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# AAATE position paper A 2003 view on Technology and Disability

## Introduction

The European Year of People with Disabilities has marked a step forward in disability issues. In this year, disability issues have been on the stage across Europe as never before; national governments and the European Union have been engaged in designing and pushing up policies; the Madrid Declaration "non discrimination plus positive action results into integration" has inspired in many ways this process; although the concrete actions that have been actually implemented may be seen as just drops in the sea, many seeds are being sown that – if well cultivated - will help shaping the future towards an inclusive society.

Awareness has increased over the latest years on the role that technologies - and especially those technology that are commonly referred as *assistive* - can play in supporting full participation of people with disabilities in society. *Accessibility* - especially referred to information society - and *assistive technologies* (*AT*) have been well in the agenda of the European Year of People with Disabilities.

As the 6<sup>th</sup> Framework Programme (FP6) of the European Commission was published in 2002, AAATE expressed appreciation for the possibilities it was opening for developments in the field. Especially it welcomed the new instrument called "Network of Excellence", and worked out a position paper on how Networks in this domain could help mobilise resources for the advancement of AT in Europe. AAATE actively encouraged its membership to submit Expressions of Interest: the response was quite high, thus indicating to the European Commission that the AT sector yields great scientific, social and industrial importance, deserves a well-defined place in the 6<sup>th</sup> Programme, and can rely on a significant amount of actors and expertise in Europe. As FP6 Calls began to open, a great number of projects were in fact submitted.

In fact most institutions - where the bulk of the AAATE membership originates - already are active with respect to AT and DfA issues in their respective countries. Most of them have considerable experience with international collaboration, having participated - or being currently involved - in international R&D projects or EU initiatives (such as eEurope / eAccessibility) in this domain. On the whole, they are the owners of immense know-how resulting from long-term experience that has never been exploited to its fullest in the European arena.

Witness to that was the AAATE 2003 Conference that took place in Dublin in September 2003. It was an extraordinary and inspiring event: certainly the most important scientific event in the AT field in Europe during the European Year of People with disabilities. Just to give a concise picture of the Conferences relevance, the conference included over 200 peer reviewed scientific papers



(distributed across 35 sessions in 5 parallel tracks), 16 invited papers (distributed across 6 plenary sessions), poster sessions, an exhibition and satellite events. Key themes were:

- *Guidelines and Standards*
- User centred approach
- *Interdisciplinary practices*
- New technologies

Attendance was about 400 scientists mainly from Europe, but also from all over the world. Scientific officers from the European Commission - from both DG EMPL and DG INFSO - offered an informative overview of EC policies in a plenary session devoted to this topic. The wealth of material submitted for this Conference – and quality-checked by the Scientific Committee according to scientific standards – is collected in a *book of proceedings*. As previous experience teaches, this book is destined to be considered as the compendium of assistive technology research, development and applications. At least until the next Conference, it is a "must" for everybody - whether academic, industrialist, clinician, policy maker – who needs to access and pick up state-of-the art knowledge

Based on the previous position papers and in the light of the Dublin experince, AAATE wishes to summarise and point out a number of issues and reflection that should guide development and action in the field of technology and disability in the coming years.

#### **Role and relevance of Assistive Technology**

The advancement of technology is one of the factors that challenged the 1980 ICIDH model of the World Health Organisation, based on the causal linear relation *impairment - disability - handicap*.<sup>1</sup>

The new ICF (International classification of Disability, Functioning and Health) - launched by the World Health Organisation in 2001 - well acknowledges this issue. In fact, according to ICF, *disablement* should be not looked at as an attribute of a given individual, but rather a *situation* that may affect any individual in case a gap exists between individual capabilities and environmental factors, and this gap restricts the quality of life and hinders fullest exploitation of the individual's potential in society.

The physical characteristics of the environment and the available technologies and products, both *mainstream* (i.e designed for the general public) and *assistive* (i.e. specifically designed in consideration of functional limitations), play a substantial role in enlarging or bridging such gap, depending on the way they are planned, designed, and implemented. Their role is clearly acknowledged by ICF in classifying them among *environmental factors* that contribute to generate or overcome disablement.

