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Moving towards inclusive design guidelines for socially and ethically aware HCI

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Abstract

Most people acknowledge that personal computers have enormously enhanced the autonomy and communication capacity of people with special needs. The key factor for accessibility to these opportunities is the adequate design of the user interface which, consequently, has a high impact on the social lives of users with disabilities.

The design of universally accessible interfaces has a positive effect over the socialisation of people with disabilities. People with sensory disabilities can profit from computers as a way of personal direct and remote communication. Personal computers can also assist people with severe motor impairments to manipulate their environment and to enhance their mobility by means of, for example, smart wheelchairs. In this way they can become more socially active and productive. Accessible interfaces have become so indispensable for personal autonomy and social inclusion that in several countries special legislation protects people from 'digital exclusion'.

To apply this legislation, inexperienced HCI designers can experience difficulties. They would greatly benefit from inclusive design guidelines in order to be able to implement the 'design for all' philosophy. In addition, they need clear criteria to avoid negative social and ethical impact on users. This paper analyses the benefits of the use of inclusive design guidelines in order to facilitate a universal design focus so that social exclusion is avoided. In addition, the need for ethical and social guidelines in order to avoid undesirable side effects for users is discussed. Finally, some preliminary examples of socially and ethically aware guidelines are proposed.

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1. HCI and people with disabilities

Most people living in developed countries have direct or indirect relationships with computers in diverse ways. In addition, there exist many tasks that could hardly be performed without computers, leading to a dependence on Information Technology. Moreover, people not having access to computers can suffer the effects of the so-called digital divide (Fitch, 2002), a new type of social exclusion.

People with disabilities are one of the user groups with higher computer dependence because, for many of them, the computer is the only way to perform several vital tasks, such as personal and remote communication, control of the environment, assisted mobility, access to telematic networks and services, etc. Digital exclusion for disabled people means not having full access to a socially active and independent lifestyle. In this way, Human-Computer Interaction (HCI) is playing an important role in the provision of social opportunities to people with disabilities (Abascal and Civit, 2002).

2. HCI and social integration

2.1. Gaining access to computers

Computers provide very effective solutions to help people with disabilities to enhance their social integration. For instance, people with severe speech and motor impairments have serious difficulties to communicate with other people and to perform common operations in their close environment (e.g. to handle objects). For them, computers are incredibly useful as alternative communication devices. Messages can be composed using special keyboards (Lesher et al., 1998), scanning with one or two switches, by means of eye tracking (Sibert and Jacob, 2000), etc. Current software techniques also allow the design of methods to enhance the message composition speed. For instance, Artificial Intelligence methods are frequently used to design *word prediction* aids to assist in the typing of text with minimum effort (Garay et al., 1997). Computers can also assist the disabled user to autonomously control the environment through wireless communication, to drive smart electric powered wheelchairs, to control assistive robotic arms, etc. What is more, the integration of all of these services allows people with disabilities using the same interface to perform all tasks in a similar way (Abascal and Civit, 2001a).

This is possible because assistive technologists have devoted much effort to providing disabled people with devices and procedures to enhance or substitute their physical and cognitive functions in order to be able to gain access to computers (Cook and Hussey, 2002).

2.2. Using commercial software

When the need of gaining access to a PC is solved, the user faces another problem due to difficulties in using commercial software. Many applications have been designed without taking into account that they can be used by people using Assistive Technology devices, and therefore they may have unnecessary barriers which impede the use of alternative interaction devices.

This is the case for one of the most promising application fields nowadays: the internet. A PC linked to a telematic network opens the door to new remote services that can be crucial for people with disabilities. Services such us tele-teaching, tele-care, tele-working, tele-shopping, etc., may enormously enhance their quality of life. These are just examples of the great interest of gaining access to services provided by means of computers for people with disabilities. However, if these services are not accessible, they are useless for people with disabilities. In addition, even if the services are accessible, that is, the users can actually perform the tasks they wish to, it is also important that users can perform those tasks easily, effectively and efficiently. Usability, therefore, is also a key requirement.

2.3. Social demand for accessibility and usability

Two factors, among others, have greatly influenced the social demand for accessible computing. The first factor was the technological revolution produced by the availability of personal computers that became smaller, cheaper, lower in consumption, and easier to use than previous computing machines. In parallel, a social revolution has evolved as a result of the battle against social exclusion ever since disabled people became conscious of their rights and needs. The conjunction of computer technology in the form of inexpensive and powerful personal computers, with the struggle of people with disabilities towards autonomous life and social integration, produced the starting point of a new technological challenge. This trend has been also supported in some countries by laws that prevent technological exclusion of people with disabilities and favour the inclusive use of technology (e.g. the Americans with Disabilities Act[1] in the United States and the Disability Discrimination Act[2] in the United Kingdom). The next sections discuss how this situation influenced the design of user interfaces for people with disabilities.

3. User interfaces for people with disabilities

With the popularity of personal computers many technicians realised that they could become an indispensable tool to assist people with disabilities for most necessary tasks. They soon discovered that a key issue was the availability of suitable user interfaces, due to the special requirements of these users. But the variety of needs and the wide diversity of physical, sensory and cognitive characteristics make the design of interfaces very complex. An interesting process has occurred whereby we have moved from a computer ‘patchwork’ situation to the adoption of more structured HCI methodologies. In the next sections, this process is briefly described, highlighting issues that can and should lead to inclusive design guidelines for socially and ethically aware HCI.

[1] Americans with Disabilities Act (ADA). Available at http://www.usdoj.gov/crt/ada/adahom1.htm, last accessed January 15, 2005.

