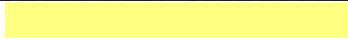




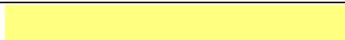
BRIDGE

assistive
technology
against
social
exclusion

Assistive technology against social exclusion



assistive
technology
against
social
exclusion



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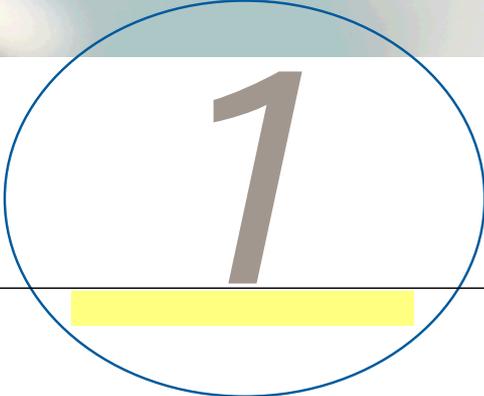
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section



Introduction



THE SUBTITLE OF THIS REPORT sounds like the slogan of a political or social campaign! Although as professionals working in the field of European Assistive Technology we are not born campaigners, the BRIDGE project has been carried out with the enthusiasm of those who have important issues to raise.

The authors hope that this report will make a useful contribution to the current, European-wide discussion on disability and social exclusion. In particular, we are interested in the role that Assistive Technology (AT) can play on the road to social inclusion. As the reader will learn from the content of the report, social, educational, and professional inclusion are fundamentally about human and democratic rights. Inclusion means becoming a full and valued member of society, not an associate. Inclusion means equality. Inclusion means quality of life. Inclusion means the real entitlement to *opportunities*, and not just AT tools.

The BRIDGE project and this report aim to move Assistive Technology up the policy agenda of health, education and social service providers at all levels of activity - local, regional, national and European. It informs policy makers and policy implementers about how AT services can be improved and extended. The author's target audience also includes the end users of AT services, their facilitators, their representative organisations, and professionals, including those working in the public sector, non-governmental organisations, foundations and charities. This report's wide range of human stories may also be of interest to that part of the media concerned with the rights and issues of people with disability.



... a delicate process that demands teamwork and professionalism ...

Those readers who hope to discover that Assistive Technology is somehow the latest post-industrial panacea will be disappointed. There is room for optimism that "things are getting better" but only within the realistic parameters that are determined by the nature of the disability, the personal motivation and drive of the individual, the social and political context, and the availability of financial and human resources. This report shows some of the possibilities offered by AT and describes aspects of its evolution towards today's "state of the art".

The report also offers insight into the difficulties encountered in striving to ensure that Assistive Technologies become effective tools for inclusion and the conditions that have to be met for successful service delivery outcomes. One thing is for sure AT devices are not aspirins that take effect as soon as they are swallowed! The introduction of AT devices into the lives of people is for the most part a long-term and delicate process that demands teamwork and professionalism, time and experience. In presenting real stories and explicating underlying processes this work will contribute to bridging the wide gap between end user expectations and most AT service delivery systems in Europe.

BRIDGE is a European project, funded by the European Commission in the framework of the Programme against Social Exclusion. European projects often run the risk of merely providing

comparisons between situations in the different member states. While it is true that Assistive Technology service delivery varies across European countries, BRIDGE highlights the *common* issues currently engaging consumers and providers of Assistive Technology services in Italy, Germany, Spain (Catalonia) and England. Recognising the right of European citizens to full participation and equal opportunities, the BRIDGE project demonstrates that at *all* levels of decision-making, including the European level, there is a need for some common approach and policy towards Assistive Technology. This conclusion is based on the recognition of the opportunities provided through Assistive Technology for social inclusion - opportunities for improving the quality of life of people with disability, and, in some cases, for saving or rationalising precious public resources. Furthermore, where Assistive Technology models of good practice are sensitive to social and cultural diversity, successful outcomes often follow.

The authors, representing five non-commercial, European Assistive Technology centres (for their names and a brief description, please see the final page), have pooled their experience and philosophies in Assistive Technology service delivery to form the basis of this report.

ASSISTIVE TECHNOLOGY IN THIS REPORT

THE FIELD OF Assistive Technology is very broad and embraces a wide variety of professionals and equipment. This report is concerned with four specific aspects in AT provision: Augmentative and Alternative Communication, Computer Assisted Access, Environmental Control and Powered Wheelchair Mobility. They represent new and important responses to the needs and expectations of people with disabilities in which the impact of developments in information technology and electronics is felt strongly. The authors are well aware that these particular components of Assistive Technology are not fully representative of the breadth of work in the field; however, the issues raised here are pertinent to other branches of Assistive Technology.





section

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Europe - towards
an inclusive society



THE BRIDGE REPORT IS being published at a time when the European Commission is implementing EU policies against social exclusion. The development of new policy initiatives is based on the recognition that the inclusion of people with disabilities is no longer a question of their empowerment only, but a challenge for society as a whole, in all realms of life: school, work, home, leisure, transport, sports, design and so on.

The development of policy instruments aimed at building an "Inclusive Europe" has been enriched by the contribution of **The Madrid Declaration**. In this important document, representatives of organisations of people with disabilities in Europe and the European Commission set down their vision for the European Year of People with Disabilities (2003) including the development of a framework for action. The document, then, promotes many core principles, among which the following are particularly relevant to the field of assistive technology:

- Disabled people do not want charity but equal opportunities.
- One of the conditions for equal opportunities is having access to resources, services and opportunities in education, work and leisure.
- Disabled people have the right to inclusive services and services promoting the highest level of independence possible.

Importantly, the declaration explicitly highlights the demand for accessible quality services promoting independent living based on the needs of disabled people.

The population of people with disabilities is not an insignificant group. Although it is difficult to find reliable statistics, some figures are available. For example, according to The Madrid Declaration 50 million Europeans have a disability. In a recent report issued by the Italian Institute of Statistics (ISTAT) there are 3 million disabled citizens in Italy, while the German counterpart (Statistisches Bundesamt) in Wiesbaden reports more than 6 million people with registered disabilities in Germany. This represents more than 8% of the total German population.

Experiences of exclusion by people with disabilities are overwhelming. As reported by European Commissioner Anna Diamantopoulou in September 2000, more than 50% of people with disabilities are excluded from the labour force compared with less than 25% of the remainder of the population. Of those in the labour force, people with disabilities are 50% more likely to be unemployed, and to remain unemployed for longer periods, than the working population as a whole. Exclusion from the labour force is an economic disadvantage not only for people with disabilities but also for the whole European society.

People with disabilities do enjoy support for positive action and improved policies. For example, in a recent survey 97% of the European population acknowledged that more has to be done to include disabled people in mainstream society (Eurobarometer Survey 2001).

Assistive Technology can make a significant contribution to building an Inclusive Europe. However, Assistive Technology is not a straightforward or undemanding collaborator in the fight against social exclusion. Technological aids can be powerful tools in promoting inclusion but they





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cannot provide the sole solution to any one set of problems; rather, their successful use relies on the merger of many varied factors, and it is for this reason in particular that qualified independent Assistive Technology centres play an essential role in ensuring that technology is put to the best use.

In the following chapters we will discuss changing opportunities for people with disabilities following technological progress, and explore how people with disabilities, and those with whom they live and work, can benefit best from these technological solutions.

THE CHALLENGE IS NOT only to provide a better assistance to those excluded (or at risk of exclusion), but also to actively address the structural barriers to social inclusion thus reducing the incidences of social exclusion.

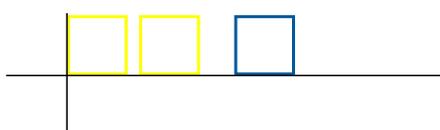
EC Communication: Building an Inclusive Europe

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section 2



Europe-towards an inclusive society





section

3

Assistive Technology
and social
inclusion



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Assistive Tecnology promoting independence

The benefits of technological progress

HUMAN BEINGS HAVE always been inventive in developing tools and devices to improve the efficiency and ease with which everyday tasks are accomplished – from the humble bicycle and light bulb to the cell phone and the electronic notebook. We all enjoy the opportunities that tools like these offer, not least in their ability to improve the flexibility and autonomy of our modern lifestyles.

The last decade saw an enormous increase in the application of advanced electronic technology to general consumer goods. Today, for example, microprocessors can be found in most household appliances, cars, telephones and, of course, computers. They are the outstanding example of the technological revolution in daily living, often performing multiple tasks within integrated environments.

Many people with disabilities are able to take full advantage of the opportunities presented by mainstream technologies.



THE CELL PHONE IS one of the best examples of versatile mainstream technology from which people with disabilities can benefit. Cell phones provide:

Greater freedom -allowing people to call and to be called everywhere and at any time of the day or night;

New opportunities -allowing people to receive text messages and news updates on any subject;

Integration with other tools -allowing people to use the same tool for various functions (personal organiser, answer phone, fax machine, email, pocket calculator, alarm clock).

Moreover, there are many other instances of mainstream technologies that have proved useful for people with disabilities - for example, the voice recognition software used in access to computer technology or simple telephone inquiry services.

Yet, there remain many hidden technological barriers within mainstream consumer products. Many of these could be avoided if the principle of "design for all" was respected and implemented across the board – a minor design change here, an extra electronic component there. Designers that keep the special needs of disabled people in mind will also produce better products for the general public, while at the same time addressing their social and moral obligations.



... many hours of skilled rehabilitation engineering ...

Assistive devices

MANY PEOPLE WITH DISABILITIES are denied the benefits that such tools provide: depending on their physical or cognitive abilities and needs, they might use different devices, adapted products or mainstream products, but in unique ways, to improve their autonomy and to fully exploit their personal resources.

It is important for consumers, producers, funding agencies and service providers to define clearly the concept of technologies supporting independence for people with disabilities. If all stakeholders in assistive technology could agree on a common language, communication and the exchange of ideas would be enhanced and the rights of people with disabilities better safeguarded.

According to the international standard ISO 9999, "aids" for people with disabilities are defined as tools for individual use in daily life that are designed to enhance independent living. That is: "...any product, instrument, equipment or technical system used by a disabled person, especially produced or generally available, preventing, compensating, relieving or neutralizing the impairment, disability or handicap...". So, some aids are designed and manufactured specifically for people with disabilities, such as powered wheelchairs, while other mainstream technologies may also prove useful and effective for people with disabilities. For instance, many people with hearing and speech impairments benefit from the use of cell phone "text messaging". Where a lack of *design for all* excludes people with disabilities from many technologies, mainstream microtechnology can be made available to users with special needs by finding creative and imaginative solutions. For example, a standard trackerball normally manipulated with the hand, can be mounted in such a way that it can be operated with the user's chin or a single toe.

In other cases, more complex adaptations have to be made, requiring many hours of skilled rehabilitation engineering. Most European AT Centres, where they exist with sufficient resources, have experience and competence in meeting the challenges of adapting standard products to individual requirements.

E-BOOK



THE ICT INDUSTRY has been investing huge resources in the development of the "e-book". Its impressive storage capacity, the possibility of downloading new texts from the Internet, its portability and its voice output potential are likely to be valued by many people with disabilities.

BUT.... can an e-book be easily fixed to a wheelchair? Can people without good hand control scroll down pages? Can the font size be enlarged to acceptable standards for low vision needs? At the moment the answer to these questions, typically, is "No". Yet, the solutions to meet these needs have been available for a long time, and are easy to implement and cost-effective if integrated into the industrial design process at an early stage. To secure the e-book to a wheelchair, for example, would require no more than a simple universal thread mount!



TRACKER BALL



FOR SOMEONE WITH fine motor difficulties, the button functions on a trackball may need to be externally accessible to avoid involuntarily presses whenever the "ball" is rotated. The simple solution of soldering an input socket to the trackball's electronic circuit board addresses this need. An external switch can then be connected to the trackball but physically mounted in an optimal position for the user, for example to be activated with a foot, head, arm, etc.

Assistive technologies designed for people with disabilities

WHILE THE "DESIGN FOR ALL" principle largely remains unfulfilled, the particular needs of specific populations of disabled people have been met during the past 20 years with specific, often ad hoc technological solutions. Although ad hoc in nature and involving small adaptations to the ubiquitous microprocessor, these solutions are ingeniously versatile and more often than not enhance the independence of disabled people by overcoming physical barriers that would otherwise be insurmountable.

Below are some examples of the most commonly used AT devices. In our selection we have focused on those categories of assistive technology that are most familiar to the Bridge Partners.



An overlay keyboard

The personal computer (PC)

The PC is a powerful and versatile tool par excellence, and can be customised according to the user's needs and skills. Access to the PC for disabled people is often provided via "special input and output devices". The PC is so widely used by disabled people that a wide range of specialised PC products, designed for people with disability, is commercially available across Europe.

Special computer input devices

- Including keyboards: adapted keyboards, enlarged keyboards, and small, programmable keyboards, etc.
- Pointing devices: special mice, trackballs, joysticks, head controlled mice, etc.
- Other direct input devices: voice input, eye gaze, etc.
- Indirect switch and scanning systems: to allow people with minimal motor control (such as small movements of a finger or hand, the closure of an eyelid, etc) to access a PC.

Special computer output devices

Including: braille readers and writers and screen reading software with speech synthesisers, hardware and software screen magnifier, etc.

Software

Software lies at the heart of the PC's strength and versatility. Standard (and normally inaccessible) programs are adapted or buttressed by supportive software, available for education, leisure, work and rehabilitation

Powered wheelchairs

Powered wheelchairs provide great independence to people with disability. They are highly sophisticated, both in terms of materials used and the operating mechanics. For many years powered wheelchairs could only be controlled via hand-operated joysticks. Today these standard joysticks can be replaced by customized joysticks or emulators that allow the user not only to drive the wheelchair but also to control their environment, access a PC, or use a speech output device.



highly sophisticated wheelchairs

Environmental control systems

Today environmental control systems are rapidly spreading into mainstream life. These are systems that enable people to control more easily their home environment or workplace, including the lighting, the television and Hi-Fi set, the telephone, doors, windows, kitchen equipment, etc. For people with disabilities these systems allow the easy control of a domestic house relying on specific remote control technologies, for example using "intelligent" interfaces (adapted to the user's needs). Such "smart" and relatively low-cost technologies offer people with disabilities, and elderly people across Europe, a better quality of life and greater independence.

Communication aids

High-tech communication aids enable communication between people by means other than natural speech. Voice output communication aids may use recorded and/or synthesised speech to replace or augment spoken language. For people with significant difficulties in developing literacy, words, phrases and sentences may be represented in graphic symbols as well as words, and accessed via the user interface. There are many different speech output devices (well over 100) commercially available in Europe, each with different features and possibilities.





Assistive Tecnology and social inclusion

Education and work

IN EDUCATION, TECHNOLOGICAL aids can support reading, listening, written work, drawing, spoken communication and access to reference material: atlases, dictionaries, encyclopaedias, etc. Often, these aids are useful not only to disabled people but also to teachers and other students. That is, through electronic, mediated means teachers can tailor information presentation to the individual needs and skills of pupils. Further, they can support the effective interaction between the disabled student and their classmates, fostering social inclusion.

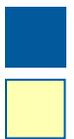
In the workplace people with disability can carry out most activities through their PCs or other assistive devices for telecommunication and environmental control. Access to remote telecommunication devices provides opportunities to work or to study from home.

ALTERNATIVE WAY OF WRITING

IT IS JUST ANOTHER day at school in a small town. Pupils in the classroom are particularly quiet and focused on a written assignment. The teacher has asked them to comment on the philosophical statement that "the degree of civilization of a culture is measured against its capacity to accept diversity".

This is the end of a project that began some months ago and included the main aspects of social legislation, reports of personal experiences and participation in discussion groups.

Apart from the occasional sheet of paper being turned by a classroom assistant, a constant clicking sound can be heard. Sara is writing her assignment. Sara has cerebral palsy, a condition that affects some 8,000 newborn babies in Europe each year. She cannot walk and speaks with great difficulty. She also has great difficulty using her hands. Instead of using traditional "pen and paper" she accesses a PC with an infrared device placed on top of the monitor and electronically linked to a "transmitter" attached to her forehead. This input system allows her to control the screen pointer and move it around the screen. With it she can select, click and drag screen items. Sara also uses a virtual on-screen keyboard. This behaves like any other keyboard and is connected to a unit of standard word processing software, Microsoft Word. Finally, Sara completes her assignment. She reads it through once more before printing and presenting it to her teacher.



