studies. We can observe that there is political support for the case studies, since some of the existing libraries and compilations have been made by the European Commission and Member States, either directly by their own staff or through their funding.

4.1.4 Organisational issues

To ensure the success of e-inclusion measures, to overcome digital divides, some organisational efforts are necessary. Some body or bodies need to be tasked with or need to take the initiative to push those measures. Since e-inclusion involves many different stakeholders, collaboration, whether structured or unstructured, ad hoc or ongoing, is a vital ingredient. Such organisational efforts have been made, at least to some extent. The Commission's orchestration of the Riga Declaration is a good example. Member States came together in Riga and agreed a set of targets for e-inclusion by 2010.¹⁰⁴

European industry has also declared its support for multi-stakeholder partnerships. For example, Digital Europe and AGE put out a joint statement in which they said, "Industry needs to work closely with the community organisations across the age divide to help develop

¹⁰² <http://www.epractice.eu/en/factsheets/>

¹⁰³ For example, the UK government has appointed Martha Lane Fox, the prominent dot.com entrepreneur, as the UK e-inclusion champion.

¹⁰⁴ Ministerial Declaration, Approved unanimously by Ministers of European Union (EU) Member States and European Free Trade Area (EFTA) countries responsible for eInclusion policy, Riga, Latvia, 11 June 2006. http://europa.eu.int/information_society/events/ict_riga_2006/index_en.htm (accessed 7 February 2009).

products and trainings tailored towards the needs of the older citizens. We believe that multi-stakeholder partnerships and the scaling of social investments need to be an integral part of any projects.”¹⁰⁵ Intellect, the trade association of the UK IT industry, has said that the development of industry and third sector sustainable partnerships is crucial to transform services through ICT and that the third sector is key to the delivery of services to the socially excluded.¹⁰⁶

In a report to the UK government, Foley et al. noted that “Social exclusion is frequently a multifaceted problem that requires joint intervention by many agencies working in partnership. Partnership working poses numerous challenges. A digital inclusion strategy can provide the guidance or leadership to address some of these problems and encourage joined up working.”¹⁰⁷

These and similar calls for multi-stakeholder partnerships and collaboration have not gone unheeded by governments. In their Declaration, made in Riga in June 2006, EU Ministers invited other authorities, civil society and industry to work together with the European Commission, Member States and other countries to address the needs of the elderly population and, in so doing, to create new business opportunities.¹⁰⁸

Like most other calls such as those cited in the previous paragraphs, the Riga Declaration did not mention *how* these stakeholders should work together, what mechanism should be used to stimulate collaboration, how best to structure that collaboration or how to create some mechanism by means of which that collaboration can really be implemented.

In the absence of such a mechanism, the Commission expressed its fears 18 months later that the Riga targets may not be met because of fragmentation of efforts and lack of collaboration. It said the level of political and stakeholder commitment should be raised.¹⁰⁹ This was perhaps one reason by the Member States joined together with the Commission to form the Ambient Assisted Living Joint Programme and the associated AAL Association.¹¹⁰

Many good practice case studies also provide evidence of collaborative efforts, sometimes involving industry, civil society organisations and governmental entities.

¹⁰⁵ EICTA and AGE, “Active Ageing in the Information Society”, Position paper, November 2007.

www.eicta.org/web/news/telecharger.php?iddoc=727. EICTA is the abbreviation for the European Information and Communications Technology and Consumer Electronics Industry Association, comprising 59 multinational companies and 39 national associations from the 27 Member States. It has since changed its name to Digital Europe. AGE - the European Older People’s Platform is a European network of organisations of people aged 50+.

¹⁰⁶ <http://www.intellectuk.org/content/view/826/47/>

¹⁰⁷ Foley, P., C. Codagnone and D. Osimo, *An Analysis of International Digital Strategies: Why develop a digital inclusion strategy and what should be the focus?*, Research Report, Department for Communities and Local Government, London, October 2008.

<http://www.communities.gov.uk/publications/communities/internationaldigitalstrategies>

¹⁰⁸ Ministerial Declaration, Approved unanimously by Ministers of European Union (EU) Member States and European Free Trade Area (EFTA) countries responsible for eInclusion policy, Riga, Latvia, 11 June 2006.

http://europa.eu.int/information_society/events/ict_riga_2006/index_en.htm

¹⁰⁹ European Commission, *European i2010 initiative on e-Inclusion: “To be part of the information society”*, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2007) 694 final, Brussels, 8 Nov 2007.

¹¹⁰ http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/launch/index_en.htm

4.1.5 Ethical issues

E-inclusion raises ethical issues, both at a macro and micro levels. At the macro level, one can say that society has an ethical obligation to ensure the e-inclusion of all citizens (or at least to offer the opportunity of inclusion). At the micro level, e-inclusion related projects may raise ethical issues, for example, in regard to informed consent, data protection, monitoring or surveillance of senior citizens suffering from some degree of dementia, and so on.