[2] Disabilty Discrimination Act (DDA). Available at http://www.disability.gov.uk/dda/index.html, last accessed January 15, 2005.

3.1. First approach: adaptation of existing systems

For years, the main activity of people working in Assistive Technology was the adaptation of commercially available computers to the capabilities of users with disabilities. Existing computer interaction style was mainly based on a standard keyboard and mouse for input, and output was based on a screen for data, a printer for hard copy, and a 'bell' for some warnings and signals. This kind of interface takes for granted the fact that users have the following physical skills: enough sight capacity to read the screen, movement control and strength in the hands to handle the standard keyboard, co-ordination for mouse use, and also hearing capacity for audible warnings. In addition, cognitive capabilities to read, understand, reason, etc., were also assumed.

When one or more of these skills were lacking, conscientious designers would try to substitute them by another capability, or an alternative way of communication. For instance, blind users could hear the content of the screen when it was read aloud by a text-to-voice translator. Alternatively, output could be directed to a Braille printer, or matrix of pins. Thus, adaptation was done in the following way: first, detecting the barriers to gain access to the computer by a user or a group of users, and then, providing them with an alternative way based on the abilities and skills present in this group of users. This procedure often succeeded, producing very useful alternative ways to use computers. Nevertheless, some drawbacks were detected:

- *Lack of generality*: the smaller the group of users the design is focused on, the better results were obtained. Therefore, different systems had to be designed to fit the needs of users with different characteristics.
- *Dependence on the current technology*: the design frequently depended on the specific systems being used (hardware and software). As a result, when the state of art evolved, these designs were no longer valid for the new technologies.

Therefore, most of the efforts devoted to this form of 'patchwork' adaptation were not reusable for other users, and they became useless when new incompatible devices and applications appeared.

An added difficulty was that the evolution of technology frequently produced less accessible systems than the previous ones. For instance, consider the case of graphical user interfaces (GUIs). For years, blind people used common computers adapted with voice or Braille for output. Nevertheless, the technological evolution made personal computers and workstations more and more graphic based. Interaction style with these machines is based on visual artefacts (windows, icons, unfolding menus, etc.) used by means of pointing devices (such as a mouse) that select icons by clicking on them. Consequently, people with visual impairments, who were previously able to use standard alphanumeric displays without any serious problems, were not able to use these new interfaces as they lack visual feedback to locate the mouse in the right place (e.g. to point to the correct icon or menu). To solve this problem, many research teams devoted large efforts to translate the content of graphical user interfaces to alternative media.

This experience taught people two lessons: Technology does not evolve by itself towards the production of more accessible computers. It is necessary that social and political factors gain influence over this process. On the other hand, 'ad hoc' adaptation of existing devices can produce good results, but they lack adaptability and generality. Nevertheless, these procedures are still necessary for some people with severe disabilities who cannot use standard devices, as will be discussed later (Abascal and Civit, 2001b). These issues point towards certain risks that require specific action by HCI designers when designing accessible devices and services.

3.2. Second approach: application of human-computer interaction paradigms to assistive technology

Studies on Human-Computer Interaction have grown in importance over recent years. There are many possible reasons for this growing interest: the diffusion of personal computing among a wide variety of users, the need for reaching a larger market, the demands for more ergonomic computer systems, etc. As a result, diverse methods, techniques and tools have been developed. Some of them provide an excellent background for the design of user interfaces for people with disabilities.

3.2.1. Independence between the interface and the application

One of the most interesting contributions is the clear separation of the application level from the interface level; that is, the application running in the computer is independent of the devices and methods used for interaction. In this way, HCI designers can design application-independent interfaces that communicate, on the one hand, with the application (by means of the well-defined input/output procedures) and on the other hand, that also communicate with the user. Thus, designers can develop interfaces adapted to the needs and characteristics of the user without modifying the application.

The independence between the application and the interface is even more important when the design is focused on users with disabilities. Due to the great diversity of residual abilities that must be considered for interaction, a wide range of different interfaces are needed to cater for specific user requirements. Independence allows the use of different interfaces for the same application, depending on user needs. It also permits a single user to use the same interface in order to gain access to different applications avoiding unnecessary and confusing changes.

3.2.2. Advanced user interface design techniques

Among the diverse interface design techniques developed within HCI, the most promising are the ones that try to cope with non-standard interaction.

The application of methods emerging from the Artificial Intelligence area allows the design of intelligent interfaces that try to bridge the cognitive gap between the user and the system. In this way, the interface acts as a translator between two entities (the user and the system) with diverse objectives, points of view or languages (Maybury and Wahlster, 1998).

When the design style is rigid, users often have to adapt to the computer's features. Inversely, HCI allows the design of interaction systems that adapt to the user's features. The design of adaptive interfaces requires a user model based on observable parameters that are relevant to the interaction, e.g. extent of vocabulary or ease of communication. Reasoning on these parameters in relation to the model, the system can produce assumptions about the user, allowing the interface to dynamically adapt to his or her characteristics (Stephanidis, 2001a; Kobsa, 2001). These kinds of systems are also especially interesting for people whose physical or cognitive performance changes over short periods (for instance throughout the day).

Other advanced user interface design techniques relate to affective computation and pervasive computing. Affective computation considers affective and emotional features, such as user moods, to enhance communication and performance (Picard, 2003). These techniques are applied to affective mediation systems that serve as communication channels between two people. The inclusion of affective clues to show the mood of the user can tremendously enhance the ability to communicate (Murray et al., 1996).