Recreation

ENJOYING LEISURE is essential to a good quality of life. Recreation means being able to choose one's favourite activities, carry them out for as long as one wishes to, and share them with friends and family. Many of today's people with disabilities in Europe do pursue hobbies and activities of their own choice. Although disabled Europeans have long had access to a range of leisure activities, it is only as a result of relatively recent computer-based technologies such as the Internet and DVD that they now have a wider range of recreational opportunities. Accessing a computer to listen to one's favourite music, or renting and watching a video downloaded from a website are just two simple ways of bringing recreation into the disabled person's home. Accessed via the favoured input system (keyboard/mouse emulator or environmental control system, for example), this is likely to increase the individual's sense of independence and spontaneity. Assistive technologies enable many children with severe motor disabilities to play with battery-operated toys (for example, puppets, trains, remote-controlled cars and tape recorders, etc.) and recreational software. The importance of shared participation in play cannot be overemphasised.

PEOPLE WITH VISUAL IMPAIRMENT USING THE INTERNET

SEVEN AND A HALF MILLION Europeans have visual impairments. Many are currently using computers for work, communication or leisure. John is one of them. Screen reading is possible for him through the use of software that translates information shown on the screen – letters, numbers, icons, and symbols – into spoken words.

Alternatively, the computer is able to translate all this information into Braille when the computer is connected to a Braille display.

In cases of low or poor vision, specific software can be used to serve as a "screen magnifier", enlarging characters or sections of the screen.

However, there are some limitations to this technology for John. He cannot always read or understand screens (for example, many multimedia Internet websites) that use pure graphics in the form of images and multiple colours. Where this is the case, it is important that multimedia designers understand that there are often simple, off-the-shelf solutions available. For example, an image can be linked to a caption or description label that can then be "read out" by a voice synthesiser or Braille display.

Unfortunately, relatively few programmers make use of these simple and low-cost solutions that can reduce frustration and increase accessibility.



Health and rehabilitation

ASSISTIVE TECHNOLOGY CAN also help to improve the quality and speed of professional intervention. For instance, assisted access to the computer technology and communication aids can support professionals and clients / patients in early neuropsychological, cognitive and language rehabilitation. In general such aids allow early enhancement of the patient's independence, with positive effects on their psychological well-being. This can have important implications for the effectiveness and efficiency of more long-term therapeutic interventions.

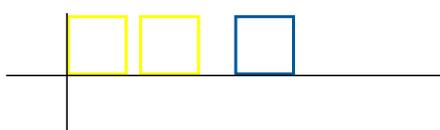
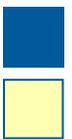
A POWERFUL BOOST TO REHABILITATION

SEBASTIAN IS A YOUNG MAN who underwent neurosurgery to remove a brain tumour and was subsequently admitted to a Rehabilitation Centre. At the centre great care was taken to enable Sebastian to communicate with the staff, his family and the other patients.

Sebastian cannot speak and needs ongoing assistance in all aspects of daily living: getting dressed, eating, toileting and moving around. He can keep his head upright and slowly, and precisely, move his right index and middle fingers. He shows good comprehension skills, and is highly motivated to communicate.

Initially, intervention supported Sebastian in using a simple electric buzzer connected to a switch to attract attention. Later he was introduced to a portable symbol-based communication aid with voice output. This greatly increased his ability to communicate his needs and thoughts autonomously, and to interact with a variety of other people.

Now Sebastian uses a computer and a communication aid based on spelling and the written word.



Home

PEOPLE WITH MOTOR DISABILITY using environmental control systems can perform many activities of daily life such as turning on lights, opening doors and windows, using a video-controlled entrance system, answering the telephone, or switching on the television. Environmental control systems can also be used to send messages, request help and carry out automatic functions to ensure safety within the home.

INDEPENDENCE AT HOME

MANY EUROPEANS are disabled in traffic accidents each year. It is estimated that in Italy alone 16,000 people each year acquire a severe disability as a result of a road traffic accident. Among the most serious consequences of road accidents are spinal lesions. According to the Italian Health Department there are around 70,000 people with spinal lesions, and each year this number increases by between 800 - 1,000 people; more than 70% of these people below 30 years of age. Another serious consequence of road accidents is brain injury. Most victims experience multiple disabilities (sensory, motor, neuropsychological, behavioural and language deficits).

Sabrina's spinal lesion caused a complete paralysis of both legs and one arm. She can use her eyes to point and make a gross movement with her forearm. Sabrina can speak but only those familiar with her speech understand what she says. Using an environmental control system she can still control her house from her bed or wheelchair. As she cannot press the keys on the system's remote control device, she uses a customised switch, which she operates with her forearm. With this she can choose from several options by tracking a visual scan on the panel of the remote control device. Using this system Sabrina can open and close her window blinds, windows and doors, and operate the television and video recorder. The same system enables her to operate a "hands free" telephone. Despite her speech difficulties she can then talk over the phone to her family and friends.



section

4

AT Service delivery
in Europe



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THE PREVIOUS SECTION has given an insight into the ways in which people with disabilities might benefit from technology. But how is service delivery in AT organised? How have policy makers and service providers, from the countries of the BRIDGE partnership, responded to the possibilities of AT and the rising demands for AT from people with disabilities? And, most importantly, is there common practice, and a shared vision, for AT service provision across Europe?

A clear outcome of research carried out in this project is that none of the countries of the BRIDGE partnership, Italy, England, Germany or Spain, can claim a comprehensive and coherent AT policy that recognises the complexity and uniqueness of the needs of individuals and their rights to life-long AT services. Perhaps unsurprisingly then, the answer to the last question is NO. There is, as yet, no pan-European approach towards AT.

Despite the variety of approaches to AT service provision identified, three critical issues appear common to the experience of the BRIDGE partners: services, funding and formal recommendation.

Services

Policies and services

Although there is a widespread recognition of the fact that AT offers valued opportunities for people with disabilities, policies are often fragmented and not coordinated between institutions. This is reflected in the ways in which services are organised and operate. For the public, it is often not clear who to seek for advice and provision of AT.

Although there is a tendency in many countries towards decentralising service delivery in areas such as health, education and employment, our experience suggests that decentralised models of provision struggle to function adequately where services are not evenly distributed and networks of AT centre peer support are not established. Fragmentation in AT service delivery weakens its efficiency.

Expertise

Local professionals in health, education and social services, typically the first point of reference for people with disabilities exploring the possibilities of AT, often lack knowledge and skills to identify and support AT solutions.

Specialised services

Notwithstanding the growing request for qualified services, independent AT centres that provide assessment, training and follow-up are very rare, and not all citizens have easy access to those services that do exist. Not only is there a difference between the various European countries described, but disparity of services and information can also be found within countries and regions, with some regions failing to provide any services or access to services.



Funding

Although some countries provide funding opportunities for the subsidy of AT devices and services, this situation is, again, inconsistent within and between countries. Consequently, not all Europeans have the same opportunities.

Funding arrangements for AT often vary within countries, regions or communities. The public health sector in many cases provides the greatest contribution of funds. Factors influencing the provision of funding include the age of the recipient, their disability and the type of device required. Generally speaking, funding for the school-age population is more easily available than for adults. Funding may be provided directly to the child's family or their school, and is provided by different agencies in different countries. Adults and those not in full time education often experience greater difficulties securing subsidised funding for devices.

Hi-tech aids are often excluded from national registers of devices funded by health services. In some cases funding is obtained for devices but not for customisation to individual needs, training, replacement nor upgrading of equipment. In some situations the user will become the owner of a subsidised device. In other circumstances devices will be loaned to the user for a significant period, but will remain the property of the funding agency. Many regions or countries do not manage funding for Assistive Technology for work or leisure purposes.

In some countries, insurance companies play a central role in funding AT devices.

Formal recommendation

In case of public or private funding, it seems reasonable to require a formal recommendation for highly specific and sometimes sophisticated devices. However this is not always required. Where it is required, it does not always have to be approved by an AT expert or a specialist service.

In the case of both private and public funding, recommendations frequently require authorisation by a doctor, regardless of their degree of expertise in the AT field. Indeed, in some countries manufacturers or distributors may be supported in their recommendations following their own assessment if conducted in the presence of a doctor. Often, advice and support from independent AT Centres is not sought. Few formal recommendations of devices include a detailed individual plan for support and development, detailing commonly agreed objectives.



Service delivery system in Italy

Introduction

From an administrative point of view Italy is divided in Regions, Provinces and Municipalities. In some cases, like health, legislative policies are delegated to the Regions that work closely together with the Provinces or Municipalities for the implementation of their policies. There is a far reaching process of devolution taking place at the moment in Italy. It is transferring power to the Regions and resulting in different services or funding opportunities for aids between the Regions.

Until now all citizens, regardless of their income, are covered for their primary health care by the **National Health System (SSN)**. The SSN is co-ordinated by the Ministry of Health in Rome but most executive and legislative tasks are delegated to the Regions. Local Health Units (ASL) deal with managing and delivering health services. These ASLs, the executive branches of the national health system that usually cover areas ranging from 100.000 (rural areas) to 500.000 inhabitants (cities). Currently they are developing into autonomous "agencies" working on a semi commercial basis. The ASL provides services with suitable staff or stipulate contracts with private care deliverers.

Social services are provided by local authorities (Municipalities).

Education in Italy was, until recently, a state responsibility. Most schools in Italy are still public although their increasing levels of autonomy, make them more and more independent. The Provincial and regional School Offices co-ordinate school policies at a local level, right through from Primary to Secondary school. There are few private schools, mainly religious institutes, but their number will probably rise as the government has announced far reaching changes in the national educational system empowering the Regions with legislative tools to reform instruction. Since the nineteen seventies Italian educational politics have favoured the integration of children with special needs in mainstream schools, providing with extra manpower where necessary.

Funding

There are few funding opportunities for technological aids and services in Italy. People injured at work, with sensory or motor disabilities, are guaranteed a minimum level of prosthetic assistance and supply of aids by the SSN. The aids provided for free or those partially funded by the **National Health Service** are included in a list called "Nomenclature Tariffario" (NT), last updated in 1999. Only few technological aids from ISO category 21 are included and those included refer mainly to sensory and communication disabilities. Through public procedures of purchase, based on the free competition between aid selling companies, each local ASL selects its supplier. This system, introduced to cut public spending, is not very flexible and thus risks being unresponsive to the real needs of the disabled. Especially in the sector of technological aids, where relatively





low numbers but expensive solutions are common, it is a current practice to prescribe aids that have to be personalised or that are part of a solution composed of different devices interfaced among each another. By being excluded from the category of medical necessities, computer aids, special interfaces, software and environmental control devices are not included in the NT. The NT does not recognise the costs of assessments, the personalisation or the training in using the aids.

The national law on disability (no. 104 of 1992) has transferred responsibility for legislation in the field of social participation, mobility and accessibility to the Regions thus creating opportunities for the latter to fund aids for communication and environmental control. At the moment not all Regions did so. Emilia-Romagna, for example, fund aids for computer access and environmental control at home, whereas others, such as Basilicata, Lombardy and the Marches, in support of social integration, fund electronic and computer aids in other spheres of life also. Generally speaking aids to improve learning are entirely ignored.

When disabilities are the result of an accident at work or an occupational disease, the **National Institute for the Insurance of Accidents at Work (INAIL)** will fund the necessary aids. INAIL runs centres specialized in rehabilitation and in the construction of mechanic and electronic prostheses.

A recent law obliges companies to employ disabled people. A Technical Commission, working for the Provinces, has to work out a programme for reinstatement to work based on the person's abilities, including the adaptation of the work place. A lump-sum contribution for **adapting the work place** can be established, if the disabled person's working capacity is reduced by 50% or more. The funding also provides for telework solutions.

Funds are allocated, according to laws on school finance, to back up projects for **integration in schools**. National funds are given out to the Regions and directly to the schools depending on how many disabled children are involved. Projects can include the purchase of aids or services. Projects that are the result of the collaboration between school, health- and social services are favoured, although this model of collaboration is not very widespread. In the academic field special funds are available for technical and didactic aids and for staff members that support the integration of disabled students in the **university**.

There are **private organisations** (Associations, Consortiums and Foundations) which provide services to the disabled, such as assessments or professional courses for reinstatement at work. They are rarely able to provide aids to the disabled directly. However, incidentally humanitarian associations (Misericordie, Red Cross, cultural or voluntary clubs) subsidize the purchase of aids when government aid is lacking.

Italian citizens can subscribe a **private insurance**, guaranteeing them a maximum sum insurable in the event of an accident or disabling disease but few do. The money can, of course, be spent to buy technical aids, but there is no direct link between the insurance and the rehabilitation process.

The Ministry of the Treasury provides two measures to financially support the purchase of aids



that are not totally funded by any public authority:

- **VAT reduction** from 20% to 4%;
- Expenses for aids are deductible from the annual income tax of the individual.

This deductibility is possible for all devices that compensate for a disability but has to be certified by a doctor. The VAT reduction does not include aids or software purchased in case of intellectual or psychiatric disorders.

Prescription

The prescription of an aid under **Health**, the preliminary stage in obtaining the authorisation for the supply, must, by law, be made by a specialist doctor who is competent on the pathology. Sometimes the doctor takes into account the advice of a AT centre in choosing the correct device although for the law in no case the assessment by a AT Centre is obligatory for prescriptive purposes, except in Tuscany. Nevertheless it can be recommended on the basis of internal regulations within the ASL.

If an AT Centre is within reach, specialists and doctors might involve them for a more accurate assessment and aid selection procedure. This cost saving potential of the AT Centre is not always recognised by the Health institutions.

AT Centres

Some regions in Italy, in accordance with the 1992 outline law No. 104, have started recognising the importance of AT centres, giving them resources and a role as advisors and information suppliers. Usually the centres have a certain number of technical aids on display that can be tried out by the users, and a multi-disciplinary team to assess and advice users. Most of them are closely linked to health, social services and/or academic institutes, although not all their services are refunded. Some are specialised in aids for people with sensory disabilities or educational software applications for people with learning disabilities. Since 1997 most well known non-commercial AT Centres specialising in high tech aids have collaborated in a national network called GLIC. Although there are big differences between them, the services provided for by the GLIC associated Centres include:

- Information about available aids and local resources and services in the area covered by the Centre
- Assessment and advice
- Support in installing, personalising and training in using the aid
- Assistance with the administrative procedures necessary to obtain prescription and thus financial support for buying the aid
- Training of professionals working in the field of disability and research in the field of technical aids.

Although there are examples of efficient AT Centres in Italy -some are active members of international AAC and AT organisations- most Regions have not included them in their health





plans. Where an AT Centre is set up as a private initiative, the official relationship with the ASL is often not defined, which creates confusion or conflicts of competence. These difficulties are definitely favoured by the fact that many institutions don't have a clear picture of a AT Centre and its potential role. Even when an AT Centre is created under Health services, they normally do not have executive power in prescribing aids, neither in evaluating the quality of the aids offered in case of an open tender.

In the AT Centres connected to the GLIC network different professional figures are employed. Rehabilitation therapists and speech therapists work alongside medical specialists such as neurologists, child neuro-psychologists and psychiatrists. In some Centres education experts such as teachers, educationalists and professional educators are among the staff members. In the few Centres created by the ASL it is possible that non medical technical staff (experts in computer and electronic devices) is under represented.

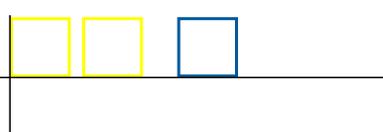
In the area of **employment** there are no specific support services or centres for aids except the recent creation, in each Province, of a Technical Commission in which representatives of Health, Social Services and the Ministry of Labour collaborate. Its task is to match the disabled person's abilities and the available working places and to evaluate necessary adaptations of the working places.

As far as the **school** area is concerned, there are H-Groups that assess pupils with special needs and plan personalised didactic curricula, sometimes choosing aids directly for the students. These school related AT centres are not very widespread.

General considerations

At the moment there are no specific forms of evaluation or certification of technical aids in Italy. It is possible to gain qualifications in the field of AAC and AT by attending courses organised by some of the AT Centres. Most initial training courses for speech therapists, physiotherapists, psychiatrists don't pay the necessary attention to developments in AT. Only since 2001 the university course for occupational therapists has been recognised. Until then this specific professional profile didn't officially exist.

Generally speaking knowledge about the opportunities offered to people with disabilities by technological aids is not very widespread, both among professional carers, policy makers and the disabled persons and their representing associations.



Service delivery system in Germany

Introduction

There is a mix of funding responsibilities for the provision of technical aids in the Federal Republic of Germany. Except the agencies of the social- and the unemployment assistance, whose expenses are covered by taxes, the German social security and rehabilitation scheme is substantially refunded by employee's and employer's contributions. Compared to certain other countries (e.g. Italy, UK), where a National Health Service covers basic provision with health goods and services for all inhabitants, the situation in Germany is less concise.