In today's and future society this is particularly true, as technology becomes increasingly inseparable from the user in all aspects of life, such as home and school life, work and leisure, mobility and communication, participation in family, and social and civic life. In this view, the prevalence of people exposed to disablement is progressively more significant (estimated at 18% of

<sup>&</sup>lt;sup>1</sup> If I write by means of an ordinary pen, and my colleague who is quadriplegic writes by means of a portable computer equipped with a virtual keyboard and a head-controlled mouse, we both experience no disability with respect to the task of writing. Conversely, I would experience a disability ("not being able") if I had no pen, as my colleague would do without his assistive device. That means that disability cannot be looked at as an attribute of the persons: conversely, it depends on the situation.



the whole population by 2020). This segment includes persons who were born with functional limitations, or acquired them later in life, persons who are temporarily impaired due to accidents and trauma, and elderly population – especially the "old old" – whose range of functions are reduced due to the ageing process or to pathologies that frequently occur in the older population.

The lesson embedded in ICF is that overcoming a disablement may involve something more than just a device, it often requires a *mix* of mainstream and assistive technologies whose assembly is different from one individual and another, and from one context to another. We may label it *assistive solution*.

Research themes related to Assistive Technologies (AT) that expand capabilities of people with disabilities and elderly people - as well as Design for All (DfA) issues and barrier-free technologies – have been considered in the previous  $3^{rd}$ ,  $4^{th}$  and  $5^{th}$  Framework. Significant results have been achieved. In several programmes a vision has been pursued that any technology-based products and services should be developed in such a way as to prevent disadvantages or exclusion of parts of the population. In addition to that, a DfA network of centres of excellence related to access to the Information Society has already taken wing within the e-Europe / e-Accessibility initiative. Although not directly related to funding, such network is the result of a wide consultation exercise carried out by EC that acknowledges the critical relevance of the subject.

However, the ideal world where this vision is internalised by society as a whole and is fully endorsed by scientific & technological developments is a long way off from achievement. At the same time, the technological environment is rapidly changing with considerable impact on peoples' lifestyle. *Should similar efforts not be renewed and maintained in this area, there is a substantial risk that future technological developments will contribute to create new barriers to the disadvantaged populations.* Moreover AT is likely to continue to be confined within a marginal market niche, lacking industrial strength, and the potential benefits of technology - in terms of advantage to the individual's quality of life and participation in society – effectively will be denied to significant parts of the population. Besides social and ethical implications, this would be sure to bring about economic (e.g. increased social costs for assistance of marginalized people) and industrial (loss of competitiveness with US AT industry) drawbacks.

Conversely, adequate investment in this area would help exploit the tremendous market opportunity represented by this segment of population, due to the combined effect of its growing size and its increasing interest in technology (studies on the diffusion of ICT equipment, for instance, clearly indicate faster uptake by people exposed to disablement than by other people).

AAATE believes that this DfA and AT should be looked at as part of the same domain of knowledge, rather that deal with these as two distinct domains, as it was more common in the past.

In today's society, AT (sometimes labelled also as *enabling* or *empowering* technologies) and DfA (sometimes labelled also as *inclusive* or *universal* design) should be regarded as components of a continuum whose primary aim is to exploit the individual's capabilities at their fullest. Although there is favourable discussion around the idea that the people's needs should be met as far as possible by means of DfA solutions -and sometimes the exact border between what should be considered "for all" and "assistive" is not always well defined - nevertheless it is generally acknowledged that AT solutions will continue to be needed to address a wide range of functional problems.



As part of a continuum, mainstream and assistive technology should work together and thus be complementary and compatible. The same expertise on users' needs should guide the development of both. On the one hand, resources should be allocated to the development of DfA concepts that guide the development of a living environment accessible to everybody, i.e., where products are *inclusively* designed from the earliest (concept) stages of development (barrier-free technologies). On the other hand, resources are required for the advancement of the AT domain, in order to overcome the present situation of fragmentation and unequal distribution across countries, and support developments that enable individuals to exploit their capabilities to their fullest in the knowledge-based society.