Pervasive computing technology has a huge influence upon social and ethical issues (Jessup and Robey, 2002). It allows the design of ubiquitous context aware systems (Hansmann et al., 2003) that can be used to design smart homes for disabled people with environmental control, wireless communications and access to telematic networks and facilities (Abascal et al., 2001). In the smart home context, location-aware computing would be used to accurately locate disabled users for safety reasons. In order to do that, wearable devices that can communicate with the network infrastructure can be very helpful. They would also allow personalising the environment to user preferences and needs. Passive alarm systems that fire when a set of biomedical parameters are out of range and call a support centre if necessary are a frequent application of these systems. It is crucial that such services which aim to support vulnerable groups should be designed to be socially and ethically aware of their specific needs and wants.

3.2.3. User needs awareness

The HCI discipline has developed procedures, methods and tools that facilitate the design of more effective interfaces better adapted to users' specifications (for example, performing a task analysis and developing scenarios of use, identifying their frequency of occurrence, their difficulty and importance to the user) (Muller et al., 1997). However, it is still important to make computer designers aware of the existence of users with restricted abilities. It is easier to develop interfaces for disabled people if, from the first steps, computers are designed bearing in mind that they are also going to be used by diverse user groups (including people with disabilities) by means of diverse interfaces. Current research and initiatives on inclusive design in general will be relevant sources of information for designers. Examples include Clarkson et al. (2003); the new British Standard on managing Inclusive Design (BS 7000-6); CEN/CENELEC Guide 6[3]; and initiatives from the European Commission such as the European Design for All eAccessibility Network[4]. This aspect of inclusive or universal design is described more fully below.

[3] Available at http://www.ibn.be/cencenelecguide6.pdf, last accessed January 15, 2005.

[4] EDeAN is available at http://www.e-accessibility.org, last accessed January 15, 2005.

4. Universal accessibility and HCI

In parallel to the enhancement of design methods, tools and techniques, a new vision of the problem developed. The universal accessibility[5] philosophy (also called 'universal design,' 'inclusive design' and 'design for all', with slight differences in connotation) stresses the need for producing user interfaces without added unnecessary barriers (Stephanidis and Savidis, 2001). These interfaces should be suitable, or capable of being easily adapted, for all people, even if a number of users would need special equipment to use them. As previously mentioned, modifying existing interaction systems in order to be used by specific users results in expensive and rigid solutions. The universal accessibility focus avoids the need for 'patchy' solutions by taking into account the needs of all the users from the starting point.

One of the main interests of people with disabilities is to be able to use standard software running on standard devices, as they are cheaper and more regularly updated than specific software and hardware. Since it aims to produce systems that can be used by everyone, no matter what their physical or cognitive skills, Universal Design is a sound option to promote digital inclusion (Stephanidis, 2001b).

The approach, however, must be realistic. Due to the great diversity of users' characteristics, it is almost impossible to consider all users in the design phase, but it is possible to avoid unnecessary barriers to accessibility that are frequently added on later. This design philosophy enhances the usability of the product and it is also extremely beneficial for non-disabled people trying to use the system under special conditions. This is the case for most web accessibility recommendations. These are focussed on eliminating unnecessary web design features that are not accessible for people with disabilities, but they are also helpful for people accessing the Web in special conditions, such as working in noisy or mobile environments.

It is important to clarify that Universal Design does not solve all accessibility problems. For instance, it cannot make people with visual impairments see the content of the screen; however, it can produce systems with alternative texts for images that can be read by a screen reader (and so can be used by people who are blind). Therefore, some people will still need special equipment usually based on Assistive Technology to access their computer. Even if there are people thinking that Universal Design substitutes for and excludes the use of Assistive Technology, it is clear that both are necessary and complementary (Abascal and Civit, 2001b).

5. Social and ethical issues

From the time of the industrial revolution, family relationships have notably changed in industrialised countries. The extensive family including grandparents, aunts and uncles, parents and children living in the same house, has evolved to a nuclear family including only parents and children until the latter become independent. In

[5] Trace Center (University of Wisconsin–Madison) is one of the key actors in universal accessibility definition and progress: Available at http://trace.wisc.edu/world/, last accessed January 15, 2005.

many cases, modern houses and flats are not designed for big families, and the lack of adequate space and full-time carers for disabled people may restrict their integration into both family life and the community in general. Thus, some disabled people who used to form part of the extensive family may now live in either relative isolation or in residential institutions, which would very much limit their autonomy. Consequently, people with disabilities living more or less autonomously need, and usually welcome, technological support. This calls for design guidelines that are socially and ethically aware of the need for autonomy and how to ensure that it is supported (as presented later in Table 1).

However, in order to introduce computers to help people with disabilities, it is necessary to overcome two extended misconceptions: the attitude of people with disabilities to computers, and also the hypothetical users' inability to handle complex devices.

The first misconception is frequently formulated as 'people with disabilities reject computers'. However, there is no evidence that disabled users dislike the use of novel technology any more than other people do (except, of course, very young people who are usually especially enthusiastic about technology). If rejection exists, it is frequently due to the low quality of the interface, automatic teller machines being a good example, where the text may be too small or the screen and buttons may be too high for people in wheelchairs. Moreover, some studies show that adequately trained disabled people are in general able to use specific interfaces (Bjørneby et al., 1999). The origin of this misconception can be found in the fact that technological aids have frequently been introduced without a deep study of user needs, an adequate training period, a good support service, and in many cases, the technology has substituted the provision of human care. These conditions lead to a certain failure and, consequently, rejection.