The statistical table of expenditures for health provides the basis of the following discussion. The most important funding organisations for health and rehabilitation services including the provision of technical aids are those of the statutory and the private health insurance (GKV/ PKV), the statutory care insurance (PV), the statutory accident insurance (BG), public spending, employers and the statutory retirement insurance. The statutory insurance for care (PV) finances only those technical aids which are mainly care related. Due to the rather inscrutable regulations for rehabilitation services, every funding organisation is liable to accept any request for the supply of technical aids. The majority of funding organisations have agencies on local, regional and national levels and offer a wide range of different services. Despite this nearly half of the annual costs for technical aids were financed by private means.

Commercial distributors generally provide the advice for and delivery of technical aids. Non-commercial, independent advice and assessment is legally not required. Recent economies in the statutory social insurance scheme do affect the service delivery system, too. Case flat rates and other cost reduction measures are likely to complicate the possibilities of individual adaptation of technical aids in practice.

With the setting up of a new legislation (July 2001) represented by the Social Law Book, Part IX (SGB IX) an improvement concerning co-ordination and co-operation of the involved actors as well as more transparency by compressing the regulations dealing with the provision of aids has been intended. The SGB IX is focussed on participation issues of people with disabilities and is designed to meet demands in the sectors of medical rehabilitation, participation in working life and participation in society.

Funding

In 1998 private funding and the financing of the statutory health insurance (GKV) covered more than 90% of all costs for technical aids. Other funding possibilities are given by the private health insurance (PKV), the statutory care insurance (PV), the statutory vocational accident insurance (BG), public spending (social assistance, etc.), employers and the statutory retirement insurance



as mentioned above. The new regulations in the SGB IX of 2001 sum up the jurisdictions towards funding technical aids supply.

Technical aids in primary health care

The most frequently used funding opportunity comes from the statutory health insurance scheme (GKV). The Catalogue of Aids (Hilfsmittelverzeichnis) forms the guideline for every medical prescription of technical devices. All listed aids are tested for medical and technical standards before publishing. This compilation is revised and updated periodically by the medical service of the central associations of the statutory health insurance (MDS) and external medical and technical experts. A supply funded by the statutory health insurance is mainly aiming at issues of medical rehabilitation and prevention in order to compensate impaired functioning and to increase or secure personal abilities and independence.

The supply with technical aids funded by the health insurance is increasingly settled in this kind of case flat rates. This economy measure has been established to ensure cheap basic support, where personalisation and adaptation of the aid doesn't seem necessary. If a person prefers a more expensive aid, the difference between the fixed amount of the case flat rate, reimbursed by the statutory insurance scheme and the retail price of the aid has to be paid by the user himself. A special feature is that, according to the principle of non-cash benefit for all payments of the statutory health insurance, devices remain property of the business dealing with medical supplies or in special cases, of the statutory health insurance itself despite of the users' own contribution.

Technical aids in school and education

Special schools have to guarantee that the essential infrastructure including necessary technical aids are available on the spot. Required aids can be funded by the administrative region in particular the responsible supervisory school authority.

In case of distance learning or tele-teaching programs, assistive technology devices generally have to be funded by the user. The social assistance scheme can cover costs for the supply if the user can't fund it. According to the German social legislation (SGB IX and the federal law of social assistance (BSHG)), social security agencies have to help to enable people with disabilities to take part in social activities of the community, to obtain an appropriate learned profession or to make them independent of any care as far as possible.

Mobile and transportable communication aids which are to be used either in school or at home, as a part of the Catalogue of Aids (§ 128 SGB V) are fundable by the statutory health insurance.

Technical aids for workplace adaptations

- Benefits contributing to participation in working life are to a big part of public funding by the Federal Labour Office, executed by regional and local offices. A variety of possible payments for different measures of vocational training- and rehabilitation are given. Workplace adaptation including the provision of technical aids and other technical aids for e.g. mobility and housing, which do ensure the working capacity of people with disabilities, can be financed.
- The so-called "accompanying aids for working life" which include technical aids ensuring participation in working life, too are financed by the Main Welfare Office and implemented by

regional offices. The costs for the “accompanying aids for working life” are refunded by an equalisation levy paid by employers with at least 20 employees, who engage less than a rate of 5% people with disabilities.

- In case of work related accidents and diseases causing or threatening to cause a disability, the statutory vocational accident insurance scheme financed by employers’ contributions, amongst other rehabilitative and preventive measures, funds necessary technical aids. The funded rehabilitation measures serve the purpose of restoring health and mitigating the consequences of the injury that reduce of working abilities.

The unifying aim of all vocational rehabilitation efforts is to integrate the person with disability into work again, regardless which funding opportunity comes into question.

Funding of additional services such as needs assessment and training

Training with prescribed devices, though widely recognised as necessary, normally isn’t included in the supply with technical aids. More and more often a special case flat rate limits the costs the business dealing with medical supplies has to take account of. In practice this means a strong limitation of all additional services.

Of course there are possibilities for assessing the needs, training and upgrading of technical devices. But not within the service delivery system itself and not systematically. People living in residential homes can e.g. profit of accompanying services. Any occupational, physical, speech therapist or pedagogue can perceive special needs for additional training and adaptation of used devices as well as the need for a new aid. In an outpatient context the family doctor can prescribe training with a newly delivered aid. This can be carried out by a therapist. But this is rather unusual.

Prescription

If the required technical device is to be funded, a prescription by a physician is needed. Depending on the kind of technical aid and specific circumstances of the supply at least, one cost estimate by the business dealing with medical supplies is necessary. There is only one exception. If the required technical aid is a care device it is funded up to the amount of 2557 Euro by the statutory care insurance. The person needing care can apply for these aids on his/ her own without a medical prescription.

In order to prescribe a technological aid an independent assessment by an AT centre is not required. In general the device distributor will advice over the suitability of a particular device. Before funding the aid a verification of the distributors suggestion for the supply can be carried out by the medical service of the statutory health insurance.

AT Centres

In general there are three different areas covered by AT centres in Germany:

- There are quite a lot of centres for communication aids also covering the area of computer





- access to a certain degree. These centres are mostly associated to special schools.
- For visually impaired and blind people, about 40 centres associated to specialised clinics for ophthalmology exist. There are advice centres at some universities, too, which are run by peer counsellors.
- There are only a few centres covering the sectors of mobility, daily living aids and home adaptation.

The assessment services provided by the existing centres are not obligatory in the context of purchasing technological aids. The centres offer an expert opinion on the relevance and suitability of required AT. The report can be used alongside a medical prescription in order to support the choice of the suitable aid. In addition, training possibilities for clients of AT centres play an important role. The few AT centres in the field of mobility and home adaptation are important independent local advisory bodies frequented in particular by AT clients and by specialists in the field of rehabilitation, too.

In general there is no basic financing for AT centres by public authorities in Germany. Some of these centres finance their advisory service in the framework of funded projects. Advice centres for communication aids affiliated to schools can be funded partly by the different local administrative districts.

Only few centres have an interdisciplinary team available. In special schools there is only one person, usually a teacher or an occupational therapist, responsible for the advice concerning AT. FTB's advice centre, as well as a small number of other centres in Germany, employ several professionals: an occupational therapist, a psychologist and different engineers covering the different aspects of the supply process. Consultations with staff members of the whole rehabilitation centre, for example outpatient caregivers, external therapist and the medical doctor are possible.

General considerations

In Germany all technological aids have to be tested for technical standards and certified with GS test marking by the Technical Control Board (TÜV). In addition, the medical service of the central association of the statutory health insurance (MDS) is obliged to develop generally accepted quality standards for specific aids. According to these standards a proof test towards user applicability is needed for the registration in the Catalogue of Aids. German-wide there are five independent accredited laboratories like FTB's test centre, producing expert opinions on the therapeutic benefit of the tested aid. Compared to this a systematic evaluation concerning the quality of services in terms of advice and supply is not known.

The vocational training in the field of orthopaedic technology, and several therapeutic professions like occupational therapy, comprises some main issues of AT and technical aids. The education in the field of AT is mainly based on a variety of different courses and workshops, advanced vocational training and training on the job. Research centres for assistive technology are emerging at different universities.

According to the Federal Statistical Office the proportion of expenditure for technical aids related to the total amount of expenditures for health in 1998 was 5,5%. The biggest part of this



percentage is presumably covered by expenses for e.g. glasses and hearing aids and not by assistive technology in particular. This throws a significant light on the recognition of the benefit of technical aids in general. The chances and opportunities assistive technology can offer to people with disabilities seem to be underestimated in the German system for health and social security.

section 4



30



AT Service delivery in Europe



Service delivery system in England

Introduction

Since the late 1940s and early 1950s (The 1948 Education Act and the later birth of the welfare state) health, education and social services in England have been (and largely remain) “free at the point of delivery” That is, services are funded centrally from revenue raised through taxation and users are not additionally charged when using services. “Free at the point of delivery” does not necessarily equate with “adequate” or “equal” in terms of availability and distribution. In England the three services are largely decentralised for the purpose of service delivery systems. Central government provides a legal and regulatory framework but this does not guarantee/equate with equal opportunity to and access to AT services. For example, there is a statutory requirement for the provision of wheelchair and environmental controls but not for the provision of communication aids.

There is some regulation of relevant professionals, for example, there is a statutory requirement for Speech and Language Therapists to be registered members of the Health Professionals Council. Indeed, the transparent disparity in provision between one region of the country and another has led to the widely used expression of “post code (zip code) lottery for services” amongst users and professionals. To complicate matters still further the decentralised structure prevalent in England shows poor geographical correlation between one service and another. So, for example, a large health authority might overlap with a number of education and social service areas. For example Speech and Language Therapists working in Camden and Islington Community Health Services NHS Trust in London may be involved in liaison with up to six different education authorities in the negotiation of funding for AAC systems , wheelchairs, or environmental controls for the children they support. Subsequently key specialist services, like those supporting AT needs, are highly fragmented weakening efficiency and (probably) cost-efficiency, in service provision. This highly fragmented model hampers local/regional efforts and initiatives to integrate AT funding and service delivery between the three services.

The advent of AT (as defined in this report) began in England during late 1970s. Developments in service provision have been led by local/regional government organisations, for example, health service based Communication Aid Centres and Non-Government Organisations (NGOs). A basic summary description of such organisations and delivery systems follows:

ACE centres & Communication Aid Centres - Essentially, such centres provide for children and adults through the support of local professional teams and families. These centres conduct initial assessment for adapted computer technology and/or AAC systems make recommendations for equipment (including in some cases loan of equipment) and make limited follow-up contacts. Local professional teams and families are responsible for seeking funding for equipment. There is currently no central government funding although a new Department for Education & Skills initiative (Communication Aid Project) may change this model to some degree within the next few years. Equipment is purchased by local teams/families directly from manufacturers and on-



going day-to-day support and local professional teams and families in liaison with manufacturers carry out maintenance of equipment, where appropriate.

Wheelchair services - like ACE Centres and Communication Aid Centres, local wheelchair services will assess users' needs. Unlike such centres, wheelchair services stock wheelchairs and will directly provide them and maintain them. Maintenance is carried out through subcontracting the service to approved wheelchair repairers. It is possible that the provision of complex seating systems may involve manufacturers at the assessment stage. People with complex needs may also access specialist seating assessment teams (typically located in health setting such as a hospital). Such seating assessment teams provide a similar service to the ACE centres and Communication Aid Centres

Environmental Control Services - Environmental Control Assessment Services typically make an initial assessment individual's needs followed by a further assessment involving a manufacturer. The installation, maintenance and any follow-up is conducted by the manufacturer only.

However, twenty-five years of rapid technological development and increasing user demand has exposed the weaknesses in fragmented infrastructures within and between health, education, and social services. More recently, central government has recognised a need to rationalise and consolidate aspects of these early and somewhat ad hoc AT initiatives. It is envisaged that this will lead to better networking of resources and expertise, the raising of professional standards, and above all equity in provision for potential consumers of AT products and services.

Where there is good practice in AT service delivery, it is generally in the form of effective interagency collaboration between two or more of the public services and bound by a genuine multidisciplinary ethos. Oxfordshire, a large rural region of England, provides a modest example of how collaboration between key services can cost-effectively improve service delivery in one aspect of AT, speech output devices. Here the funding, delivery and support of speech output devices for all children and students in full-time education is met by contributions in money and/or kind by all three agencies. 30 - 40 children have directly benefited from this three-year collaboration.

There have been a number of key developments in the way funding for AT is organised. For example, under the Local Management of Schools initiative funding for the support of children with special educational needs involved the delegation of budgets to individual schools. However, local schools are not duty bound to spend this budget on special education needs.

Funding

A rich and complex mosaic of funding mechanisms is used to fund AT aids:

Central and local government taxation funds the provision of some but not all AT aids via its local education and regional health authorities. For example, in the case of Environmental Control Systems, funded by health services, funding is only available for certain items such as access to TV and Hi Fi equipment, front door intercom and latch but not for motorised doors, window



openers and curtain control. Individuals wishing to use such facilities must seek funding from private or charitable sources.

Charities and other voluntary organisations (a strong tradition in England) provide funds, usually on a case-by-case basis, for specific AT aids.

The client or their family may make purchases

In a recent survey of communication aid users 26% responded that their aids were fully funded by Health services, 17% reported that their communication aids were funded by education services, and 24% were fully funded by charities.

It should be noted that the substantial costs of assessment, training and support are funded in a similar fashion. Also refer to Community Care (Direct Payments) Act (1996) and The Carers and Disabled Children Act (2000) described above.

In general, the perception and some of the reality is that children in full-time education receive greater benefit in the provision of AAC systems and equipment supporting access to computer technology than adults or elderly people, whereas adults and the elderly are better resourced in terms of wheelchairs and environmental control systems.

So, for example, although there is no statutory requirement to provide AAC systems schools do have a legal requirement to ensure that children have access to the National (Educational) Curriculum. Families and schools have recognised that limited access to AAC systems and adapted computers denies the student such access. Subsequently, significant pressure has been exerted (often successfully), on local authorities to satisfy this requirement. However, the case for funding of AAC and computer access technology for adults not in employment appears less easily achieved.

Wheelchair services are likely to be supporting a broad range of needs including adults and the elderly with acquired needs and children (typically with congenital difficulties) from a single (small) budget. The population of adults requiring wheelchairs is greater than children. Such needs might include a high number of occasional users (elderly person unable to walk long distances, to the shops, for example), and frequent users (elderly person unable to walk). A standard, relatively inexpensive, wheelchair may meet such demands. Wheelchair services are therefore likely to provide equipment for a high number of adult or elderly users relatively cheaply. It is possible that children requiring wheelchairs (powered or attendant propelled) represent a more complex caseload often requiring expensive seating systems. Also, children continue to develop and change physically for many years and subsequently require more frequent assessment and replacement of such equipment. It seems that wheelchair services may struggle to meet the demands of this complex changing population.

In the case of Environmental Control Assessment Services, needing to prioritise services to large heterogeneous caseloads, adults in independent living situations are likely to present a higher priority than children living with parent(s)/carer(s). Within limited budgets adult needs maybe prioritised over children.

Professionals in the field have recognised a shortfall in funding in the provision of follow-up



training and support for AT. In some instances funding may be provided to individuals in lieu of services (Community Care (Direct Payments) Act (1996) and The Carers and Disabled Children Act (2000)).

In many instances manufacturers of AT equipment may offer some training in system use (typically one-off training) when items are originally purchased. Subsequent support is provided from local services (usually Speech and Language Therapy services), which are centrally funded. Where independent mobility and environmental controls are offered support services may be subcontracted to manufacturers or commercial service providers. Assessment Services may include estimated costs of training and support, as well as the costs of kit, in their recommendations but the provision of finance beyond releasing funds to pay for equipment is usually considered on a case-by-case basis.

Recommendation and Prescription

A variety of agencies are involved in the assessment and recommendation of AT aids.

Health service funded organisations, such as Communication Aid Centres, Environmental Control Services and Wheelchair Services, prescribe AAC devices, environmental controls and powered wheelchairs

Education service funded organisations, such as the Centre for Micro-assisted Technology (CENMAC) and the ACE Centres, (partly funded by education), recommend adapted computers

Non-government funded organisations, such as AbilityNet (a charity supporting computer technology to adults and children with disabilities), and other AT specialist charities adapt computers.

Specialist private consultants (AAC devices, adapted computers, environmental controls) are also very active in assessment and recommendation of AT equipment.

No, not by law or regulation. Many assessments are independent, (for example, those provided by The ACE Centres, the Communication Aid Centres and the various wheelchair and environmental control clinics) and offer unbiased advice because they have no commercial AT interest. In practice, users won't be publicly funded unless there is substantial evidence to support the relevance and suitability of the AT aid. However, there is a vigorous private AT sector where vested interests and divided loyalties may lead to biased and compromised assessment and provision. The campaign to ensure objectivity and the separation of assessment from provision needs to continue.



AT Centres

Education funded organisations (The ACE Centres) and NGOs (such as Abilitynet) operate an open referral policy.