As a matter of good practice, some projects have made commitments to act ethically, to comply with national legislation, to check their practices with independent ethics committees. In some (relatively few) cases, projects have produced specific deliverables and guidelines dealing with ethical issues.

Ethical issues were a focus of the workshop in Bled, Slovenia, in May 2008,¹¹¹ as well as the Ministerial conference on e-inclusion held in Vienna in late 2008.¹¹² The SENIOR project has convened many meetings, workshops and a conference dealing with ethical issues emerging from the use of ICTs for the e-inclusion of senior citizens.¹¹³

From our literature research, interactions with stakeholders in the aforementioned workshops, interviews and case studies, we developed an ethical guidance for e-inclusion (Chapter 3 above).

4.1.6 Stakeholders, including the e-excluded

Broadly speaking, stakeholders include those who are concerned about an issue, those who have an interest in an issue, those who can do something about the issue and those affected by an issue. The e-excluded can be regarded as a set of stakeholders in themselves, whether they realise it or not.

Identifying relevant stakeholders is important for two main reasons: first, to identify their needs and interests relevant to our objectives and, second, to enlist their support and collaboration in producing the roadmap.

Among e-inclusion stakeholders are the following:

- Industry
- Civil society organisations
- Policy-makers at the European and Member State level
- Local authorities
- Standardisation organisations
- International (or intergovernmental) organisations
- Healthcare providers
- Data protection authorities

¹¹¹ Rogerson, S., “Ethics and e-Inclusion: Exploration of issues and guidance on Ethics and e-Inclusion, Contribution to the European e-Inclusion Initiative”, Report of the High-Level workshop held in Bled, Slovenia, 12 May 2008, [published] September 2008.

http://ec.europa.eu/information_society/activities/einclusion/events/workshop_ethics/workshop/index_en.htm

¹¹² European Commission DG Information Society and Media – Unit H.3 ICT for Inclusion, Report of the e-Inclusion Ministerial Conference, held in Vienna, 30 Nov. - 2 Dec. 2008.

http://ec.europa.eu/information_society/events/e-inclusion/2008/index_en.htm

¹¹³ www.seniorproject.eu

- The media
- Academia

E-excluded stakeholders include senior citizens, disadvantaged young people, immigrants and the disabled. However, the e-excluded can be further segmented, as mentioned below.

SENIOR has emphasised its design of a “dialogue” roadmap, which means that interactions with stakeholders, preferably as early in the process as possible, is a key objective.

4.2 SECOND STAGE – IDENTIFYING NEEDS AND GAPS AND LESSONS LEARNED

4.2.1 Needs

We can and should be more precise in identifying e-excluded as a pre-requisite for developing the targeted strategies to meet their needs. An input paper from the SENIOR consortium to the Commission’s 16 March 2009 meeting of experts was an attempt at doing so.¹¹⁴ Various other reports and studies have documented the situation of the e-excluded, a recent example of which is a report produced by Ofcom, the UK communications regulator.¹¹⁵

The Ofcom research looks at the reasons why 30 per cent of UK adults do not have the Internet at home and the barriers that prevent them from taking it up in the future. The research identified two main groups of people without the internet who don't currently intend to access the internet at home, one of which is the self-excluded.

Forty two per cent of adults stated that their main reason for not having the internet at home was due to lack of interest or need. The self-excluded tend to be older and retired and 61 per cent have never used a computer. This group shares a sense of indifference, with many struggling to express any reason why they should have the internet at home. Some also felt they were too old or believed that it is for younger people. More than two fifths (43 per cent) of adults who currently do not have access to the Internet at home say that they would choose to remain unconnected even if they were given a free PC and broadband connection.

The second group was the financially excluded. Thirty per cent of adults stated that their main reason for not accessing the Internet at home was that it was too expensive or that they did not have the knowledge or skills to use it. Half of respondents in this group(51 per cent) gave as their main reason expense or costs while just under three in ten (27 per cent) said the cost of a computer or not owning a computer was their main reason for not having an internet connection,. Concern about not being able to afford the monthly payments is a factor among those who cannot afford the internet.

The Ofcom research also looked at ideas to encourage Internet take-up, including half-price computers and discounted monthly tariffs.

We need some research on the impact of good practice case studies and, in particular, whether such case studies influence other practitioners and policy-makers.

¹¹⁴ See also Wright, David, “Structuring e-inclusion stakeholder needs”, *Journal of Information, Communications and Ethics in Society*, Vol. 7, No. 4, 2009 [forthcoming].

¹¹⁵ See, for example, Ofcom, *Accessing the internet at home: A quantitative and qualitative study among people without the internet at home* by Ipsos Mori, London, 10 June 2009.
http://www.ofcom.org.uk/media/news/2009/06/nr_20090610.