The second frequent misconception is formulated in this way: 'technological devices are too complex to be used by people with disabilities'. Many experiences show that this is not true. Designers who have had contacts with older and disabled users mention the good adaptation and efficiency levels that these users are able to reach when the device adequately fulfils their needs (Zajicek, 2001). If the user-system interface is appropriately designed, there is no reason for a misuse or abandonment of the device. It is evident that bad designs are difficult to be used not only by older and disabled people, but also by everyone. As Thimbleby (1995) wrote, 'badly designed systems handicap all users'.

5.1. Positive impact on social and ethical issues

The emerging alternative is the development of technology that allows disabled people to live on their own with the highest comfort and minimum risk. Computers can help them to experience a more autonomous life (Taipale and Pereira, 1995). Therefore, the development of accessible interfaces has a direct effect on socialisation, and such issues must not be overlooked during the design process, or negative impact will be the result. Let us summarise some areas of impact.

5.1.1. Direct personal communication

Alternative and Augmentative Communication[6] systems provide alternative communication methods for people with speech and communication impairments. Many diverse high-quality communication aids for AAC are on the market as a result of the research in Assistive Technology. Communicators are usually based on portable PCs, provided with accessible input devices and speech synthesisers for text-to-voice translation (Abascal and Gardeazabal, 1998). Human interfaces have been highly optimised to minimise the number of keystrokes needed per word. Systems to enhance input speed, such as word prediction, are frequently included (Garay et al., 1997).

5.1.2. Remote personal communication

To reduce the isolation of disabled people, different kinds of interpersonal telecommunication services (like video-telephony or electronic mail, which can include speech, image and text transmission) are provided by means of telematic networks (Roe, 2001). A proof of the great need for these services is provided by carers who state that people living alone often tend to use alarm systems to simply 'speak to anybody' if they do not have other opportunities for personal communication. Interfaces for remote communication frequently include similar features to those used for direct communication, with the addition of facilities for terminal operation (Abascal and Civit, 2000).

5.1.3. Security

Safety and health are very important for disabled people living alone. Good interfaces provide quick and reliable communication channels to obtain urgent help in case of situations of illness and home accidents. This is crucial for the security of many people who experience motor restrictions, leading to potentially risky situations which could be more common occurrences in an independent way of life. *Tele-alarm* services equip users with devices that automatically or manually generate calls to a remote surveillance centre when they suffer an emergency due to an accident, disease, or security problem (Lindström and Martin, 1995). Different ways to operate this service over diverse supporting technologies are offered (for example, telephone, text telephone, video-telephone, interactive TV, etc.).

Tele-care is proposed as a distant medical attendance service. In some cases care is limited to health advice by means of speech or/and written communication. More complex systems may include distance exploration, diagnostic and therapeutic advice. Remote patient monitoring and transmission of physiological constants may be required in these cases. In such services, it is important to consider the privacy as well as the security of the individual, and designers need to be aware of ethical and social issues.

5.1.4. Social integration

Computers contribute to enhance social inclusion and autonomy of users with disabilities giving them access to education, labour, information, communication, leisure, etc., often through telematic networks. For instance, remote services exist that enable

[6] The International Association for Augmentative and Alternative Communication, ISAAC, publishes a Journal entitled Augmentative and Alternative Communication. More information can be obtained from http://www.isaac-online.org/, last accessed January 15, 2005.

access to everyday activities by people with severe motor restrictions. *Tele-working* offers the possibility of carrying out remunerated work from the home using a personal computer and telematic communication. *Tele-learning* offers different levels of distance education using computer-aided instruction technology through telematic networks, in addition to the usual remote teaching methods. It is said that tele-working and tele-learning were conceived at first for disabled people, even if currently they are used by people with other kinds of restrictions (e.g. people living in very isolated villages).

In addition, several services exist for daily life support, and a whole range of new services which will especially benefit people with disabilities are possible through, for example, third generation phone systems and Bluetooth technologies (Gill, 2004). Tele-information services offer to older and disabled people valuable information about different aspects of everyday life: public transport, emergency telephone numbers, relatives' addresses, etc. In some cases they may include advice about everyday tasks, and developing and planning agenda (e.g. schedule for medical treatment, doctor's appointments, special days like birthdays, holidays, and so forth).

Finally, there is an increasing provision of services directly focused on enhancing social relationships through leisure and group support. This may include provision of information, discussion groups, chatting, hobbies, cultural activities, etc.

As a conclusion, it is clear that the combination of personal communication, security and access to integrated services provides people with disabilities more opportunities for social integration and carrying out an independent way of life. But the effectiveness of all these services for disabled people is highly dependent on the availability of human-computer interfaces well adapted to the physical and cognitive characteristics of the users. All the services noted above suggest the need for extended socially and ethically aware guidelines to ensure that the diverse needs of vulnerable users, users who can often most benefit from such new technology, are taken into account.

5.2. Negative impact on social and ethical issues

Paradoxically, some of these services can have a negative impact over people's socialisation, often because they can restrict some aspects of earlier social interactions.

5.2.1. Social isolation

The provision of personal communication and security assistance through telematic systems is frequently accompanied by a reduction of direct contact with relatives, friends and care personnel. For this reason some users may feel that the technology provided to them reduces the human relations they had previously and, consequently, they reject this technology. For instance, the provision of remote services via the Internet could lead to situations of social exclusion of the user if he or she is prevented or discouraged from participating in certain activities—at universities, workplaces, etc.—because there is an alternative way to perform similar activities, for example distance universities, tele-work, etc. This is a difficult problem because the provider of the remote service does not have the responsibility for restrictions in traditional services. In these cases, it is crucial that social authorities provide compensating measures to enhance user social participation. In addition, there is a need for further legislation against discrimination and for institutions devoted to the surveillance of the rights of users with disabilities. Examples do exist, however. The UK's Disability Discrimination Act (DDA) says that employers must make reasonable adjustments for their disabled employees. In addition, Part 4 of the DDA, the Special Educational Needs and Disability Act 2001, specifies that schools, colleges and universities must make reasonable adjustments for disabled students. How this legislation actually works in practice only time and litigation will tell.