Health funded organisations (e.g. Communication Aid Centres) typically require a medical referral. For example, a London based Communication Aid Centre requires a referral from the Consultant overseeing the individual's.

In terms of "geographical area" all AT centres, whether independent, private, or public tend to be regional or even local. There is no national co-ordinating centre comparable to the Swedish Handicap Institute in Sweden or other continental European equivalents.

In terms of "activity area" most AT centres still specialise in the same area(s) of activity as when they began.

(a) Communication Aid Centres focus primarily on AAC devices, which includes consideration of seating, and access but rarely advise on the other AT areas such as access to computer technology and environmental control.

(b) Some centres such as the ACE Centres can integrate the assessment of AAC devices, seating, access issues and adapted computers

(c) Wheelchair clinics focus on mobility only

(d) environmental control assessment services focus on environmental control systems only

The advent of truly integrated AT assessment services remains elusive despite the need and demand for it since the 1980s, and a regional model for integrating all AT activity under one roof (a one-stop shop for all) is along way off still but should be feasible within the next decade.

As with the funding of AT aids a tapestry of idiosyncratic funding approaches has evolved over the last twenty years. Some AT centres are solely funded from the public purse (CENMAC, a micro-technology assessment organisation serving the London area, is solely funded by education, the Communication Aid Centres are solely funded by health, as are wheelchair and environmental control services), and some from private or charitable funds alone (Abilitynet & SCOPE). A few are funded from a combination of public and charitable funds (the ACE Centres), Again this will vary enormously from centre to centre and according to the range of AT activity undertaken. In each case the historical perspective and the centre's origins will play a substantial part in defining its professional makeup and modus operandi.

(a) The ACE Centres include teachers, speech and language therapists, occupational therapists, physiotherapist and technical staff.

(b) A Communication Aid Centre because of its health service background might typically include some or all of the following: a speech and language therapist, an occupational therapist, a rehabilitation engineer, paediatrician and psychologist.

(c) An NGO such as AbilityNet would probably have a computer engineer, a technician, and a teacher.

(d) A wheelchair service is likely to include a rehab engineer and occupational therapist

(e) Environmental control services are to employ a rehab engineer as central to their assessment.

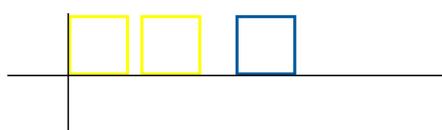


General considerations

Only medical equipment provided by the National Health Service has to be officially certified with a CE marking. This applies to all AT aids recommended by health service employees or contractors. Different health & safety criteria are applied by education and social services to AT equipment. As one would expect in a highly devolved AT service delivery system, there are no national standards of certification or evaluation that are consistently applied across the three key public services (education, health, social services)

Throughout the country there are only a handful of accredited AT courses and qualifications for undergraduates and postgraduates. They range from a one-year diploma in ICT and special needs to an AT module for undergraduate occupation therapists or a Masters degree in AT.

No, not a substantial factor. Most therapists and special needs teachers receive only the minimum of AT information during initial training. One or two universities offer some good AT modules but few of these are mandatory. Most practitioners either "learn on the job" when called upon to deliver AT services. Some attend short post-graduate courses where and when these are available. However, there is a strong move to improve both initial and post-graduate training for AT practitioners. So "watch this English space" to see what materialises over the next few years! Although the obvious answer to this is "No", one must recognise the considerable changes that have taken place during the past twenty to twenty-five years. From being a complete "non-issue" or at best "a good idea", politicians and both national and local administrators within all three key public services are aware that there is a growing issue vis-a-vis AT and its delivery to a significant number of disabled and/or elderly people. The gap between user expectation or demand and service supply may no longer be widening as a result. Recent central government initiatives such as the Communication Aids Project may indicate a better future for some AT users at least. Furthermore, the networking and integration of precious AT resources is now understood as a concept and even recognised as a priority by some forward-thinking policymakers and service providers. This was not the case a few years ago. But the jury will stay out for a bit longer before substantive conclusions can be drawn about where AT service delivery is really heading in England during the first decade of a new millennium.



Service delivery system in Spain (Catalonia)

Introduction

From an administrative point of view Spain is divided into 17 autonomous communities. Some communities have the *governmental* power to design and implement services for the disabled with regard to health, social services, education and employment. Central Government is in charge of co-ordinating policies. *Municipalities* participate in providing services in some areas and *Provincial authorities* (Deputation) offer some social services too.

The three main administrative authorities in collaboration with one another can provide generic services (for instance, CRID, a metropolitan consortium in Barcelona) for disabled people. However, the normal trend is to make plans separately and to make agreements with private institutions. Very few specific services for AT can be found, though this is a strongly emerging field.

At present, the country is going through a complex process of transferring power to the autonomous communities, also the innovation of technology is an attractive resource demanded by society and one which institutions are keen to offer. In this changing situation, it is difficult to define the data, criteria and clear administrative links between each service devoted to disabled people in our country. To simplify matters and as an example, the services discussed here principally relate to Catalonia.

It is noticeable that people will benefit from different services or funding opportunities depending on the community or area in which they live.

Funding

There are several ways of acquiring funding for technological equipment and services in Spain; for instance, the **Centro de Ayudas Técnicas** (CEAPAT) is a National Service. One of its services is to provide for adaptation or construction of specific equipment for disabled people with no cost to the user.

The **Catalan Service for Health** (SCS) covers 99% of the cost of all kinds of orthopaedic devices for disabled people (Catalog de prestacions ortoprotetiques, 2001), mainly devices for prevention and rehabilitation. Also some devices for everyday living such as electronic alarms, bath adaptations, motor wheelchairs are provided. SCS covers all people regardless of their income, except for audiphones for impaired people. In this instance children below the age of 16 years will be supported. Despite the fact that these clear criteria exist, families and users may have difficulties getting the devices they think they need, such as a wheelchair for a child.



The **Catalan Institute for Social Services (ICASS)** complements the SCS catalogue for other devices required to support their social inclusion and participation in society (transport, home adaptation, communication). ICASS will cover 50% to 80% of the cost, in devolution after 6-12 months. A disabled person can apply for an adapted electronic staircase at home, a computer, an electronic communicator. ICASS covers people from birth to 65 years old who hold a disability certificate. Income is means-tested to ascertain the amount of funding awarded. When demands are rejected families and users may make repeated applications. In this sense a simple demand can precipitate a complicated administrative process.

The **Department of Education** plans to subsidize all devices and special materials needed in the school environment, sometimes in collaboration with other public institutions - for instance, to build a ramp or to install an elevator in a school. The local Municipality may help out with the cost or the maintenance of the device. It covers all individuals from 6 to 16 years old (flexible for 3 to 5 years and over 16, if in full time education). The Department covers 100% of the cost of the devices, funding pupils in mainstream or special school. Private or semiprivate schools (normal or special) may have very different opportunities depending on the demand, the priorities of the local delegation or the annual budget. In general devices for communication and computers to access the curriculum are provided within 4-8 months of the request.

There are also **private organizations** that may fund equipment. Special mention must be made of the **ONCE** institution. The ONCE Foundation is mainly dedicated to supporting blind people (although they are now expanding their services to other people with disabilities, mainly motor). They cover 100% of the cost of any tiphotechnic device during the education period and for working purposes. If a device is needed in other periods or contexts they will cover a 50% of the cost. They may, in certain cases, subsidize other equipment such as a mobility device for a motor disabled person. The ONCE Foundation will also support the organization of a working station, to the sum of 751.27 Euros, for a blind person with a permanent working contract.

Other private organizations (Insurance Companies, Associations, Consortiums and Foundations) provide services for the disabled such as assessment, lending equipment or offering professional courses. They are rarely able to provide devices directly to the disabled. For instance, an insurance company can cover the cost of devices for a person after an accident. The criteria for providing the appropriate device are not clearly defined and can vary from case to case. Incidentally, **humanitarian associations** (Red Cross, Cultural Clubs, Religious Institutions) subsidize devices and professional support in some very specific cases.

Prescription

In order to obtain simple devices (like a switch) or adaptations from the **CEAPAT**, a simple request from a professional, family or user is required. For other materials a report and assessment may be needed.

The prescription of a device under the **Catalan Service for Health**, has to be made by a specialist



doctor (generally from the Rehabilitation Hospital the person is attending). The medical team will evaluate the need for a device and a doctor will prescribe it.

If the prescription of a device is under **Social Services**, then no prescription is requested, only a report from a professional involved with the person. A team of specialists will evaluate the demands against a set of criteria in order to issue the authorization for a subsidy.

In the case of equipment for general use in a class room and technical devices for use in school the **Department of Education** will request a formal request from the director of the school and the assessing team from the local area (EAP). Normally they will have to authorise their demand by attaching a prescription from a specialist service, for instance UTAC (Unit for Augmentative Communication Techniques), but other services can authorise it too.

For **private institutions**, the criteria for prescribing can vary. Normally, they will ask the Rehabilitation Hospital or a specialized service for a specific report on what is needed.

AT Centers (Assistive Technology Centers)

As has been noted, very few of the centres mentioned here are specific for AT, though they may include AT in their general services.

In Spain the **CEAPAT** (a governmental centre) in Madrid with four territorial branches spread all over the country, is the main centre for resources ear-marked for disabled people. They supply instructional courses, evaluation sessions, information dissemination, etc. All ages and practically all needs are catered for. In Madrid there is also a special team for pupils with physical disabilities to assess their schooling needs overall and it can set up AT if needed, though with a lot of difficulties, as it seems. Many other multidisciplinary teams like this one can be found in other communities.

In Catalonia, some specific AT centres have been organized. Mainly devoted to augmentative and alternative communication and computer access for people with motor disability. For instance, **UTAC-Sirius** has been working in the field of AT for the last 10 years. It is a service run by the Foundation Bosch&Gimpera connected to the University of Barcelona and subsidized by the Department of Social Services (Catalan Government). It caters for children from birth to 5 and adults over 17. Another three units (**UTAC-Education**) cover communication and other topics related to the children (positioning, special school materials, mobility), during the schooling age. One of these units (the Reference one) is run by Espiga Foundation in contract with the Department of Education (Generalitat de Catalunya). Other two units were created recently (UTAC-Palau and UTAC-Lleida) out of the infrastructure of two public special schools and they attend the schools in the North and West part of the country. Both services are free for the users. The Program for Information Technology in Education (**PIE, from the Department of Education**) deserves special mention. It provides schools with software tools, including programs for communication, access to computers, etc.

Many other centres are emerging now. Society has started to recognize the importance of AT centres, and the government is giving them resources and defining a role for them to act as advisors and information suppliers. For instance, **Maresme Foundation**, near Barcelona is helping several schools to implement AT. **Centre Pilot** in Barcelona has opened a center for AT. It is a



private institution under the umbrella of the Health Department. **Pont del Dragó** is a centre offering assessment in AT in the Barcelona area especially for adults. It is supported by the Municipality of Barcelona. **Guttmann Foundation** is a hospital for people suffering from trauma injury, and has an internal service in AT. **Terrassa Centre for independence** subsidized by a Banc Foundation, mainly devoted to old people. In Mallorca a new service, **NOUSIS**, a private initiative, is starting up in order to cover all ages. **ACESO** from the University of Valencia is a new service providing help especially to the students at the University.

In general centres may be linked to health, education, social services, academic institutes, universities, governmental institutions, municipalities or other public administrative bodies as well as to private institutions. In addition, a number of shops or dealers that provide technical devices take on a kind of formal assessment, which is not always very helpful.

Providing a service for disabled people is the main objective, though procedures may vary. Generally, they adopt a very macro-perspective, technology-centered approach and on a "one-point" assessment scheme. Knowledge of real context, interpersonal and functional needs and follow up are not always assured however.

None of the services available in Catalonia is a specific centre with clearly defined criteria directed by the administration. So, full time professional staff are rarely available. Normally, there are expert professionals working for an institution which has an internal agreement to run the service for a specified number of hours per week. Most of the centres are private initiatives working under different "umbrellas" (Social Services, Education, Health). The public administration subsidizes or contracts out their services. Each centre has its own criteria, assessment method, theoretical background and a heterogeneous team. Although confusion or conflict of competence can occur, consumers are provided with a range of diverse options for support.

The main professional figure in most teams is an expert in education, (psychology, pedagogy, teaching), speech therapy and physiotherapy. There are a limited number of other services involved including medical specialists such as neurologists, a rehabilitation doctor and a computer expert or occupational therapist. As they are not always part of the group, it is clear that professional figures are under represented in many of the teams.

A few of these centers have a number of technical aids on display that can be tried out by the user. Lending services are not available for AT. Interdisciplinary cooperation is hard to bring together to assess and advise the users. Sometimes difficulties occur due to "overbooking" of cases or lack of time or lack of expertise and also because of the high cost of the assessment and follow up.

Fortunately, it does look as if the situation will improve in the near future. For instance, the Department of Education is working on a plan to rationalise the special support (including AT centres) that schools need nowadays. It recently ran a survey which found that 0.14% of school students have motor disability. The Department of Social Services has just published an integrated plan aimed at the disabled.





assistive
technology
against
social
exclusion

General considerations

Awareness of AT seems to be more wide-spread. People, institutions and government are willing to participate and have lost the reticence of 10 years ago. The dissemination of new AT centres seems to be guaranteed, but the quality of the service is not reliable. There are not many specific AT centres covering the full range of services (research, assessment, follow-up, dissemination) in our country. Also it seems that the support varies from region to region and between groups of population (some motor disabilities appear to have better chances than others; mentally handicapped people are rarely seen as candidates for AT).

The field is complex because people working in many different disciplines interact. In future, better trained professionals will be needed and a more coherent organisation of the centres within a particular geographic area according to age groups or other criteria. Also the interdisciplinary team model should be emphasised and research programs promoted.

Training of professionals working in the field of disability and research in the field of technical devices are needed. The administration will have to work hard to organise the network of services that the needs of society are generating and which will cater for the life span of the disabled. For instance, the sport, leisure, work and University context will need far more support if it is to make the inclusion process started at school age a reality.

Maybe some research (basic and applied) connected to the commercial field would partly solve some of the biggest problems encountered in this area: (a) the linguistic appropriateness to each community; (b) cost; (c) the dependence on commercial imports from other countries and (d) loan and maintenance of the devices. Some companies, such as Esclatec in Barcelona, are trying to improve this point. But production should be guided by less improvised plans and designs. Last, but not least, AT centres have to take into account the overall needs, perspectives and preferences of the disabled person and their family. AT is an excellent help for many people, but not for all. Some may need it at certain times in their lives, not always when the professionals say so. As it says in the introduction to this report, Assistive Technologies can be an effective tool for inclusion, but the implementation of AT devices into people's lives is for the most part a long-term and delicate process that demands teamwork and professionalism, time and experience.





section

5

Case histories



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Introduction

The 10 case histories presented in this chapter are real stories. They have been chosen by the BRIDGE project consortium to represent a sample of the possibilities and problems evident in current AT service provision across Europe. The case histories cover a variety of areas of interest and intervention including school, work, daily living, leisure/play and rehabilitation, involving young and middle aged Europeans with different disabilities.

The BRIDGE project would like to thank Agni, Andrea, Àngel, Carlo, Claire, Dirk, Federica, Juan, Paul and Rita for agreeing to let us share their experiences.



1. Personal details

- Name: Agni ☺
- Gender: Female
- Date of birth: 1966
- First assessment contact: 1996
- Primary disability: spastic tetraplegic
infantile cerebral palsy

2. Background and context

Agni is disabled in all four limbs with spasticity in the movements of her trunk and head. Mimic and speech production movements are slightly impaired, too. Impairment on the left side of her body is more severe than on the right. Her right hand has sufficient strength and dexterity to be used very well for many daily living activities like eating, washing, combing hair or handwriting. Supported by her right hand, she is able to use the spasticity of her legs and trunk to stand up.

This enables Agni under certain conditions to independently transfer from one position to another. However, for independent mobility she relies on a powered wheelchair with a joystick controlled by her right hand.



Agni was born as second child in a big city in Germany. Soon after she moved to Greece where she spent the early part of her childhood. At the age of six she returned to Germany and attended a school for disabled children. She remained at school for 13 years followed by a two-year extension. On leaving school she lived at home. In 1988 Agni was offered an opportunity to take up further education and vocational training.

Access to training required that she demonstrated her working and learning ability during a four-week stay at a training centre. At the age of 23 she left home and moved to this residential training centre.

In the pursuit of independence Agni found herself fighting barriers to independence based on her cultural background, her gender and her disability. In 1994, after taking exams, she began training as a commercial clerk in a large centre for vocational rehabilitation. The severity of her disability required her to live in a residential home with access to care staff around the clock. Agni's care needs were estimated to be equivalent to level two on Germany's nursing care insurance scales. This equates to having assistance at least three times a day for support in activities such as personal grooming and hygiene, nutrition and mobility, and additional help for household provision several days a week. In 1997 she moved to her own flat close to the rehabilitation centre. The concluding stage of vocational training involved working as an office assistant.