The report of the aforementioned Bled workshop said there was a need to “Develop and maintain a good/bad practice case study library which illustrates the ethical dimension of ICT services and products used to promote social inclusion and improved quality of service to those in most need.”¹¹⁶ In fact, there are already libraries of good practice now, such as that compiled by the Commission on its ePractice.eu portal, even if few of them are devoted to the ethical dimension of new technologies.

The fact that 40 per cent of the European population does not use or have access to the Internet suggests that the needs for available broadband, accessibility of computers and services, affordability, training and education, and the raising of awareness of the benefits of e-inclusion still exist in spite of the good efforts made so far. In other words, the efforts so far need to be redoubled.

Similarly, the fact that the EC and Member States have had to introduce anti-discrimination measures (for example, against ageist discrimination) suggests that remains an issue too.

4.2.2 Gaps

Many projects, conferences, workshops and stakeholders have observed the need for co-ordination of e-practices on the European level. The BEEP project, for example, in its final report, said that “E-inclusion is a broad field to cover, including a wide range of potentially at-risk groups and involving different scientific and research disciplines that have a contribution to make. The importance of contextual factors that vary across countries, regions and user communities, and range of different policy measures and instruments that are relevant is rather broad. For all these reasons, there is an urgent need for a concerted co-ordination exercise to consolidate the scientific/research base and to bring this to bear in the policy sphere. Co-ordination and facilitation of informed dialogue between the main stakeholders – the user communities, policy makers and researchers – is also essential if the ensuing policy approaches and measures are to be well-targeted, practicable and acceptable, and, if the policy impacts are to be verifiable.”¹¹⁷

Since the BEEP final report, others have continued to make similar comments. For example, the Bled report says, “a pan-European platform on ethics and e-inclusion clustering relevant stakeholders (industry, society, academia, ethicists etc.) could favour dialogue and sharing of good practices.”¹¹⁸

Academics too have said much the same thing. For example, Eggermont et al have commented that the delicate relationship between ICT and the elderly should be a reason for creating a flexible network of policymakers from various fields, spokespersons of senior citizens’ organisations and representatives of the business community.¹¹⁹

¹¹⁶ Rogerson, S., “Ethics and e-Inclusion: Exploration of issues and guidance on Ethics and e-Inclusion, Contribution to the European e-Inclusion Initiative”, Report of the High-Level workshop held in Bled, Slovenia, 12 May 2008, [published] September 2008, p. 6.

http://ec.europa.eu/information_society/activities/einclusion/events/workshop_ethics/workshop/index_en.htm

¹¹⁷ Best eEurope Practices (BEEP), Final project report, Deliverable D11.3, September 2003, pp. 39-40.

<http://www.beep-eu.org/>

¹¹⁸ Rogerson, op. cit.

¹¹⁹ Eggermont, Steven, Heidi Vandebosch and Stef Steyaert, “Towards the desired future of the elderly and ICT: policy recommendations based on a dialogue with senior citizens”, *Poiesis & Praxis*, Vol. 4, No. 3, Sept. 2006, pp. 199-217 [p. 213].

4.2.3 Lessons learned

There are various lessons to be learned from e-inclusion good practice case studies. From those included in this report, for example, one can highlight the following lessons:

- Even among mixed groups of stakeholders, one can learn not only new things, but also things held in common.
- Public relations are important for stimulating stakeholder interest.
- Patience and learning from others yield value.
- Projects are more likely to succeed where they are well rooted in the needs of stakeholders.
- Different stakeholders have their own agendas. There is a need to find common ground and to support each other socially and politically.
- It is important to understand your stakeholders and where they are coming from.
- A commercial mindset is useful, even in non-commercial enterprises.
- Understanding what motivates stakeholders is important. It is also important in undertaking any supposed good practice to be able to successfully motivate stakeholders who may ask “Why should I? What is in it for me?”
- It is more important to concentrate on uses and applications than particular technologies.
- Sustainability depends on having the necessary resources.
- New skills will disappear without frequent practice.
- There is unlikely to be only one way to do something, just as it is unlikely that there is such a thing as “best” practice.
- Don’t accept the status quo or traditional ways of doing something as a model for the future.
- Sharing new ideas and good practices will stimulate synergies and create economies in efforts (avoidance of duplication).
- The sooner stakeholders can be engaged, the better.
- Good practices should be easy to use.
- Good practices should be conducive to building a community.
- Training and motivational support are vital.
- Good practices should “sell” well. Communicating the good practice should not be an after-thought.

4.3 THIRD STAGE – FORMULATING A STRATEGIC RESEARCH AGENDA

The key component of a roadmap is a strategic research agenda, which comprises several elements – the additional research need to help overcome exclusion, the performance of the research, a view of what is expected from the research (which should be a fulfilment of the roadmap’s objectives) and the steps that need to be taken to implement the agenda according to a set of milestones.