5.2.2. Economical barriers

Even if computer services are fully accessible, there is still another important barrier: the economical one. Many of the special requirements of users with disabilities imply extra hardware and software, more difficult installation and maintenance and, if using remote services, slower communication and longer usage times, resulting in higher prices for the same service, although broadband connections, if available, are helping to alleviate this problem. As a result, users would become discriminated against and isolated because of their economical limitations. Institutions have to consider compensatory actions to balance the price of equipment and services needed by people with disabilities. Designers should also avoid expensive technology when cheaper alternatives exist. (See Table 1 for guidelines in this sense).

5.2.3. Key ethical issues

One of the most delicate aspects of the development of human interfaces for assistive devices is the one related to ethics. When researchers try to substitute a lost capability by means of a computer, privacy and freedom are often restricted.[7] For instance, the most advanced systems intended to survey the health of chronically ill patients and elderly people living at home log data about pulse, blood pressure, sugar in blood, etc., and send them to a hospital that monitors any relevant modification in these parameters. Although these systems prove to be very useful in preventing many different risks for patients living at home, they are often rejected because they limit personal freedom and autonomy. This is due to the fact that the hospital can immediately receive information about where they are, what they do, how many hours they sleep, if they have drunk or eaten something forbidden, etc. Services that monitor the health status or the location of the users for security may detract from their capacity and freedom for taking decisions. Ethical considerations have in fact been identified as a major barrier to the delivery of tele-care, and it is suggested that clear guidelines are needed for maintaining the privacy, confidentiality and proper use of electronic medical data (Tang et al., 2000). In Table 1 a draft scheme of ethical aware design guidelines can be found to support this need.

Similar ethical problems arise when different kinds of implants and prostheses are used to detect a person's automatic reactions in communicating with the computer. For instance, the monitoring of body parameters (such as electric brain signals) to detect agreement, disagreement, fatigue, understanding, etc., can be used for early detection of anomalous situations such as depression or anxiety. Nevertheless they can limit the freedom of the person who might find it difficult to decide what information he or

[7] This issue is especially complex when speaking about users with cognitive disabilities (Bjørneby et al., 1999).

Table 1
A first approach to socially and ethically aware design guidelines

Risks	Description	Guidelines for HCI designers
Design of inaccessible devices or services	Devices or services that cannot be used by people with special needs, even if they have adequately adapted equipment	Develop a sound study of user needs Ensure user participation in the design Use guidelines towards a design for all approach to design
Loss of privacy	When personal information is stored and/or transmitted without the authorisation of the user	Do not store or transmit personal information without user awareness and authorisation Avoid storing or transmitting unnecessary personal information Use procedures to ensure anonymity (e.g. pseudonyms) Use secure means to transmit and store authorised personal information
Loss of autonomy	When decisions about the user are taken by other than the user or the person(s) authorised by the user	Avoid unnecessary automatic or external decisions by the system Inform the user about decisions taken automatically or externally Allow intervention only by authorised personnel
Economic factors	Devices and services out of the financial capability of the users because 'excessive' technology is used	Minimise the use of 'fancy' or expensive technology Avoid features not needed by the user that make the product more expensive When possible, select the lower cost choice
Invasive and/or socially unacceptable location systems	Systems for personal location that invade personal freedom and/or devices for location that are socially unacceptable	Use location systems only with stakeholders' awareness and consent Delete location information after convenient usage and do not record it unnecessarily Use discrete location devices, use 'tagging' devices only with strict ethical considerations

she wants to give to the machine. Even though such systems could provide important information, a natural reaction could develop against monitoring of internal reactions.

5.2.4. Loss of privacy

The need to use an intermediary system for communication makes it possible that private communications can be heard by strangers. In many cases, users with disabilities cannot choose the place where they use this service or may not be aware how public their communications might be. In addition, some interfaces for people with disabilities record and monitor personal information about the user. For instance, assisted communication methods can record the content of the conversation and location methods[8] can be used to find people with disorientation problems. Monitoring aspects of smart homes can also have a negative effect on the privacy of the individual.

[8] Privacy restrictions due to location systems may affect all kinds of users in pervasive environments (Beresford and Stajano, 2003; Miles et al., 2003; Davies, 2003).

6. Inclusive design guidelines

Accessible design requires knowledge and experience from the designer, but most HCI designers have no previous experiences in designing for people with disabilities. Even if they are aware of accessibility issues and they are willing to 'design for all', they can suffer great difficulties due to their lack of experience in this field[9]. In addition, professionals may want to design more inclusively, and know that in many cases they may have to do so to comply with legislation, but they are likely to be struggling with exactly how to go about it. Design guidelines are a good way to incorporate design criteria coming from successful experiences obtained by other designers. Guidelines may present problems, however, such as incoherence and unreliability, and when they are too numerous they may be difficult to handle, but they prove to be a good method in order to transmit satisfactory design experiences within large design groups or for the external world. Nevertheless, to be sound and trustful, guidelines must have been validated with real users by means of sound experimental procedures. In addition, methods and tools are needed to help designers to apply them (Vanderdonckt and Farenc, 2001; Clarkson and Keates, 2001).