3. Starting a process: the demand

Agni felt that living independently had been a big and important life change and on leaving vocational training she feared she would have to return home to her parents. To avoid this when the training ended, Agni would be required to find a new job, and try to maintain her independence, living alone in her own flat. Whilst she completed her vocational training, she was given the opportunity to start independent living training. This involved living in a technologically "smart home" with reduced access to care. This was in sharp contrast to the situation in the residential home where care was always available. Every day involved training in issues concerned with independent living. The expert team working in the "smart home" included an occupational therapist, a professional caregiver, a social pedagogue and a technician. At weekends there was no training programme.

FTB's advice centre manages the training flat, which is in every way wheelchair "friendly". Many AT devices are integrated within the flat such as the visualized EIB System (European InstaBus, a standard of building services engineering), electric door and window openers, together with many other technical solutions for home adaptation.



FTB Smart-Home kitchen

4. The search for a solution

Assessment profile

Agni was 30 years old when she consulted FTB's advice centre for the first time. Over a number of appointments her personal skills, care needs and the rehabilitation aims were assessed in order to prepare her for the independent living training course. Agni's participation in the process, in terms of social, physical and motivational factors, was assessed as these factors play a very important role in every rehabilitation process.

It became apparent that, although Agni was an adult with a strong will and good communicative abilities, she had little knowledge about how to manage independent living; that is, life outside an institution. For example, she said that she wanted to be close to her previous residential companions. This request was deemed to have a number of benefits for Agni as she faced the uncertainties of independent living. The benefits included the close proximity of her friends and



familiar public facilities. Subsequently, the training focussed on information and advice aimed at finances, finding suitable accommodation, and job hunting.

Specific aims of the independent living training were:

- clarifying Agni's social and financial background for independent living
- obtaining a reliable estimate of outpatient care provision and personal assistance
- supporting Agni's independence with shopping, money management, and nutrition.
- training Agni to organise a schedule and keep a diary together with her caregivers and to see whether she was able to cope with the spontaneous daily changes to appointments and personnel.

During her time in independent living training Agni was also encouraged to use and evaluate several technical aids.

Acquisition of aids

Training in independent living required Agni to engage in more autonomous and self-determined activities than she had ever done before. Carers working with her on these tasks identified three

important factors:-

- Agni quickly mastered many tasks required for independent daily living.
- Her need for outpatient care could be reduced from three to two visits a day.
- Permanent assistance and social welfare were not necessary.



During the training process with Agni other AT needs were identified and AT solutions found. For example, some changes to the equipment in her current flat were required such as:

- an electric door drive for the entrance door
- a vertical pole to ensure safer transfer in and out of her bed
- handles and closomat toilet



Transfer from bed to wheelchair and trying out different possibilities for toilet transfer

Agni was using a standard powered wheelchair. It was about eight years old and would soon need to be replaced. Training and assessment identified a high priority for a new, specially equipped, electric wheelchair. The new wheelchair specification would support Agni in:

- maintaining an appropriate posture
- transferring between objects and chairs
- conducting general household activities
- improving mobility inside and outside the house.



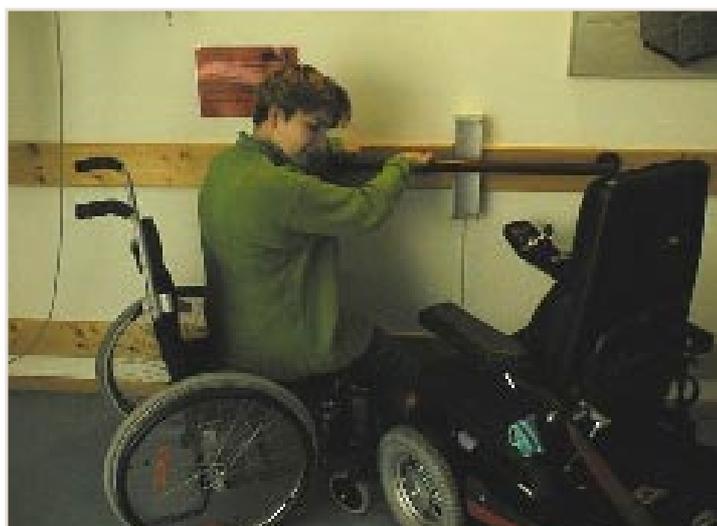
Training and support

Wheelchair-related training was conducted during the independent living training and followed up in the subsequent months and years. The training focussed on Agni's ability to transfer herself in and out of the chair and between chairs. New skills using the wheelchair in household activities and activities outside the house were also developed. In a period of nearly two years Agni had the opportunity to trial three adapted and expensive wheelchair models in different training situations.



Documentation of training: independent transfer from electronic wheelchair (sitting height of 45cm) to manual wheelchair

The long period during which Agni trialed the various wheelchairs was due to the reluctance of the health insurance company to pay for all the special wheelchair adaptations recommended by the independent living team at FTB. The health insurance company were only prepared to fund a cheaper and less suitable model.



Technical implementation of aids

The training and assessment experiences of Agni and the independent living team identified a suitable wheelchair incorporating a range of features. The most important of these included:

- a low sitting position to ensure that her lower leg length was approximately 40 cm., a feature which would allow Agni to transfer safely between her powered chair, her manual wheelchair, the bed and the toilet

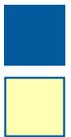


- a flexible seating system with electric adjustment at the ankle and gradient seating for optimum postural control and dealing with uncontrolled muscle spasms
- a lift function to improve Agni's competence in household and working activities (for example, reaching cupboards, shelves and wardrobes, or doing the shopping in a typical shop or supermarket)
- a robust, flexible and manoeuvrable construction ensuring rugged and reliable use both inside and outside buildings.

5. Living with AT

Six months after the training was completed Agni found a suitable home. Most of her identified technical requirements were installed before she moved in. Agni reported that living on her own with AT support, and personal assistance when she really needed it, was a very positive experience. However, as noted above, the health insurance company refused to fund the recommendations and were only willing to fund a different and cheaper model. It was this much less suitable wheelchair that was eventually delivered. The new chair did provide some better postural management control but a sitting height of more than 60 cm significantly reduced Agni's ability to transfer safely from the wheelchair in the way that had been so successful during the training phases. In other words the new chair reduced her degree of autonomy and self-care. After one week Agni refused to use the chair: she wanted her old lower chair and expressed great frustration about her reduced independence. However, her old chair was broken. Seeking advice from FTB the independent living team were able to loan her an unadapted but low and flexible wheelchair. Although her posture was not well supported and her outdoor mobility was significantly reduced, she used this chair for two years. Interestingly, Agni considered the loan chair rather useful when travelling as it was easy to carry and small enough for most car boots. Long-term use of the loan wheelchair revealed a further unforeseen requirement for a second, small and flexible powered wheelchair that would be convenient for use indoors and offer the opportunity to travel easily with friends.

At this point the long battle for the funding of a suitable wheelchair began again. Several multi-professional meetings (attended by an occupational therapist, physiotherapist, caregiver, social pedagogue, and technician) were convened to explore strategies to secure funding for the recommended wheelchair. Enquiries were made to the medical insurance company by Agni's occupational therapist, physiotherapist and doctor. A reduction in additional personal support and a corresponding increase in Agni's independence were itemised. A detailed comparison was compiled of additional costs, incurred through the need for personal support in transferring Agni from her chair and helping her in activities of daily living, placed against the expense of the recommended wheelchair. Eventually the health insurance company agreed to change Agni's wheelchair. In 2000, 2 _ years after the initial recommendation, a wheelchair, matched to Agni's needs, was delivered!



6. Outcomes and reflections on the process

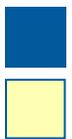
Agni's difficulties with mobility and transfer have been overcome with the provision of a suitably adapted wheelchair. Indeed she has sustained independence in daily living activities on her move to a new home and city.

FTB conducted a cost-benefit analysis on the basis of the results of the independent living training. Taking into account all the technical equipment needed under outpatient conditions, a potential for savings between Euro 70.000 and Euro 160.000 over a five-year follow-up period to the initial training was outlined. Even a two-year follow-up calculation indicated savings between Euro 20.000 and Euro 40.000. This is remarkable because more than Euro 30.000 in additional costs for technical aids, home adaptation, and the independent living training itself, as well as Euro 850 per annum for the case management, had to be included.

Agni moved to a new job as an office assistant in a newly-founded small company that provided home adaptations for disabled and older people. However, she overestimated her own abilities to make this bold transfer. She was unable to maintain her role in the new job and at the same time undertake a second job as a peer counsellor. After six months both parties cancelled the contract. Despite this setback Agni found work as a guide in a showroom for home care relating to AT solutions. She reports that this work is better suited to her personal skills.

It is clear from Agni's experience that the provision of a technological aid does not equate directly with guaranteed success. Improving independence and participation in society requires strong will and effort from the user as well as a skilled professional team to guide the advisory and training process.

Unfortunately, after more than 50 contacts over a six-year period, FTB's involvement ended when Agni moved to another town 100 km away. Because of the structure of the German rehabilitation system, case management paid by a health insurance company doesn't exist. The only possibility for closer, continuous guidance is given via a legally appointed custodian. Agni does not want this kind of support because that would restrict her independent decision-making. So she tries to manage her life in a new city with a new job mostly on her own.



1. Personal details

- Name: Andrea ☺
- Sex: Male
- Date of birth: 1960
- First assessment contact: 1992 (first intervention)
November 2000 (second intervention)
- Primary Disabilities: C.P. Motor impairment (tetraparesi distonica,)
- Associated Disabilities: anartria

2. Background and context

Andrea was born with tetraparesi distonica (dystonic tetraplegia), a severe form of Cerebral Palsy. He has very limited independent movement and is totally dependant on others to support him in performing activities of daily living. His physical difficulties affect his speech and he is intelligible only to people that know him well. Andrea's primary school education was in a special school, moving to a mainstream environment on transfer to secondary school. His schools and his family have always worked hard to promote the development of his full cognitive potential. As a result Andrea has achieved a high level of academic ability and motivation, graduating in Philosophy from the University of Bologna. When at school and during his time at university assistive technologies were not generally available to disabled people. Andrea could only access written material by relying on his mother and friends to read aloud to him. When at university this involved reading specialist publications and complex scientific texts. Andrea recorded his work by dictating to a scribe and thus relied completely on those that knew him well and understood his speech.

During this time at university Andrea was intensely engaged in the social life of the university, and together with friends and volunteers travelled both in Italy and abroad.

On the death of his mother Andrea moved into a residential home. He soon reported that he was unhappy with this form of institutional living, complaining that it imposed unwelcome rules on his lifestyle and limited his opportunities and liberty. For example, organisational problems such as a shortage of residential staff limited opportunities for him to travel freely in town, and to enjoy cultural and social activities. Furthermore, he was less able to rely on the support of friends as by now many had married and had children. This limited the time they could spend with Andrea.

A further illustration of the problems of residential homes became apparent during the three



years that Andrea was engaged. At this time he describes being acutely conscious of his and his fiancée's limited privacy. More recently the residential community moved into temporary accommodation before again moving to a new and permanent location. As a direct consequence of this, Andrea has been required to share his room with another male resident.

In 1992 Andrea joined the staff of the Documentation Centre on Disability, in Bologna. His post was supported by a state subsidised contract. He began writing articles for the review of the Centre and he became actively involved with a group in the Centre working on diversity issues in education.

Andrea visited Ausilioteca on 12 occasions between 1992 and 1995. The principle aim of the visits was to identify ways in which he could access computer technology to aid writing. From the technical perspective, the first central difficulty facing Andrea and the team of professionals was the identification of a suitable method for using one or more switches. Andrea experiences profound difficulties moving his trunk, limbs and head with accuracy and consistency. He often needs to adjust his physical position making any fixed switch mounting impractical. In addition, Andrea's natural speech is not sufficiently consistent or intelligible to use speech recognition software. A series of investigations has, therefore, explored Andrea's ability to make consistent and reliable physical movements in the operation of a switch.

The following **solution for autonomous writing** was the most satisfying.

Method of input to technology: Andrea was able to move and control his tongue with consistency and reliability, and without significant effort. He was able to activate a humidity sensitive switch with the tip of his tongue and the switch provided auditory feedback when activated. In order to maintain the switch position in front of his mouth it was mounted on an adapted headstick helmet. This proved successful in maintaining a suitable position despite Andrea's involuntary head movements.



Software: the proposed writing software was designed so that Andrea was able to select letters, using his switch, from a matrix using a simple scanning procedure. After some training he was able to use the software more or less independently.

Because Andrea was unable to fix his eye gaze at the computer screen for long periods, the use of a text based VOCA (voice output communication aid) with synthesised voice and auditory feedback was also tested. Although the testing was rather successful unfortunately this particular system was not funded by the National Health Service and was thus not purchased. This meant that whenever Andrea wanted to write longer texts he needed to change position in front of the



screen every 10 minutes or so. Difficulties with funding then meant that the technical solutions recommended were not fully available until 1996.

Increasing demands at the residential home meant that the staff were unable to support Andrea's computer access. In 1997, the computer was transferred to the Documentation Centre where Andrea worked and where he had access to a personal assistant. His productivity rose and he started mastering the system, increasing his writing speed significantly.

Use of the computer at the Documentation Centre precipitated an update in his system. For instance, Andrea expressed a wish to use commercial software like Microsoft Word, Internet Explorer and Outlook, to accommodate an exchange of files with colleagues and to allow him access to Internet and email. The Ausilioteca team introduced the new software, including *Clicker Plus* (Crick Software Ltd), a commercial software package allowing indirect access to standard PC applications. This proved to be the most useful keyboard emulating software for Andrea and he familiarised himself with it quickly. The switch access position and technique remained unchanged.

For a number of years now this software has proved satisfactory in supporting Andrea's access to the PC and in writing. He had been participating in a distance learning course for disabled people on the most commonly used applications under Windows.

Andrea's experiences paved the way for new initiatives including, for example, in 2001, the provision of a fully equipped computer workstation at the Documentation Centre. The workstation can be personalised for those with special needs working in, or visiting, the Centre (involving, for example, the use of switches, software with scanning options, and on-screen keyboards).

3. Starting a process: the demand

In November 2000 Andrea revisited Ausilioteca, expressing a keen desire to explore opportunities to live independently. At that time the city of Bologna, in collaboration with the Association of Disabled Persons (AIAS), was planning to build small apartments designed for disabled people to live independently. At this time the project was still in an early phase, but did provide an opportunity to explore the possibilities for adapting accommodation to meet some of Andrea's needs. Two aims were defined:

- To trial technological aids including for example, an environmental control system for controlling lights and curtains, security systems, and use of a telephone.
- To support Andrea in experiencing independent living for a limited period (a few hours a day on occasional days).

To do this the project employed AIAS Ausilioteca's *Casa Amica*, a show apartment for independent living. *Casa Amica* offers the possibility to explore assistive technology solutions for independent living in a protected environment and with professional support. Andrea and



Ausilioteca invited a representative of AIAS, a professional carer from the residential home where Andrea lived and a rehabilitation therapist of the local health unit, to the initial meeting in Ausilioteca.

4. The search for a solution

Identifying appropriate solutions

In the absence of almost any intentional motor control, Andrea needed to explore various other forms of support that could help him to control certain aspects of daily living.

Aids for daily life

Aids for remote control: The first assessment at Ausilioteca, in preparation to the testing in Casa Amica, was principally concerned with finding methods for control of the television and the video recorder. A remote control device with scanning functions (GEWA III) was tested using his tongue switch. After a period of training the GEWA III was loaned to Andrea for a trial of one month at the residential home. At the end of the loan period Andrea felt very positive about the system.

Aids to lift Andrea: In Casa Amica the therapist and Andrea tested several "person lifters" and the necessary accessories to facilitate the job of his carers and friends.

Environmental control with a scanning function: To open doors, windows, and shutters, to switch on and off the lights and to control some electronic equipment, Andrea initially used the GEWA environmental control system loaned to him beforehand and already familiar to him. However, this system relied on Andrea having fast visual scanning, and this proved difficult and unsatisfactory as a long-term solution. Instead, the trial of an environmental control system with auditory scanning was undertaken, and the system *Sicare pilot* proved to be a much more successful option.

Telephoning system: A complex new integrated systems involving a special telephone with voice amplification remote-controlled infrared were tested and proved successful in meeting Andrea's needs. To dial the number and to respond to incoming calls Andrea again used a remote infrared control (GEWA III, Sicare Pilot).