4.3.1 Research agenda (market, technological and social policy research)

To close the digital divides and to bring the e-excluded into the Information Society, several types of research are needed, i.e., market research, technological research, and social policy research.

Market research

From work done on the SENIOR project, it appears that some empirical research is needed to provide evidence of the impact of good practice case studies. Do they influence other practitioners? Do they influence policy-makers? The ePractice.eu portal could conduct a survey of the people who have submitted more than 1,100 case studies to ask whether they have been influenced by other good practices. Others at the Member State level could undertake similar such empirical research.

The above-cited Ofcom report on *Accessing the Internet at home* provides a good example of the kind of detailed empirical research which is needed across all European countries, to better understand why some people are not using the Internet and what measures might be taken to reduce the numbers of e-excluded citizens.

Along those lines, some market research on what excluded groups want from ICTs would be useful.

Technological research

Research continues to be needed on improving the accessibility of affordable products and services as well as networks that enable the products and services that are appropriate for the e-excluded (and perhaps for the rest of the population too).

The AAL Association plays an important role here as do individual companies and standardisation organisations, such as ETSI, CEN, CENELEC and the World Wide Web Consortium (W3C). Strictly speaking the latter is not a standardisation body as such. Rather it is a forum, but the European Commission has said that all public websites should comply with its Web Content Accessibility Guidelines.¹²⁰

Social policy research

SENIOR envisages social policy research addressing issues including the following:

- Engaging users in social networking
- Overcoming ageist discrimination
- Ethical guidance
- Improvements in trust and confidence
- Meeting new challenges from ICT to privacy and data protection
- Raising awareness of stakeholders, including the e-excluded, of the benefits of e-inclusion
- Exchange of best practices
- A better understanding of senior citizens' ICT needs and views
- Effects of existing policy initiatives
- How ICT engagement develops over time

¹²⁰ <http://www.w3.org/TR/WAI-WEBCONTENT>. See also European Commission, European i2010 initiative on e-Inclusion: "To be part of the information society", Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2007) 694 final, Brussels, 8 Nov 2007, p. 4. The EC says that as of the end of 2006 a minority of surveyed public websites were fully compliant with these Guidelines. See also European Commission, "Commission wants a web that is better enabled for the disabled", Press release, IP/08/1074, Brussels, 2 July 2008. <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/1074&format=HTML&aged=0&language=EN&guiLanguage=nl>

4.3.2 Performing the research

This element in the roadmap addresses two main questions. How should the aforementioned research be carried out and who can or should do the research.

Mechanisms for carrying out this research already exist, notably by means of the existing EC Framework Programmes and those at the Member State level. The mandate of the AAL Association could be broadened to include marked and social policy research (it already supports technological research). Whatever mechanisms are used, however, the key is better co-ordination so that the identified research needs are addressed.

4.3.3 What's expected from the research

Research may help to (re)define priorities and possible approaches as well as need for legislation, codes of good practice, etc.

To ensure the roadmap's objectives are being achieved, there is a need for some means of evaluation and metrics for measuring the impacts of the research and how well it is co-ordinated.

4.3.4 Next steps and scheduling with milestones

A roadmap should be a living document, which means it needs to be updated, its objectives revisited, its timetable for implementation adjusted.

A more detailed roadmap

As mentioned above, a more detailed roadmap based on this outline (or some version of it) should be made as a result of a co-ordinated involvement of stakeholders.

Building consensus for the roadmap

Policy-makers at the Commission and in the Member States have a key role to play here. A "Riga II" Declaration in support of the roadmap would be highly desirable.

A mechanism or a champion to ensure the roadmap is implemented and followed.

There should be a focal point, a mechanism or EU champion tasked with ensuring the roadmap is implemented and followed.

ANNEX – INTERVIEW QUESTIONS

Eight of the case studies in section 2.6 were constructed based on interviews. The following questions were used in the interviews:

1. What was the good practice all about?
2. Which stakeholders were involved?
3. When did the case study start (and finish if it has)?
4. Who provided the funding and how much funding was provided?
5. Where did it take place?
6. Why was the project initiated? What was the rationale for it, why was it deemed necessary?
7. What lessons were learned and are those lessons valid for others?
8. Is the project (the good practice) sustainable or does it need ongoing financing?
9. Why is it (or was it) a candidate for a good practice?
10. What criteria do you think a good practice should meet?
11. How should a good practice be selected?
12. Did the project involve any ethical considerations? If so, what were they?
13. How were ethical issues dealt with or resolved?
14. What has been the reaction to the good practice / case study / project? Has it, for example, won any awards?
15. Where can one find more information about the project?