In particular, AT initiatives continue to suffer from a somewhat vicious circle. Despite its economic significance (over 20,000 products available in the EU with estimated turnover 30 billion Euros), the sector is still characterised by high fragmentation of the market. It is dominated by SMEs that are often highly competent in solving individual problems, but have limited R&D and market capacity. Large industries, that possess high innovation potential, substantial R&D capacity, and huge market penetration, often are not prepared to provide competent responses to such an individualised range of need. Moreover, above a certain threshold of costs, the target population has limited purchase capacity, thus making financial support necessary from public agencies that act as intermediaries between the user need and the market supply, which consequently eventually become - in most Countries - the actual dominant forces on the market. Service delivery aspects play an important role as the requirements expressed by these agencies may not be in line with end-users' actual requirements if they could negotiate directly with suppliers.

To this end, an interdisciplinary approach is required that involves design & engineering competence, clinical expertise, socio-economic knowledge, understanding of industrial and market issues, insight into public policy matters, and, last but not least, the perspective of end-users.

#### Priority areas within the assistive technology domain

As mentioned before, a disability can be overcome by an *assistive solution* often composed of a *mix* of mainstream and assistive technologies that is different from one individual and another, and from one context to another. Thus a broad view should be taken of the entire *technology chain* that encompasses:

- the built environment
- the transport / mobility infrastructure and devices
- the communications infrastructure and devices
- the ambient intelligence distributed accross the environment
- the individual devices specifically designed to compensate for functional limitations.

Any links of the chain should be compatible with each other; having just one link missing or incompatible is sufficient to generate a disablement even when the other links work perfectly (similarly to what happens when a bug in the operating system of a computer makes the user stuck even when running a perfectly coded application). When looking at the various components of the technology chain, it is apparent that a range of diverse competences is needed that must be integrated within an interdisciplinary context.

This range of topics needs to be approached through three main different perspectives:

- Technology / design issues
- Socio-economic and policy issues



• Human issues

Each of these includes three dimensions:

- development of new knowledge (expanding the knowledge base; anticipating future scenarios)
- interdisciplinary integration (creating common terms of reference; developing tools for practice)
- knowledge transfer (education and training; information dissemination)

In particular, the last dimension has a key role in making any advancement instrumental to an inclusive society. *Education* and *training* for professionals and users are major avenues for transferring knowledge to all actors involved, along with a network of Internet-based information services delivering information in the various EU languages.

*Technology / design issues* are related to the tangible shape that technologies should assume in terms of infrastructures, products, and services. Major topics under this heading are:

- inclusive (universal) design of buildings and building automation infrastructures
- inclusive design of ICT-based systems and services distributed in the environment
- inclusive design of transport infrastructures and systems
- inclusive design of human-computer interfacing, whatever form the computer may be
- specific interfaces related to disabilities (e.g. acquisition / processing of physiological signals)
- assistive technologies for personal care
- assistive technologies for mobility
- assistive technologies for communication
- assistive technologies for sensory impairments
- assistive technologies for restoration of function (motor, visual, hearing)
- assistive technologies for managing an coping with cognitive disorders
- "orphan" technologies (for solving very specific problems that are usually neglected due to the small size of their target group, e.g., dea



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- fblind)
- information systems for assistive technologies
- standards, compatibility, and interoperability
- testing and certification

*Socio-economic and policy issues* are related to the implementation of AT and DfA and their impact in society. Major topics under this heading are

- implementation of DfA and AT in legislation and regulations
- service delivery systems for assistive technology
- cost-effectiveness of solutions
- effectiveness vs abandonment of AT
- socio-economic impact of mainstream vs assistive solutions
- industrial coherence
- AT in the workplace
- AT in education

*Human issues* are related to the knowledge of the user needs, the human factors involved in the implementation of Dfa and AT, and the impact of AT solutions on the user's way of life.

- expanding the knowledge-base of users needs
- expanding the knowledge-base of other stakeholders (e.g., formal and informal carers)
- matching technology with the person and the environment
- outcome measures
- usability of products and services
- user participation in the design of solutions
- user's role in the the decision-making process in adopting solutions

# New challenges ahead

The above categorisation provides a consistent picture of how the AT domain should be approached in the current times, as far as research, development, service delivery and policy are concerned. However, the context is always evolving and pushing to continuous critical reflections.