Calling system: In order to provide Andrea with a reasonable level of personal security in the home, it was necessary to provide access to a system that could call for assistance or raise an alarm. Two solutions were trailed: (1) *A radio phone connected to a service centre:* this is a listening device, working on the same principles as the *baby monitors* used at home with babies and young children. This device provided continuous auditory monitoring of the flat and allowed Andrea to seek personal support when required. Although Andrea could switch the system off, it did have the potential to compromise his privacy at times, (2) *A radio alarm bell:* a commercially available radio alarm was customised for switch access. For complete security, it had to be within Andrea's reach at all times and this was considered a disadvantage. Despite some inherent disadvantages in both systems Andrea was able to use them both successfully.

Aids for writing and workings

Personal Computer: Andrea identified suitable word prediction software with embedded scanning options (WIVIK) and a mouse emulator. The software solution, WIVIK, is principally used for the Microsoft Word software application and web navigation. He also achieved success with a new, lighter, tongue-activated switch with a more subtle and aesthetic mounting.

A “switcher” interface: as a single switch user, Andrea required a simple way of swapping between several assistive technologies, for example changing the switch function for PC access to environmental control, or remote alarm. Ausilioteca developed a *switcher* (a latching switch box that sat between his switch and the devices he wished to control) that was built, subsequently, by a commercial company.

Independent living

In total Andrea experienced three periods of independent living in Casa Amica:

- first period (2 days): this involved organising and testing some essential logistics (carers, volunteers, and staff that needed to be co-ordinated).
- second period (3 days): this involved testing technological living aids.
- third period (5 days): this involved the monitoring and evaluation of Andrea’s autonomy.

During his time in Casa Amica Andrea was assisted by a professional carer, friends, volunteers and a group of boy scouts. Other people present included a representative of AIAS and another individual with an acquired disability, who also used a wheelchair. It was appreciated that the disabled member of the assessment team played a significant role in focussing Andrea’s thoughts and energies on issues of independent living. Andrea was excited about his newly found access to the freedoms that others take for granted, such as planning meals, shopping and inviting guests for dinner.

5. Living with AT

Following the assessment, and whilst waiting for the realisation of these new-found liberties in independent living, Andrea returned to his residential home where he continued to use the PC applications identified at Casa Amica. However, he was unable to make use of the other recommendations because their purchase and support could not be funded and were too expensive for his personal budget.

6. Outcomes and reflections on the process

From an early age Andrea’s family and school staff promoted his participation in school and social life. This involved emphasising his freedom to think, share his opinions and participate as an active and valued member of society. Subsequently, Andrea developed skills and abilities that allowed him to take best advantage of AT to explore new avenues for autonomy offered by technology. These skills were particularly constructive when the assessment for and introduction of AT in support of Andrea’s life was long, complex and technically challenging.



Assistive Technology has permitted Andrea to carry out many actions and activities that were previously impossible for him to achieve independently. When appropriately equipped, and within a supportive environment, Andrea's requirement for personal assistance is reduced, although the attainment of such positive outcomes for Andrea required the energies and commitment of many people. At one time or another the professional team working with Andrea included an electronic engineer, a psycho-educationalist, an educator, a computer technician, a rehabilitation therapist, personal carers, a social assistant and Casa Amica service staff. Increasing Andrea's capabilities by beginning to meet his needs and desires for autonomy and independence has had a positive impact on his general well being. His motivation to explore new solutions and reach new milestones in independence has increased.

Working with Andrea has highlighted the multifaceted nature of autonomy and of the expectations that disabled people might have. As a person with a complex congenital disability, Andrea's life experience has involved many and varied people in organising aspects of his life in a practical and personal sense. Gaining autonomy in certain practical aspects of life reveals other, previously hidden, deficits in experience and life skills. This is reflected in the unrealistic expectations Andrea had for the role of and likely benefits of AT in his life.

The presence of an educator in the team was very useful in helping Andrea to re-evaluate his expectations and in developing a more realistic view of what autonomy for him might mean. The demand for support in functional and strategic life skills becomes an increasing priority as physical barriers are removed through the introduction of AT. Key aims identified for Andrea now include:

- to support the autonomous management of important aspects of his life such as his finances and diary;
- to offer Andrea further training in use of equipment;
- to pursue the possibility of living in a supported, independent home.



1. Personal details

Name: Àngel ☺

Gender: Male

Date of Birth: 16/3/1982

First Assessment Contact: April 1994

Primary Disability: Quadriplegic dystonic cerebral palsy

Associated Disabilities: Anarthria

2. Background and context

Àngel has been described as having "a restless mind in an unfit body". He is unable to speak. He cannot manipulate objects or move around without help, and he requires orthopaedic support to maintain posture. Àngel started attending a special school for children with cerebral palsy when he was three. He stayed there until he was 12 years old when his family moved home and he went to a new special school. He remained at his new school until he was 18 years old. Attempts were made to include Àngel in mainstream school but insufficient resources were available in Catalonia at the time to support Àngel's particular needs in a mainstream environment.

At the age of 12, Àngel communicated using a communication board with three panels and Picture Communication Symbols (PCS). He pointed to symbols with his eyes using a mixed colour-coding and assisted scanning system. This system was slow and laborious to use and required the communication partner to have intimate knowledge of Àngel's communication techniques and strategies. Nevertheless, he was competent using the system and showed good communication skills. For many years he accessed an Apple computer using two switches, one on either side of his head. In this way he was able to practise his literacy skills through access to writing exercises and develop skills in illustration through drawing applications, both at school and at home.

Àngel used a wheelchair, and, in order to maintain a stable posture, he required additional support for his hips, trunk and arms. This support mitigated against the dystonia, which was especially severe in his arms. In stabilising his body posture Àngel was able to control and organise certain physical movements that allowed him to use switches and/or a headstick pointer and thereby access computer technology.

Since age of 12 Àngel has expressed a desire to live independently whilst retaining close ties with his family, particularly his sisters. Àngel was able to satisfy this wish when, at the age of 17, he left the family home and moved into a residential home for people with physical disabilities. This is where he still lives. From here he was and is still able to socialise with his sisters at weekends and on holiday.



3. Starting a process: the demand

Àngel was referred to the Augmentative Communication Techniques Unit (UTAC) when he changed school at the age of 12. The professionals at his new school (teacher, speech therapist, teaching assistant and psychologist) sought advice from UTAC concerning the provision of independent mobility. The new school also had computers with modern, up-to-date applications and software supporting greater options and facilities for access to the school curriculum and recreation. Subsequently, the staff also wished to review his access methods to computer technology. They wanted to make changes to his communication system, in that the communication board he normally used had a very limited range of vocabulary and required a great deal of effort to use for Àngel and his communication partners.

4. The search for a solution

UTAC immediately initiated an assessment and intervention process in collaboration with professionals directly involved with Àngel, his family and Àngel himself. Priority was given to certain outcomes for essentially economic reasons, but still taking into consideration the strong and clear views of Àngel and his family. For instance, a wheelchair was prioritised over a computer or an electronic communication device.

Mobility

Àngel identified his highest priority to be independent mobility - to be able to move around freely. The use of an electric wheelchair was an obvious solution to this issue but difficulty lay in identifying a suitable method for wheelchair control. Severe involuntary movements in his arms and hands meant that hand operated systems for wheelchair control were ruled out almost immediately. It was, therefore, decided to explore the use of a foot-operated joystick. In the absence of a wheelchair with a foot-operated joystick UTAC proposed that assessment for the use of this system could be simulated in a manual wheelchair. Àngel's physiotherapist was able to position a joystick-type control at his feet and move the wheelchair in response to Àngel's manipulation of it. In this way it was found that he was able to control the directional movements of the wheelchair with his right leg and foot quite effectively.

The same year an application for a grant was made to the Social Welfare Department of the Catalan Autonomous Government, the Generalitat de Catalunya. The department met part of the cost of the chair and its adaptations while the rest was paid by the



family. The wheelchair was adapted by fitting a joystick, shaped like a tennis ball, within reach of Àngel's right foot with a stop/start control near his left foot. He needed little training to master its use and in only a short time he was skilled enough to move within and between classrooms and get about the streets of the small town where he lives.

Access to assistive technology

Initially, Àngel had used a Macintosh computer at school with a Ke:nx on-screen keyboard and mouse emulator operated by a single switch located on an articulated arm to the right side of his head. After a short while it was thought that using head movements to control the computer might interfere with the process of learning to read and write, with which Àngel was having particular difficulty. Accessing the on-screen keyboard using the head switch required him to orientate his head in such a way that his visual field shifted from the screen. This meant that he needed to relocate his place in the text each time. It was Àngel who suggested using his right shoulder instead of the side of his head to activate a switch with a sideways movement of his trunk. This proved the optimum solution, which he now uses confidently, accurately and efficiently.

Àngel quickly learned how to operate the system and setups (different dynamic screens that contain letters, numbers, drawing menus, general menus to control the computer, etc.) were prepared for him to access a large number of software and computer functions independently.

The next concern was the purchase of a portable computer, with all the necessary adaptations, for Àngel's use at school and at home. At that time, speech synthesisers in Castilian (Spanish - Àngel's normal language of communication) were available only for Macintosh computers. The means of access to this system, the Discover Switch, was very similar to the one he had been using up until then at school (Ke:nx), which meant that the modifications that had previously been made could also be adapted to it. It was, therefore, decided to apply to the Social Welfare Department of the Generalitat de Catalunya for a grant to buy a Macintosh computer with the Discover Switch access system, a switch and an articulated arm on which to mount it. A grant covering part of the cost was obtained after about a year.

Software

In developing literacy skills at school Àngel mostly used the *IntelliTalk* word processor with voice output. A speech therapist and an engineer specialising in assistive technology from the UTAC made up several Ke:nx system selection sets, that allowed him to control the functions required for writing independently.

In view of Àngel's creative abilities, another goal was to provide him with software that would enable him to express ideas, facts, stories and experiences via "plastic language" like drawings, pictures, graphic design. After some years he was proud to show his work in a local exhibition. Also had a personal presentation in ISAAC-SPAIN conference.

Àngel had been using the MacApple program that allowed him to draw straight lines and circles



on a screen in black and white, but not with colour. For painting and colouring he used a head stick to which a paintbrush or wax crayon was attached. His creations with this method were limited to combining colours and filling the paper with horizontal and curved lines made with a limited repertoire of physical movements. He showed good artistic sense in combining colours while form was not relevant. On finishing a painting Àngel would explain its abstract nature or give his work a title. In this way Àngel revealed a very creative imagination and significant cognitive potential.

The limitations of this system raised the question of using other technical devices that would be better adapted to his motor abilities and would allow him to draw in a way more suited to his needs. He quickly began using the *KidPix* drawing program with the corresponding Ke:nx selection sets which enabled him to control the different mouse and program functions and to access menu functions. Access to this software has enabled Àngel to demonstrate a high level of skill in the visual medium. He has learnt new techniques in drawing such as concepts of distance and perspective. Importantly, access to and use of this software has afforded Àngel an opportunity to express himself in colour and shape beyond the limited titles he used to summarise his work.

Communication

In parallel to the assessment process of exploring the use of assistive technology with synthesised speech output, work began on modifying Àngel's communication board to improve its functionality. The existing vocabulary was retained, but a number of new generic words, for example, the names of people, places, and social expressions, were added. An alphabet was also included, so that he could spell out words. Eye-pointing was retained as the principle channel of access to the chart but the coding system for identifying symbols on the chart was simplified. In the new arrangement Àngel eye-points to the number(s) corresponding to the symbol(s), word(s) or letter(s) he wants to select.

Àngel frequently used spelling as an alternative means of communication and his development of this particular strategy broadened his communicative opportunities. For example, his use of vocabulary became increasingly precise and the range of topics of conversation increased and diversified. As a result, it was considered important for Àngel to have access to an electronic communication device with synthesised voice output that would allow him to combine the use of symbols and writing. However, in 1994 no device supporting Castilian (Àngel's mother tongue) was available. Some time later an



improved version of the *Speaking Dynamically* software (symbol-based communication software compatible with Apple Macintosh computers) appeared on the market that integrated with the *MacinTalk* Castilian voice synthesiser.

UTAC set about tailoring this software to Àngel's communicative needs, which included translating text from the original English into his native tongue. His teacher and family provided practical advice concerning appropriate vocabulary and the layout of symbol arrays.

Recommendations for the future

It is planned for Àngel to attend an Occupational Therapy Service for young people with severe physical disabilities next year. This service combines work, occupational therapy and rehabilitation. UTAC will provide the necessary and appropriate support to broaden Àngel's opportunities and for creativity, leisure and learning. This will include:

- The use of a range of music software that will enable him to compose music and express himself creatively.
- Accessing Internet services. Internet use is another of Àngel's hobbies. For instance, Àngel uses email to keep in touch with friends and acquaintances, and he often participates in his favourite radio programmes via email. Nevertheless, web browsing is still difficult for him and improvement in this aspect of Internet use is a target for development.
- Assessing the most effective assistive technology for communication in a range of settings with different communication partners. At present, Àngel's main concern is to have a dedicated electronic communication device.

5. Living with Assistive Technology (AT)

By being able to move about independently Àngel now has the opportunity to decide:

- who he wishes to talk to and when
- where he wants to be and when
- who he wants to observe and when.

He now has opportunities to get up to mischief, an activity previously denied him! In short, he can do the things that other young people do in their learning and play from fairly early on in their lives.

Having a personal computer has facilitated Àngel's learning process enormously. It has improved his competence in writing. Particularly valuable in this respect has been his continued use of the *IntelliTalk* program. An important feature of this program for Àngel has been the auditory feedback facility providing a spoken version of the written word. This facility allows Àngel to review his work easily on an on-going basis and correct errors accordingly.

Basil, Rosell and Juan (1998, "Single switch for creativity: A case study") comment: "Drawing has

become one of Àngel's favourite hobbies and he spends much of his spare time at home on it. At school they have sought to make use of this skill in all the other subjects in the curriculum, so his school work almost always includes some kind of graphic element (maps, diagrams of the human body, etc.) done by him. Priority has been given to subjects to do with art, architecture and design which are worked on in the classroom as well as during visits to the town, museums and art galleries. Àngel impressively combines his creativity with the extraordinary skill and unlimited tenacity required to make complex drawings using a single switch." At the moment he uses *KidPix* and *ClarisWorks* with *KidPix de Luxe* software. These have allowed him to become familiar with new techniques in design and art work, improving his artistic standard.

It is important to highlight the social function that using a skill such as drawing performs. The work Àngel produces can be commented on and appreciated by the people in his immediate environment, as well as by people who have no direct relationship with him. For example, the students in Àngel's class carry out money-raising activities to help pay for outings and an annual week-long trip. As part of this activity



Àngel has designed Christmas cards, bookmarks for Catalonia's traditional book festival on Saint George's day, and many other things, that, incidentally, sell very well!

6. Outcomes and reflections on the process

Àngel uses his communication board and computer based communication software for different, complimentary, communication activities. He uses his communication board for spontaneous conversations, whereas, importantly, he uses the computer to allow himself to express feelings and experiences in greater depth. The computer-based communication system also provides additional flexibility that is not available via the communication board. For example, he can save certain important and relevant or long messages and access them again when required. However, Àngel's communication needs have still not been met fully. The computer based communication system cannot be used quickly and its user settings are limited. Àngel will benefit from exploring the use of other communication systems, and in view of his progress in writing, consideration is being given to a more portable type of communicator that combines spelling with generic messages that can be used quickly and easily in different environments.

The team at UTAC were at great pains to include and actively involve all the professionals working to support Àngel during the assessment process. In Àngel's case this proved a relatively



straightforward task, as the special education professionals working with Àngel were highly skilled and enthusiastic. Most importantly Àngel's own opinions and priorities regarding the type of assistive technology, the most appropriate form of access, and so on, were central to the process. In this way the assessment conformed to his needs and expectations. For example, Àngel prioritised independent mobility over use of communication focussed AT.

Active participation in the assessment process by the professionals directly supporting the person with disabilities is important. Even more so is the participation of the family and the person with disabilities who have to make decisions on things that affect him or her very directly. The professionals at UTAC take attach great importance to views and priorities of the person with disabilities. This ensures that the assessment process conforms to his or her needs and expectations. In Àngel's case the special education professionals had clear, well worked-out criteria with regard to the measures to be taken, so that the evaluation and assessment process was enthusiastic and effective.

Several years ago, when Àngel found it hard to imagine that he could ever have his own computer, he expressed the opinion that it was absolutely necessary for people with physical and speech difficulties to have the right tools to enhance their autonomy. The following text, written by Àngel, and included in an article by Juan and Rosell (1998, "Sistemas de signos y ayudas técnicas para la comunicación aumentativa y la escritura", p. 171), elaborates some of his views:

"Writing on a computer opens up the doors to a better future. It's very easy. I can turn it off myself and that means I'm a bit more independent, thanks to the technicians of the Augmentative Communication Techniques Unit (UTAC), who adapt the functions for me. However, I think I could still have more things on my setups. For instance, being able to start, surf and work wherever I want. The factories and the computer programmers could do a lot more. Now they can't make computers without obstacles. When I buy a computer I'd like it to be fully adapted for guys like me. I've got a drawing program called KidPix and with it I can do everything. I make beaches, houses with gardens, etc., and when I do I think I like it a lot, and moreover I try to discover new ways of making things."