Many sets of inclusive design guidelines are nowadays accessible through the Internet. See, for instance, those collected by COST219bis[10]. The guidelines with the largest impact are the ones for Web accessibility issued by the World Wide Web Consortium's Web Accessibility Initiative (W3C–WAI)[11]. For further reading on the use of inclusive design guidelines, Nicolle and Abascal (2001) offer a comprehensive discussion of the convenience of their use, tools and methods of working with them, as well as a number of examples.

6.1. A Successful precedent: WAI guidelines

The World Wide Web Consortium's Web Accessibility Initiative (W3C–WAI) is sponsored by a variety of government and industrial supporters of accessibility. They have issued diverse sets of Web accessibility guidelines that are a 'de facto' universal standard for Web accessibility. These guidelines do not need introduction because they are very well known. Even so, they are not frequently applied, and the number of inaccessible Web sites demonstrates that they are widely ignored by commercial organisations (Gill, 2004). But the sociological impact they are having on Web accessibility can teach us an important lesson, that is, how best to develop and promote successful inclusive design guidelines. We can point to some possible reasons for their success:

6.1.1. Clarity, applicability and universality

They are technically clear and straightforward, making it possible to build tools to automatically validate their implementation. In this way, the Web designer can know exactly the level of accessibility for a particular Web site. Diverse tools for HTML

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[9] In an interesting text, Newell and Gregor (1997) show the benefits for HCI designers of having experience in design for people with disabilities.

[10] Available at: http://www.stakes.fi/cost219/cosb235.htm, last accessed January 15, 2005.

[11] Available at: http://www.w3c.org/wai/, last accessed January 15, 2005.

accessibility validation (e.g. Bobby[12]) and repair (e.g. A-Prompt[13]) are currently available. In addition, these tools are mostly cross-disabilities and culture independent, and therefore, universally applicable.

6.1.2. Dynamic guidelines versus static standards

Web accessibility is an active area where frequent technological and methodological changes occur. Guidelines are dynamic and can be modified and enhanced when new knowledge about accessibility appears and when new accessibility barriers are detected, while standards are necessarily permanent. A key aspect for the success of WAI recommendations is that they have been formulated as guidelines. Time for standards may arrive when this field reaches a more stable situation.

6.1.3. Compilation procedure

A key aspect for their success can be found in the participative and open way they have been compiled. The consortium participating in the creation of WAI guidelines is a heterogeneous team composed of people coming from institutions, academia and industry. Before their acceptance by the group, the guidelines follow a careful process of proposal, revisions, etc. This process leads to a healthy consensus and enhances the universal acceptance of the results.

There are many other fields where inclusive accessibility guidelines are necessary. Are the experiences of the W3C–WAI useful for them? For instance, ubiquitous, context-aware and wearable computing have direct applicability to cover the needs of users with disabilities. Also consider smaller computers such as Personal Digital Assistants (PDAs), which require input by a stylus pointer, rather than a keyboard. The WAI guidelines specify the need to make all functionality operable via a keyboard or a keyboard interface (Web Content Accessibility Guidelines 2.0, Working Draft 19 November 2004). A stylus input would require precise eye-hand coordination, possibly making it inaccessible and unusable to some users (Gill, 2004). Therefore, if inclusive design guidelines for these fields are not issued early, followed by standards when the time is right, many devices and services will not only be incompatible with other technologies and services, but will also be closed to people with disabilities—likewise, this is true for inclusive design guidelines which are ethically and socially aware.

6.2. Ethical and social guidelines

Designers are well prepared to cope with all types of technical issues, but they can have problems analysing the ethical and social implications resulting from their designs. For this reason, these issues are frequently ignored. Designers consider that ethical and social issues are not their responsibility and, therefore, should be solved by service providers, institutions or public authorities. This is true only in part. Even if the responsibility for ethical and social aspects falls on other institutions, frequently these issues are deeply

[12] Available at: http://bobby.watchfire.com/bobby/html/en/index.jsp, last accessed January 15, 2005.
[13] Available at: http://aprompt.snow.utoronto.ca/, last accessed January 15, 2005.

integrated in the design and cannot be removed once the conception of the system has been completed. Only a design taking into account these aspects from the early stages can guarantee that the product or service is fully accessible, usable, and socially and ethically aware for people with disabilities.

The production of guidelines for socially and ethically aware inclusive design should be a collective task, maybe following WAI methodology, in order to be able to issue universally accepted and supported design criteria. As IFIP WG 13.3 members[14], the authors have supported inclusive guidelines compilation, diffusion and use and are active in promoting the discussion of ethical and social-aware design guidelines catalysing the participation of experts interested in this field. Therefore, it is not the function of this paper to issue a set of *socially and ethically aware inclusive design guidelines*. Nevertheless in Table 1 a short summary of a first approach for these kinds of guidelines is shown, in order to provide a starting point for further discussions.

7. Developing ethically aware design guidelines

Research experiences exist which can enhance existing inclusive design guidelines with further guidance that takes into account ethical and social issues. The following sections show two complementary experiences on guidelines generation for the specific case of device design for elderly people with dementia.

7.1. Case study 1

An example of technologies for people with disorientation problems where these issues are high on the agenda is electronic tagging, which is considered by some people as a suitable solution to reduce the risk to people with dementia who wander. Many ethical, legal and cultural issues have been raised by the use of tagging technologies on the wrist or ankle of a person to locate the person's whereabouts. These issues are often exaggerated by the use of the term 'tagging' which gives the negative connotation of tracking offenders (Abascal and Nicolle, 2001). Although many people are very aware of individual rights and the danger of imposing regimes of care on those who are unable to give or refuse their consent, tagging is still considered by many carers to be the least unsatisfactory and the least objectionable alternative to protect the safety of a person with dementia who wanders.