One major challenge is represented by the fact that we are facing so many changes at quick pace in relation to the penetration of technology in society, also involving changes in the people's habits and way of living. It seems that we cannot live any more without technology – who does not carry a mobile phone today – and even traditional distinction between hi tech and low tech has become more and more blurred. This trend has enormously expanded the possibilities for persons with severe functional limitations to live independently and participate in all aspects of society.

However, if we want to be successful in our work of designing and implementing assistive solutions we also need to know how the fabric of society and even the people needs may evolve in the future. We need to understand some implication the increasing societal penetration of technology may yield on the people's needs and even on the definition of assistive technology.



What's crystal clear is that information society is bringing about new lifestyles, and in parallel our living environment is becoming more and more "intelligent" and thus more adaptable to a huge variety of individual needs. Assistive solutions for people with disabilities can be achieved more easily - and at cheaper cost - than in the past, usually by means of a mixture of *assistive* devices in strict sense, *mainstream* technologies, and *ambient intelligence* (hooking the sea of electromagnetic signals we all are swimming through everyday).

The cultural relationship between man and technology is also changing. Today, we like to say we *wear* a mobile phone exactly as we would say we *wear* a pair of shoes, or a pair of spectacles, or a windcheater (that's often high technology too). Thus why do we still read in some papers sentences such as "confined to a wheelchair", while we should better say – as many people in fact do today – that one *wears* a hearing aid or a wheelchair with chin control? It's not pure linguistic exercise, if I say I *wear* my device the *design* argument is more understandable to society: the device has to be perfectly suited to my sizes, functional needs, performance requirements, environment of use, people I meet, my personal taste, my personality.

We think we all are aware we need a comprehensive approach. Interdisciplinarity is more than just a formal keyword, but a daily experience for us who work at designing assistive solutions that accommodate for not just the overall public but for meeting exhaustively *each varied individual need*. And despite the great advancement in design-for-all concepts and methods, we cannot imagine that this objective can be met only by mainstream industry or service providers.

Advancement in this field requires a broad range of competencies from different disciplines; claims for a user centred approach in terms of hard facts rather than nice buzzwords; brings about complex cultural issues (think eg to the "hot topic" of outcome measurements, where transcultural validation showed to enlighten the epistemology of such research). Hence, supporting interdisciplinary networking of competencies and expertise is becoming a growingly critical issue, if we wish to drive this process towards contributing to the creation of an inclusive European society.

#### A key player: Industry

Along with researchers, users, and people or institutions involved in policy and service delivery, Industry is for sure a key player in this field. However, the interest shown by Industry still seems quite fragmented and mainly restricted to specialised niches. We may hardly expect that such interest takes wing by itself. It is our opinion that a strong European signal would be most important for stimulating the development of Assistive Technologies and the uptake of the principles of Design for All and Products Adaptability by Industry. This at the level of both *large-players* and *small and medium size enterprises*. Without strong signals from the European Commission and national governments, Industry would not recognise the people with disabilities and older people as target groups showing an interesting potential.

In the AAATE view, the European Commission should support and develop activities aimed at:

- Awareness creation among stakeholders in the European market:
  - Making Industry aware of the potential of these target groups
  - Making Users aware of the potential that assistive technologies and design-for-all-based products can offer, so as to stimulate the demand for these products
  - Making politicians aware of the broad range of solutions that are needed for people with disabilities.



- Developing a legislative framework to stimulate the inclusive approach. In relation to this point, AAATE supports the position already expressed by the European disability Forum i.e. that without an appropriate legislative framework the development of inclusive products and services will not take place. Many major international industries developed accessible products due to the market demand generated by specific US regulations, and most such products are still available only in the US.
- Stimulating R&D in the following domains:
  - 1. Design for All:
    - Better understanding the concept of Design for All.
    - Outcome studies to prove the effectiveness and the impact of Design for All.
  - 2. Products and Services Adaptability:
    - Better understanding the adaptability concept in mainstream products
  - 3. Assistive technology
    - Development of *plug-in* concepts (easy / compatible / reliable interfacing between assistive and mainstream products)
    - Development of new Assistive Technology products, by taking advantage of the new technological developments.
- Increasing Users Empowerment:
  - Moving from a "user" to a "customer/client" approach: stimulate changes in the political and operational environment in relation to the provision of products and services for people with disabilities and elderly people.
  - Promoting the establishment of information, counselling and support services along with developing an European structure for their quality assurance for people with disabilities.