In a recent conversation Àngel talked about how past dreams can become present reality. Àngel's speech was produced using *Speaking Dynamically* software. To facilitate the reader's understanding the original conversation has been reconstructed using standard grammatical structure:

"I am now very happy because I have my portable computer and I can do what I want with it. For example, I can draw my ideas, and write and express opinions on my communication program. Now with the Internet it's fantastic because it opens up a lot of doors for young people like me. I can see things and speak to more people."



1. Personal details

Name: Carlo ☺

Gender: Male

Date of birth: 1964

Onset for acquired disabilities: July 1992

First assessment contact: January 1993

Primary Disabilities: Motor impairment (tetraplegia), spinal cord injury C6.

Associated Disabilities:

2. Background and context

Carlo is qualified as a Quantity Surveyor but chose to follow the family tradition of banking. Before the road accident Carlo worked as an office clerk for a banking agency, work that brought him into direct contact with the general public. Despite Carlo's strong "sense of duty towards work", and recognition of good career prospects at the bank, he reported that he did not find his job fulfilling, protesting that his work lacked opportunities for creativity. Indeed, before his accident Carlo described himself as "a difficult person"; being dissatisfied with many aspects of his life including strained relationships with his family. Nevertheless he reported that he enjoyed a rich social life and was able to "let off steam" through sport and travel.

In July 1992 Carlo was knocked off his scooter by a car. He suffered a spinal cord injury C6 causing paralysis of his lower limbs and limited movement of the upper limbs. In addition to difficulties with movement, Carlo now experiences reduced sensitivity to touch and some superficial pain.

Following his accident Carlo spent the next seven months at a Rehabilitation Centre. On discharge from the Centre he lived with his mother whilst waiting for his own home, an old farmhouse, to be adapted to his needs.

Carlo reported that in the period immediately after the accident he deeply felt a lack of psychological support. He described feeling completely lost; that his life needed to be totally reorganised, and that he didn't know where to begin or what support he might need.

Friends and relatives initially provided personal assistance with Carlo's everyday needs. However, many experienced difficulties in dealing with him particularly as Carlo describes himself, in this period, as an angry and destructive person. Friends also experienced difficulties balancing the demands of care and assistance for Carlo with other personal commitments. Gradually, professional services replaced the support from friends and relatives. Despite the pressures placed on his personal relationships at this time Carlo maintained many friendships and kept up relationships with members of his family. Carlo recounts how his sudden reliance on others for physical assistance in everyday activities and tasks was extremely difficult for him cope with.

On returning to his own home Carlo encountered a lack of professional support such as occupational therapy in helping him develop strategies and skills for independent daily living. This



left him searching for the strategies and suitable tools to support greater autonomy in his life. His research involved extensive reading and meetings with other people with spinal cord injuries. Nevertheless, it was not until seven years after his accident that he was able to visit a highly specialised Spinal Cord Unit in a town 250 km from his home. Carlo reported that at this Spinal Cord Unit he was finally able to access a full range of resources including suitable information, appropriate assistive technologies for daily living and training. Carlo received psychotherapy for two years which he found very satisfying.

3. Starting a process: the demand

The demand for AT aids was influenced both by Carlo's health and his career prospects. Following his accident the physiotherapist from the local Health Authority Centre for Adults with Disabilities (*Polo Handicap Adulti*), the service which co-ordinated Carlo's rehabilitation into the social and working environments) made a request for an assessment at Ausilioteca. The assessment goal was to explore and introduce suitable technologies to support Carlo in controlling (independently) his immediate environment. Carlo was first seen in January 1993, approximately six months after his accident. Interestingly Carlo now says *"It was probably too early: I didn't even know what I should have asked for: that period of my life is still very nebulous."*

A second assessment followed some months later. In Carlo's words the aim of the assessment was to: *"find the tools and techniques in order to go back to work and use a computer (keyboard and mouse) as well as the telephone"*. In order not to lose his job Carlo had to get back to work before the end of December. So the team had to work quickly to identify his needs and appropriate solutions to technical problems. His family was not present at any of these meetings, believing Carlo capable of leading his own life.

4. The search for a solution

Five meetings were organised at Ausilioteca. In addition to the staff of Ausilioteca the meetings involved an educator and a physiotherapist from the local Health Authority Centre for Adults with Disabilities (*Polo Handicap Adulti*). The educator and physiotherapist's role was to provide on-site support and back-up for Carlo's reintroduction to work. The key assessment objectives were to:

- re-examine thoroughly Carlo's work situation, matching his new abilities and needs with the needs of the company
- find the right technical solutions to the identified problems and maximise their use in the workplace.

In addition to the meetings mentioned above two visits were carried out at Carlo's workplace, together with the bank staff, in order to evaluate the practicalities involved in Carlo's return to work. One important aspect of this task was to look carefully at the difficulties in maintaining an appropriate and stable posture for Carlo and ensuring accessibility to and usability of identified solutions. During this time Carlo was recognised as a partner and team member in the search for



appropriate technical solutions. He was also able to begin building working relationships with several members of staff from the bank, his future colleagues.

Carlo, the Bank, Ausilioteca and the Polo Handicap Adulti agreed a final plan of action. The agreement involved changes to Carlo's job description and the working environment. Because dealing with the public would be tiring for Carlo, it was agreed that he move to an office and to work that did not demand high levels of contact with the general public.

In addition such work within this working environment would allow Carlo to manage his own time. Although not expressed openly, members of the assessment team sensed that staff at the Bank were concerned that Carlo's presence as a clerk could impact negatively on company image. The job initially chosen for Carlo was technical office work, specifically dealing with the up-keep of the bank's real estate. The job description included using a computer and telephone as well as handling paper documents. Carlo quickly demonstrated a high level ability in this work involving the use of adapted technologies. As a result, his job description was immediately widened to include designing the bank's local branches using Computer Aided Design (CAD) software. The bank purchased all the necessary aids and equipment. Moreover, the bank's technicians personalised the equipment themselves following guidance from the Ausilioteca specialists. Later, when some of the computer devices were damaged due to wear and tear (for example, the trackerball, sensors, and mini-headphones), Carlo replaced them at his own expense.

Workstation

The workstation consists of the desk and another work surface placed at right angles to each other (L shape).

The desk is 120cm deep (achieved by putting two ordinary tables together lengthways) allowing Carlo to sit close enough to the desk to be able to rest his arms when using the keyboard and still maintain a suitable distance from the PC monitor (19"). The space beneath the tables is kept clear ensuring that the entire space is wheelchair accessible. This layout also allows Carlo to move quickly and efficiently between work surfaces and equipment.

Carlo, together with the physiotherapist of the Polo Handicap Adulti, has designed a chest-rest fixed to his table with movable slides allowing him to work for longer periods without becoming excessively tired. Carlo's own posture support system was set up with the help of a friend and an orthopaedic company.

Personal equipment

Carlo is unable to move his fingers independently and experiences difficulty using a keyboard. To compensate for this, Carlo has been given two specially developed "splints" to support his access to the keyboard. This splint consists of two metal pointers covered by a plastic coating, and fixed on the topside. Commercially available splints for tetraplegic patients are wrapped round the user's hand and so are not suitable because Carlo needs the palm of his hand free when using a



computer trackerball. Using his customised splint Carlo can tap the keys while keeping his hand in a vertical position. Importantly, Carlo can put on and remove his specially developed splints without help.

This product is commercially available. The cursor is directed by operating a large ball sitting in a sturdy case. This gives Carlo the advantage of being able to stabilise his hand on the ball comfortably and move the cursor with accuracy and consistency. A small modification permits Carlo to access the enter control via a separate switch using his left hand. Carlo can dial the telephone by using the same splints but with drift-pins used for keyboard access. He uses headphones during the conversation, and an external switch to access the dialling tone and to "close" a phone call.



Carlo experienced difficulty using a standard mouse and this was replaced with a trackerball.

Environment

Carlo's job involves the use of a photocopier, fax and printer located in another room. Their location and position in terms of the height and accessibility of the function buttons makes it very difficult for Carlo to use them. No adaptations have been made to improve Carlo's access to these items.

Carlo also had significant problems using address books and telephone directories and was required to seek help to use them. On returning to work he converted them into electronic format. He also created a number of archives, which became a valuable resource for the whole office. However, he still needed help from a colleague when consulting other papers.

The bank has recently agreed to Carlo changing posts within the company, working instead as a back office expert in redesigning the computer infrastructure of local branches of the bank. Computer consultants external to the bank have not been required because Carlo has taught himself to use CAD (computer aided design) software. Using email and the telephone to a greater extent has solved the practical problems of communicating with colleagues.





A standard portable electric heater met Carlo's need for a warm environment. Use of a specially equipped minibus overcame difficulties in travelling to and from work. The Bank and Carlo's office were already generally accessible but Carlo still needed personal assistance to

negotiate some particularly heavy fire doors when arriving and leaving work. Moreover, this raised questions and concerns over Carlo's personal safety in the event of an emergency.

5. Living with AT

Several adaptations to commercially available products were required to meet Carlo's specific needs. Detailed assessment and provision of customised aids helped Carlo to reach a level of productivity equivalent to his peers. Moreover, exploration of the solutions to Carlo's needs and Carlo's insights and skills in computer technology contributed directly to improving efficiency in many aspects of office. Indeed, Carlo became a source of informal advice and guidance for Bank staff experiencing problems with software (informal in the sense that it was not recognised professionally as an aspect of his work!). Carlo reported that the only significant drawback to his work situation was a lack of opportunity to monitor in person developments and design changes in other branches of the bank.

Despite some initial embarrassment caused by Carlo's new status and identity as a disabled person, he reported no difficulties rebuilding relationships with his colleagues, and his colleagues proved willing to support him in many day-to-day activities (eating, drinking, putting his jacket on, putting headphones on, changing posture/position). Over time physical improvements allowed Carlo to operate equipment independently that had been denied him (sending faxes, removing sheets from the printer or making photocopies).

Carlo has continued to seek out new technologies to increase his autonomy. In 2001 he retook his driving licence, bought a car and adapted it to meet his needs. He is able to control aspects of his environment (the television, stereo and the opening and closing of windows) using standard



remote control devices. Future projects involving the use of assistive technology include: voice controls for his car, use of an electric wheelchair for travelling longer distances, greater autonomy at home (independent control of doors, windows and lights), universal voice control for all electrical appliances and a modified hand-grip for playing table tennis.

6. Outcomes and reflections on the process

The detailed assessment, recommendations and subsequent provision of assistive technologies for Carlo has proved indispensable in supporting Carlo in returning to work and maintaining his position at the bank. Although the team involved with Carlo met the deadline to ensure that he could return to work, Carlo has highlighted some disadvantages in returning too quickly (indeed he was advised by some to return to work too quickly). He suggests that he would probably have benefited from more time to have considered alternative employment which might have allowed him more opportunity to manage his own time and accommodate his everyday needs differently. Nevertheless, Carlo's reintegration into his former workplace was definitely successful from a technical point of view. In a relatively short space of time Carlo and his team of assistants managed to find acceptable solutions for managing his new job. Undoubtedly, as the key partner in the team, Carlo's capacity to learn and his motivation to develop new professional skills have contributed to this success.

Carlo's reinstatement at work is one part of his rehabilitation and has been achieved, in part, through the provision of appropriate equipment. However, the provision of appropriate equipment has been possible only through shared working between relevant members of his working environment, external service providers and Carlo himself. Social Services and the Local Health Authority have effectively created the conditions for Carlo to get back to work. Ausilioteca guided the assessment process, and the exploration of suitable technologies. Above all the constant involvement of Carlo as an active protagonist in the process was the key factor for his successful reinstatement at work. That is, the successful return to work for Carlo was not only a question of finding suitable AT devices but also a case of engaging in an on-going collaborative process to meet his needs, needs that will continue to challenge AT services over time. Interestingly, the process of Carlo's reinstatement at work revealed new, and more effective, ways of organising office procedures for all staff.

The involvement of many professional figures makes such processes rather expensive. Four assessment meetings were held with Carlo at Ausilioteca and another two at his workplace. Each typically involved an electronic engineer, a psycho-educationalist, a computer technician, a physiotherapist and an educator from Ausilioteca in addition to professionals from other participating service institutions.

In returning to work at the bank and contributing so much as an effective and productive employee, Carlo has made significant progress in his psychological and physical rehabilitation. It is likely that a conventional cost benefit analysis of this process cannot take account of these essential milestones and the many benefits for Carlo and those in his environment.



1. Personal details

Name: Claire ☺

Gender: Female

Date of birth: 1990

First Assessment Contact: 1994

Primary Disability: Quadriplegic athetoid cerebral palsy

Associated Disabilities: Dysarthria

2. Background and context

Claire is a young girl who has attended mainstream school since she was five. She relies entirely on a powered wheelchair for independent mobility. She requires assistance with all fine motor activities such as playing, feeding and personal care. As a result, she has been provided with a one-to-one teaching assistant throughout her education. Her Intelligence Quotient (IQ) has been assessed and is between 131-140, well above the national average. She has visited a private rehabilitation centre The Bobath Centre, from an early age for assessment, advice and 'hands-on expertise' in relation to her communication, occupational therapy and physiotherapy needs. In addition, peripatetic occupational therapy and physiotherapy have been provided locally during school hours.

Claire began mainstream nursery school at the age of three and a half. Her main method of communication is speech although this is quite dysarthric (poorly articulated). She was referred to the ACE Centre in 1994.

Claire has no siblings. She lives in a suburb of London in a house that has been continuously modified and adapted to suit her needs. For example, all the doors have been widened and a lift has been installed to ensure that Claire has easy, independent access to the whole house. She can also move from the house into the garden in her powered wheelchair. Claire's father works full-time in London. Claire's mother works full-time "in the home". Much of her time and energy are spent in providing the extra support and attention that a young person with Claire's needs and abilities requires in order to develop their full potential. Considerable time has been invested in developing her own computer skills and, as a result, she has achieved a high level of expertise.

Claire's parents devote considerable time and attention to ensuring that she pursues a full and rich social life. She enjoys a range of leisure activities, including the 'Girl Guides' and swimming. The computer, as well as being a tool to help realise her academic potential, has become an essential leisure activity in its own right.

For several years now, Claire has enjoyed access to a range of software that has provided an outlet for her creativity.



3. Starting a process: the demand

Claire was originally referred to the ACE Centre “for advice regarding the development of Claire’s use of the computer to access the curriculum”. This recommendation was made with the support of the therapists at The Bobath Centre who felt that the software they were using was no longer adequate to support Claire’s physical and cognitive development. The primary requirement of Claire and her parents throughout the ACE Centre’s involvement with the family has been to optimise her use of the computer as a tool for learning and leisure.

Although limited by her breathing pattern, Claire’s speech is intelligible to her family and friends. Whilst Claire and her parents acknowledge that those who do not know her well do not easily understand her speech, the family has been reluctant to use technology to aid her social communication.

Nevertheless, throughout Claire’s involvement with the ACE Centre, this is an issue, which has been under constant review. Claire and her parents have had regular opportunities to consider the use of a range of communication aids and strategies. For example, when Claire was first referred to the ACE Centre she used Bliss Symbols and Picture Communication Symbols to support her spoken communication. However, since the emergence of Claire’s literacy skills, she has adopted other strategies to get her message across and to engage her listeners. These include spelling the first letter or first few letters of a word to clarify its meaning when conversational partners have misunderstood her.

4. The search for a solution

All the key players involved in supporting Claire were invited to attend her first assessment at the ACE Centre in 1994 - her parents, her teacher, her SENCO (a teacher appointed in every mainstream schools who has whole school responsibility for supporting all children with special needs), her nursery nurse, her Bobath speech and language therapist, and her local health authority occupational therapist! The members of the ACE Centre team included teachers, an occupational therapist, a speech and language therapist, and a technical specialist. The assessment took place at the ACE Centre and lasted one full day, with appropriate breaks taking into account the fact that Claire was still only four years old. The areas addressed during the course of this first assessment included the following:

Seating and Positioning

Before the assessment, it had been reported that Claire had used both a standing frame and a Jenx Multichair when using her switches to access the computer. She brought her Jenx Multichair to the ACE Centre assessment and a few minor adjustments were made to maximise Claire’s pelvic and trunk stability. The addition of an extra section behind her shoulders helped Claire to keep her arms forward, assisting her in accessing her switches. It was recommended that consideration should be given to the height of the Jenx tray. Positioning it just above elbow height allowed Claire more support for her arms.