These issues were considered during the SCALP project (Safety Call and Localisation of Elderly and Disabled People), partially funded by the European Commission through the TIDE Programme (Technology for Inclusive Design and Equality). The project, which ran from May 1994 to June 1996, included these issues in its research whilst developing a prototype including an alarm and localisation system to meet the needs of both the patients, or residents, and their carers. The methodology to develop the prototype technology included an extensive user requirements study (Nicolle, 1998; Nicolle and

[14] International Federation for Information Processing. Working Group 13.3 on HCI and Disabilities. Available at: http://www.info.fundp.ac.be/IFIP13-3/, last accessed January 15, 2005.

Richardson, 1995). This comprised two main activities: state of the art review and fieldwork studies.

7.1.1. State of the art and literature review

As well as conducting a comprehensive literature review, key organisations working in the area of elderly people with dementia were targetted, such as the Alzheimer's Disease Society, Age Concern, and Counsel and Care for the Elderly. These organisations were either able to provide the names of publications relevant to the project, or the names of experts who could direct us to other relevant sources. Some key publications dealing with these issues included the following: Bewley (1998); British Medical Association and the Royal College of Nursing (1995); and Marshall (1997).

7.1.2. Fieldwork

Fieldwork involved interviews, either direct or through focus group discussions, and observational studies. Interviews with carers and other experts, both off-site and at the implementation site for the prototype system, identified key issues that need to be considered when caring for patients with dementia who are prone to wander. These issues included, for example, information about the activities of both nurses and patients, the frequency of wandering events, the time it takes to locate a patient who has wandered, and especially any particular difficulties and needs.

The project also conducted a survey across Europe to investigate the way people felt about the ethical and cultural aspects of using tagging technologies. Although the questionnaire covered the locating/tracking functionality of the prototype system, it also elicited people's views on tagging technologies in general, including departure alert systems which would only sound an alarm when a resident left the building.

7.1.3. Results

The user requirements identified during the project led to recommendations for the design of tagging systems so that ethical issues and the rights of the individual would be taken into consideration. For example, technology to be used in the care of people with dementia must be flexible enough to allow different levels of interface for different stages of dementia, as well as the ability to deactivate certain facilities, like an alarm button, for some people too confused to use them. The device also should not label the person, i.e. it needs to be light, discreet and aesthetically appealing. It is also important to remember that a person with dementia should not be expected to wear a design which another person might reject. Such requirements, identified during the specification of user requirements, were also considered during the evaluation phase of the prototype, thus aiming for a more usable and acceptable system.

7.2. Case Study 2

Systems used to locate individuals have a high impact on rights to privacy, including the invasion of private life and the restriction of personal freedom. Among other conditions, awareness and explicit consent are claimed to be the main ways to protect users from privacy invasive systems (Langheinrich, 2001). When users are people with cognitive disabilities, consent and awareness are frequently not possible. Here we present a study conducted within the Dalma project to detect ethical problems and to generate criteria for an ethically aware technical design (Casas et al., 2004).

The Dalma project developed an alarm and event notification system with location capacity, for use in residences, hospitals and other public or private institutions. The location system achieves a precision of a few centimetres based on small wearable devices using radio-frequency and ultrasonic technologies. This system is being enhanced with the sensing of body parameters, and integration into a Smart Home in two separate projects, Heterorred I and II (Sevillano et al., 2004).

The main benefit of Dalma is to provide safer and greater mobility to the person by detecting risk situations, such as staying in a dangerous place for too long time (leading to a risk of falling), wandering (the possibility of disorientation), absence or lost contact (missing from the residence), repetitive actions (possible behaviour denoting anxiety, escapism or other pathologies), etc. Indirect benefits are the extension of surroundings that are considered safe for the person, psychological reinforcement, and the reduction of time waiting for assistance.

The methodology to develop the ethical impact study was as follows:

7.2.1. First technical design

Rooted in previous experiences (Falcó, 1997; Casas, 2004), a first design of the Dalma system took into account only technological issues. In this way, an indoors location system using radio-frequency and ultrasonic technologies was specified, which was able to detect the location of a small tag worn by each user. The developed location system consists of several beacons fixed in the ceiling and several mobile tags. The beacons successively broadcast ultrasonic pulses that are received by the tags, which measure the ultrasound time of flight. Every tag sends its identity and the time of flight data to a central control (personal computer) via radio-frequency, to compute the tag position. The system was able to locate up to 256 tags, with an accuracy of 5 cm, and a typical temporal resolution of one new location every 500 ms.

7.2.2. Analysis of ethical impact

Ubiquitous technology allows logging many human parameters such as location, movements, communication tasks, body parameters, etc., without the consent or even the awareness of the observed person. This situation requires a suitable legal frame, but relevant legislation is different, and sometimes insufficient, in each country. There are several studies (e.g. Beresford and Stajano, 2003; Clarke, 1999; Kaasinen, 2003; LWG-OMA, 2002; Myles et al., 2003) about privacy issues for location systems, but they are not always applicable when users have cognitive disability. In this particular case (and also frequently in the development of other Assistive Technologies) Pompano (2000) argues that the laws issued to protect people with disabilities often reduce their privacy. It is evident that the problem is not in the positioning system, but in the misuse of the information it offers. The use of a positioning system provides an obvious utility for the located person, but due to their special characteristics and dependencies, it is even more critical to consider the ethical aspects related to the invasion of private life and the restriction of freedom. General guidelines cannot be applied because, for instance, many users cannot provide their consent. And even when the informed consent can be signed, it is possible that the user does not completely understand their rights to privacy and the implications of location devices.