As already sail earlier, there is a risk that, without strong signals from the Commission and from national governments - this sector will be disappearing from the stage and be looked at as a minor "additional appendix" to other sectors. In the AAATE view, such a trend would be most unfortunate and would be the worst development we could expect. We believe it would be also contrary to the interest of the European Industry and especially of people with disabilities.



## Appendix AAATE in brief

AAATE (Association for the Advancement of Assistive Technology in Europe) it is the European scientific society specifically dedicated to the advancement of technology for the full participation of persons with disabilities. As such, it is a major representative of the interest and expertise in the field, as described shortly in the following facts.

AAATE membership is individual; to-date it accounts to over 200 scientists working in the field of barrierfree technologies and AT in the domains of research, industry, and services, and distributed throughout some **90** Institutions in the various countries of the European Union and Associated States. These include research / academic institutes, clinical / rehabilitation centres, public agencies, companies, and users organisations. A forum of such Institutions has been just initiated within AAATE to provide a more effective means for the collaboration that already exists among several of them.

AAATE facts - 2003			
Membership	Number of registered members: 224		
_	Members' domains of activity: research & academic (121), Service Delivery (63), Industry (37)		
Geographical	EU 166 (Uk 36, Nl 19, S 19, Irl 16, I 14, D 13, Dk 9, Es 9, Pt 8, F 7, Fin 7, B 4, A 3, Lux 1, Gr 1)		
Coverage	European non-EU 20 (Slo 6, Bg 4, N 3, Ch 2, Sk 2, H 1, Pl 1, Isl 1)		
_	Non European 38 (Usa 8, Jp 6, Il 5, Cnd 4, Br 4, Aus 2, Other 9)		
Governance:	Renzo Andrich	from Siva Fond. Don Carlo Gnocchi Onlus, Milano I	president
AAATE	Harry Knops	from IRV, Hoensbroek NL	president elect
Board 2003	Erland Winterberg	from Danish Centre for Technical Aids, Taastrup DK	secretary
elected by the	Jan Persson	from CMT University of Linkoping, S	treasurer
Assembly	Ger Craddock	from Central Remedial Clinic, Dublin IRL	
	Pier L. Emiliani	from IFAC CNR, Florence I	
Office	C/o Danish Centre for Technical Aids, Taastrup DK		

AAATE membership includes the majority of researchers who led or participated in AT-related projects in the 3<sup>rd</sup>, 4<sup>th</sup> and 5<sup>th</sup> Framework programmes, or other programmes such as the e-Accessibility initiative. On several occasions it contributed the expertise of its membership to the EC during the development of new programmes. AAATE currently has a fundamental role in promoting knowledge and advancement in the area, by means of:

- a *Biennial Conference* with published proceedings (Lisbon 1995; Thessaloniki 1997; Dusseldorf 1999; Ljubljana 2001; Dublin 2003).
- the *Scientific Journal* "Technology and Disability" (published quarterly through IOS Press)
- International Seminars (Amsterdam 1996; Helsinki 1998; Hatfield/London 2000; Hoensbroek 2002)<sup>2</sup>
- a *website* <www.aaate.net> and related network services (discussion list etc...) for members.

AAATE has formally established collaboration agreement with the other three major scientific societies that cover the international AT scene, namely

- RESNA (the Rehabilitation Engineering Society of North America)
- ARATA (the Australian Rehabilitation and Assistive Technology Association), and
- RESJA (the Rehabilitation Engineering Society of Japan).

AAATE has also relations with various other organisations such as the EIDD (European Institute on Design and Disability), ISAAC (Int'l Society for Augmentative and Alternative Communication, and the EDF (European Disability Forum), and is registered in the *Coneccs Base* of the EU in that it satisfies the EU requirements established for "organisations of civil society".

<sup>&</sup>lt;sup>2</sup> The Hoensbroek Seminar addressed the topic "Mainstream and Assistive technology in debate", that generated a number of relevant policy recommendation in this area