When the person is not able to declare her or his consent, a conflict between two rights is established: on the one hand, the right to privacy, and on the other hand, the right to health and even to personal well-being. This dilemma can be solved, as it is in the medical field, by prioritising the protection of the person over the right to privacy. Although we are always looking to protect the person, it would be necessary that the one holding legal guardianship over the person with disability gives her or his consent.

7.2.3. Bibliography and web references search

Many authors have addressed ethical issues related to personal location, for instance, Beresford and Stajano (2003); Clarke (1999); Docket (1996); Escudero (2001); Kaasinen (2003); Langheinrich (2001); LWG-OMA (2002); Myles et al. (2003); Pompano (2000). Nevertheless, due to its special features, the particular case of people with cognitive disabilities has to be studied separately. Few authors address specifically this issue. Among them the following were consulted: Bjørneby et al (1999); Bjørneby and van Berlo (1997); and Graafmans et al (1988). In addition, existing privacy laws in the USA were considered: Communications Act of 1974, and Wireless Communications and Public Safety Act of 1999, which further amends Section 222 of the Communications Act. In Europe, Directive 2002/58/EC (EC, 2002) and EC Directive 95/46/EC (EC, 1995) were also consulted.

7.2.4. Compilation of guidelines from the proposals found in references

Dalma designers understood the potential and danger of this technology and decided to develop internal ethical design guidelines to help themselves to drive technology into a responsible and socially acceptable direction. This project distinguishes different user profiles for privacy issues: caretakers, people having sporadic crises that can be detected by the system, or people susceptible to risk of accident (especially the elderly), and people with cognitive disabilities who may be vulnerable in certain risk situations (for example, repetitive actions, positioning themselves in dangerous places, etc.). In addition to general privacy protection guidelines (e.g. Langheinrich, 2001; LWG-OMA, 2002), some special design criteria were agreed as part of the Dalma project to deal with these particular issues.

Storing. The location information of caretakers and people having sporadic crises should not be stored indefinitely; instead, it may be used solely to deal effectively with the risky situation at hand. Location information relevant to people who were continuously being located could be stored only for the time necessary to be analysed and then it should be destroyed.

Consent for location. Caretakers could be located only if they provided a signed explicit consent. However, in order to reduce the stress caused by the ‘big brother’ effect, they are only located when an alarm occurs. The continuous location of people not able to give an informed consent, due to cognitive disabilities, must be signed by their legal representative.

Data protection. When the location system is centralised, database encryption and security access controlled by passwords must be used.

7.2.5. Redesign of the proposed systems

The implemented version of the Dalma system has all the requested location functions. In addition, privacy and security matters have been enhanced: the inclusion of database encryption and passwords for centralised information; use of pseudonyms to keep the anonymity of the located people; use of secure wireless protocols (implemented in Bluetooth specification) and 128 bits data encryption for wired data through Ethernet, to avoid personal information data hacking. Location monitoring was limited to the following situations: detected risk by alarm systems, or requested by the individual user. User profiles, specifying a different treatment of location information for each type of profile, were defined for caretakers, people with accident risks, and people with cognitive disabilities.

7.2.6. Evaluation

The Dalma system has been deployed in the institution *Virgen del Pueyo* in Zaragoza (Spain). Forms were designed which would be used to identify and collect technical and ethical issues, but no ethical problems were raised during the evaluation phase of the technology.

8. Lessons learned

The introduction of new information and communication technologies should include a deep investigation of the social and ethical impact over disabled users to ensure that social inclusion, privacy and decision-making are not overlooked. This study points out the critical aspects that have to be avoided, and also describes the compensating actions that have to be taken to avoid negative effects over their lives. Legislation is required to ensure privacy and autonomy for disabled people. Actions are also needed to enhance user awareness of the use and misuse of personal information and of decisions about them that can be taken by 'intelligent' systems.

For this reason, human interface designers should work within a multidisciplinary team where experts in legal, social and ethical aspects are present. They should also be provided with clear guidelines to avoid invasive designs. Even if most of the ethical risks must be confronted through legislation, designers must also be aware of the ethical implications of their products to avoid unnecessary invasions of user rights (Bjørneby, 1997; Abascal, 1997).

These issues have resulted in a draft summary of ethical and socially aware design guidelines proposed from the authors' research experience and from the literature (as presented in Table 1). The objective is just to stimulate designers to consider, propose, study and verify these kinds of guidelines.

9. Conclusions

Developments in Human-Computer Interaction allow barriers to be overcome in gaining access to computers, resulting in better interpersonal communication by people with disabilities, greatly enhancing their socialisation opportunities.

Some factors that can detract from social inclusion have been detected, and the need for socially and ethically aware inclusive design guidelines has been stressed, in order to provide HCI designers with the necessary information to avoid ethical and social risks.

On the other hand, even if information technologies offer a challenging opportunity for social inclusion of people with special needs, it is evident that the advances in accessibility are driven not only by technology but also by the pressure over policy makers imposed by individual users, associations of people with disabilities, their families, and careworkers. Technology and social pressure, working together, can avoid this kind of digital divide and support social integration.

In addition, it is necessary to realise that the natural evolution of the market is not able to drive industry to produce more socially inclusive devices and services. These problems can only be overcome through international collaboration, standardisation and legal protection.

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