This, in turn, minimized her involuntary movements. It was recommended that the computer monitor should always be positioned directly in front of her and at eye level.



Access to technology

At the Bobath Centre, two QED Lever switches had been mounted on wedges either side of her tray. Claire activated the left switch with her left hand and the right switch with her right hand. Although she could access the switches successfully in this way, there was considerable involuntary movement in both of her arms. A range of alternative positions was tried, ultimately resulting in what was agreed to be a workable arrangement (see below).



Note that the two switches are facing her

It was recommended that this positioning should be used for two-switch access, making computer use less tiring for Claire and allowing her to concentrate more fully on the screen. It is customary with young physically disabled children to use two switches rather than one when first scanning. Two-switch scanning gives them complete control over the speed of the scan and the selection of a target object. A single switch scan requires good timing, which for younger users is often too demanding. In this way, Claire was able to

direct more of her attention to the cognitive aspects of the task in hand.

As a result, Claire's speed and accuracy of switch activation improved. She successfully used the switches to access specialised two-switch software and her gross involuntary movements were greatly reduced. Claire was asked to contribute her thoughts and opinions throughout the process of assessment and recommendation. She expressed her delight with the improvements that had been made in the re-positioning of her switches.

Everyone recognized that Claire's physiology would change rapidly over the forthcoming months and years. Indeed, it was anticipated that she would soon progress towards a faster single switch autoscanning system. From there it might be possible to continue on to some form of direct "point and click" access via a special joystick or trackerball. Consequently, it was recommended that her access should be reviewed at yearly intervals with a view to steering her towards direct pointer access at an appropriate time in her development.

Software

Specific software was recommended which was carefully modified not only to optimise Claire's access to the curriculum but also to ensure optimal progression within it. This was particularly important, given the potentially rapid development that would result from her high levels of motivation and cognitive ability. The recommendations included:

- **Software to help develop Claire's literacy skills:**

A switch-operated word processor with a word bank, rather than a predictor, because she was at



such an early stage of her literacy development.

- **Software to help develop Claire's drawing and painting skills:**

Switch access utilities were developed to enable Claire to access a range of 'mainstream' graphics programs.

- **Software to enable Claire to explore CD-ROMs for information and leisure:**

A switch access utility (Switch Access to Windows) was modified to enable Claire to access CD-ROMs containing material such as stories and multimedia references.

Recommendations for the future

The ACE Centre report emphasised that, although Claire had severe physical difficulties, there were many things that favoured her potential for future academic success. These included a high level of motivation and cognition, and increasingly intelligible speech. She had the additional advantage of a well supported mainstream setting.

It was recommended that an appropriate computer should be purchased for Claire's personal use within the classroom, along with appropriate software, a colour printer, switches and an adjustable-height trolley. Although Claire would obviously not be expected to use a computer all of the time, she would nonetheless require access to a customized computer of her own whenever she needed it. This would be the equivalent of her peers needing access to books and pencils.

It was also stressed that, if the potential of young children like Claire is to be fully realised, a constant cycle of assessment, provision, training and review must be enforced. This would ensure that the equipment and support provided would always match her developing cognitive and physical abilities. Subsequently, the report recommended a "package of services" including a biennial assessment followed by up to four training consultations within the first two years. Claire's parents insisted that the local education authority include the recommendations relating to reassessments and training 'by a specialist centre' in her 'Statement of Special Educational Needs'. This is a statutory document that defines the special needs and recommendations for pupils with complex levels of difficulty. It should also describe the extra help such pupils should receive to optimise access to The National (Educational) Curriculum.

5. Living with Assistive Technology (AT)

Whilst the Bobath Centre and Claire's parents had been keen for Claire to visit the ACE Centre for a specialist assessment, those supporting Claire at school were not, initially, as keen. Their view was that they wanted her to use the same device(s) to access the computer as the other children because they 'didn't want her to be different'.

The difference between the school's perspective and the ACE Centre's was clear. For the ACE Centre, the key issue was not so much whether Claire had access to same **tools** as the other children, but whether or not Claire had access to the same **opportunities** as everyone else. Time



was taken in persuading the school's representatives, who attended the assessment, that the recommendations in relation to Claire's use of, and access to, the computer were appropriate.

Following the assessment, the ACE Centre and the local education authority corresponded to clarify the specific computer, software & interfaces recommended for Claire. This is one of the many difficulties when recommending a computer customized for a switch user. Usually, those responsible for purchasing equipment have little or no experience of young people requiring alternative access to technology. Claire's computer arrived six months after her ACE Centre assessment had taken place. By this time, she was already five years old. Her reading skills and her interest in literacy were developing rapidly and she was keener than ever to 'write' with a computer.

As well as a computer for school use, Claire's parents bought her a home computer. Support was provided by the ACE Centre to ensure that the hardware and software for both computers worked successfully. Training was provided for those responsible for Claire's computer at school. Training was also provided for Claire's mother, who was keen to support her computer usage at home. At such a young age, the emphasis at home was, of course, more on leisure and pleasure than homework.

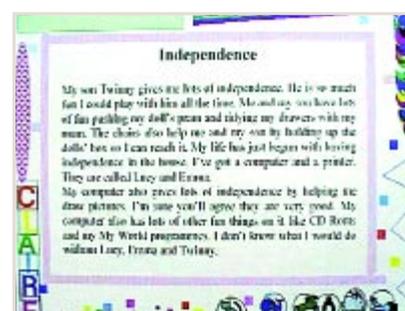
6. Outcomes and reflections on the process

Given adequate training and support, Claire's school soon became enthusiastic users of the software recommended by ACE and she was soon producing work of a similar quality and quantity as other children in her class. At home, the computer became as integral a part of her 'Toy Box' as her dolls and dolls' house.

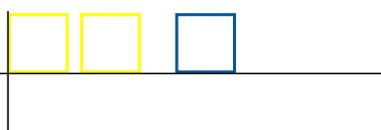
Those supporting her described the impact of an accessible and usable computer on Claire's self-image as "remarkably positive". She now had friends who played musical instruments or who played for school sports teams. Whilst Claire might not have been able to out-perform her peers in these areas, technology, appropriately applied, gave her an opportunity to excel in other areas. As a result, Claire's self-image and self-motivation were helped to flourish.

This positive self-image and attitude to the technology were summed up in the following piece of writing that she independently created and illustrated at the age of seven.

The technology she used was so important to her and played such an integral part in her life, that she gave each AT device a nickname. The title of Claire's writing is "Independence". She begins by describing how she feels about "Twunny", her wheelchair. She is so fond of it that she calls it her "son."



Claire's tale of independence



My son Twunny gives me lots of independence. He is so much fun I could play with him all the time. Me and my son have lots of fun pushing my doll's pram and tidying my drawers with my mum [...]. My life has just begun with having independence in the house. I've got a computer and a printer. They are called Sally and Emma. My computer also gives me lots of independence by helping me draw pictures. I'm sure you'll agree they are very good. My computer also has lots of other fun things on it like CD ROMs and My World programs.

The positive self-image that Claire expresses here and the part that AT plays in enhancing it are crystal clear.

Claire has continued to receive a biennial assessment from the ACE Centre followed by training and support sessions (two per year) provided for the appropriate professionals and her parents. This training and assessment has related specifically to enhancing her computer access to leisure and learning. At school the ACE Centre provides regular, on-line training and support. This entails a computer-to-computer remote link between one member of staff (with teaching and technical expertise) at the ACE Centre and a teacher and/or teaching assistant at the school. The emphasis has been on enskilling Claire's teaching assistants. It is the teaching assistants who work with Claire on a one-to-one basis with the technology that she uses. It is they, too, who have been an essential link in providing the continuity between one school year and the next and, even more critically, between one teacher and the next.

At home there is also access to an on-line remote link, this time between the same member of the ACE Centre staff and one of Claire's parents. In addition, time is set aside to modify and adapt software as required to meet Claire's changing computer requirements.

This close link between those supporting Claire locally and a specialist AT centre has proved to be invaluable to Claire. For example, by the age of seven and a half, Claire was able to use a modified joystick instead of her switches for some graphics-based activities.

Further evidence for the benefits of the extensive and tailored support that Claire has received were provided by the results in her National Curriculum Key Stage 1 tests (these are standardised national tests that all children in England have to take at the age of seven). She achieved level 3 in Literacy, Maths, and Science - that is she was placed in the top 15% nationally for all three core subjects! She was described by her teacher to be not only one of the children in her mainstream class



Video image of Claire using a joystick



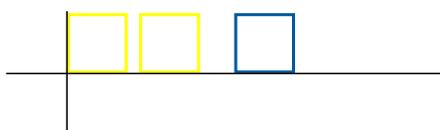


assistive
technology
against
social
exclusion

showing the greatest promise but also one of the children with the highest level of *performance*.

Claire's experience has highlighted the value and importance of AT users and their families determining the service delivery agenda, even when professionals may have some reservations. In this way genuine teamwork between the many stakeholders in the child's life can be promoted. This will be to the benefit of the AT end user and those that support them. In support of this approach it was always important that Claire's own opinions were not only heard but also valued. In this way she had some 'ownership' of the chosen solutions and, consequently, a stronger vested interest in their outcomes.

Claire continues to be a highly motivated and determined learner, who is universally acknowledged to be an excellent example to others. In terms of the benefits of inclusion, the school feels that she is *at least* as great an asset to her peers as they are to her!



1. Personal details

Name: Dirk ☺

Gender: Male

Date of birth: 1966

First assessment contact: 1994

Primary disability: Spastic & athetoid tetraplegic cerebral palsy

Associated Disabilities: moderate dysarthria

2. Background and context

Dirk was born in a little village in Western Germany. Dirk is disabled in all four limbs with a severe athetoid hyperkinesis. Mimic is severely impaired while speech production is moderately impaired. The dysfunctions in his upper half of the body are more intense. With a special input device (MEYRA Multifunktions-Fußbedienung, Code 547) he is able to steer his electrical wheelchair. Concerning many daily living activities like eating, washing or combing hair, he needs personal assistance.

Due to the severity of his motor impairment, Dirk only has voluntary control of his feet, with which he steers his powered wheelchair. He relies completely on it for independent mobility. However, Dirk was already trained by his mother at an early age to become as independent as possible.

Between 1972 - 1980 Dirk attended a special school near his home town. Following that he moved to a special boarding school.

As a young teenager Dirk was fascinated by the possibility of hearing the 'whole world' via short-wave radio and at the age of 12 his father bought him a small short-wave radio set. In 1983, he started working with his first Citizen Band (CB)



Getting CB-license

radio set which he controlled using his feet. Dirk recalls that he was happy at boarding school where he had a lot of friends. Later he said about this time and the use of the CB radio: "I used CB not only to make contacts but also as a kind of therapy for my speech articulation which has improved as a result".

Dirk finished school in 1985 with the qualification of "Fachoberschulreife 10b". Interested in computer technology, he wanted to train as a data processor. Unfortunately, his applications to the appropriate courses and training were turned down. He reports being very frustrated about these rejections.





Dirk's CB radio set

In 1985 Dirk moved to the residential home of a large rehabilitation centre for physically disabled people. There he worked in the 'sheltered' workshop. At first he was employed in the packaging department but he recalls that this was not gratifying work.

At about the same time, and encouraged by a member of staff at the rehabilitation centre, Dirk began to study for a CB licence. He identified a course on this subject that was

accessible and suitable for people using wheelchairs. As a result of his earlier experiences with citizen band radio, Dirk was already familiar with the course content and this gave him the opportunity and confidence to assist other non-disabled participants on the course. Dirk recalls feeling proud about this experience: "I felt it was wonderful that they begged me to help them - I realised that they completely accepted my disability". Dirk passed the exam and received the basic CB licence in the summer of 1986, followed by further training certificates in the following years. This interest reached its pinnacle in 1989 when Dirk made his first contact with a big radio station, allowing him to talk to the 'whole world'.

In 1988 Dirk purchased an adapted computer keyboard primarily for private use on his own computer at home. Beyond his home it was soon recognised, that with AT he was able to manage the office of the sheltered workshop. In 1994 he became a part-time worker in the orthopaedic workshop of the rehabilitation centre, becoming a permanent member of staff there in 1998. Working with a computer became increasingly important to Dirk. Although his desires for further education had been stifled some years before, he succeeded in working as a data processor in the administration of the orthopaedic workshop. In recent years his interests have shifted from the use of CB to access to and use of Internet technologies. To this end Dirk has created his own website.

3. Starting a process: the demand

Dirk's effective control of devices such as his wheelchair with his right foot, motivated him to explore how technology could further his independence. In 1988 he became aware of possible adaptations to computer input devices and contacted a company in his hometown that produced special keyboards. Dirk was able to access a computer using an enlarged standard keyboard. Beyond using a PC for leisure and personal interests access to a PC opened up new opportunities in the work environment. Having demonstrated his competence in PC usage, the assistants at the sheltered workshop restructured many team tasks and activities so that Dirk could do jobs using his PC. Dirk now works as an office worker in the orthopaedic workshop. His job includes typing orders and invoices into a database, updating the stock and fulfilling general administrative activities.



4. The search for a solution

Developments in state of the art technology and changes in Dirk's needs meant that access to and use of computer technology had to be reviewed on several occasions. This section illustrates two key points in this process. As such it describes only part of a life-long process of finding solutions to special and changing demands.

1. Inquiry

Dirk visited FTB's advice centre in December 1994 when he was 28 years old. He came on his own. Dirk wished to access and use Microsoft Windows applications by finding an effective means of controlling the computer pointer, normally done with a mouse. This problem had not surfaced earlier because pointer access was not required for work where the software applications used could all be controlled from the keyboard using keyboard shortcuts.

The assessment required two visits to FTB's advice centre. Naturally, the device had to be controlled by Dirk's foot. In addition, it had to be compatible with IBM AT, MS-DOS and MS Windows 3.x. Initially, the assessment considered the suitability of a number pad (NUM pad), with the Access Pack for Windows. However, Dirk found the pointer control too slow. A variety of *trackerballs* and joysticks were assessed but proved unsatisfactory. The best pointer control was achieved using a speed-adjusted mini-joystick (*SUNCOM Icontroller*). The pointer function switches were, however, too small to be controlled by foot. So the joystick was adapted to use large external switches. Dirk and the assessment team explored the optimum configuration of switches and after some adjustment, guided by Dirk, an appropriate set up was identified.

2. Inquiry

After five years, when Dirk was now 33, he made contact with FTB's advice centre again. The operating system (OS) used by his office PC and the software applications used at work had been changed, and it was no longer possible to use keyboard shortcuts to fulfil pointer functions. It had also been recognised that use of a pointer was likely to be quicker and easier. Unfortunately, it was not possible to replicate the pointer set up developed for his home computer because the devices required were no longer commercially available.

The solution had to be compatible with an IBM-AT and MS-NT operating system. In addition, the assessment had to discover whether the embedded accessibility in the new operating system was sufficient to allow Dirk to control all the required functions. Two earlier problems were re-identified. Firstly Dirk complained that the mouse cursor control with the built-in Microsoft accessibility options (via the number pad) was too slow. Furthermore, the enlarged keyboard used at work had been updated to a new model and did not fully support the NUM pad Access Pack for Windows (for example, drag and drop was not possible) used so successfully at home. Dirk assessed the use of a range of hardware devices at the advice centre, finding that his best pointer control was with the mouse emulator (IB DR. SEVEKE).



A report detailing the recommendations was sent to the financing authority responsible for work place adaptations. In the meantime Dirk was able to borrow the equipment from FTB.



When the joystick (with its mouse emulator) was installed at Dirk's office, it was placed to the left of his keyboard. During assessment this position had been identified as the most suitable. But after working for some hours with this new device Dirk wanted it to be placed at an angle in front of the keyboard. However, when positioned like this in front of the keyboard, the size and shape of the joystick meant that the keyboard became inaccessible.



Dirk's working place in the office

In Dirk's opinion the optimal solution was to place the joystick in a horizontal plane in front of the keyboard. Rotating the device through 90° meant that the pointer movements on the PC monitor did not directly correspond to the movements of the joystick. Dirk found this confusing and tiring. Finally, a solution was found by installing another mouse driver that could co-ordinate the movements of the joystick and the on-screen pointer.





First solution: SUNCOM Icontroller with adapted switches and an enlarged keyboard (FISCHER SCHREISYSTEME Großfeldtastatur)



5. Living with AT

Dirk has always been interested in technology and in how technology can improve his independence.

Since his keen and early interest in communication technologies like CB radio, Dirk has experienced the value and support of AT. His friends recognise him to be an expert in technology, especially in communication technology, and some of them are happy to tap into his knowledge for advice and guidance. It should also be noted that Dirk is well supported in accessing and using technology and finding solutions to new problems. Support in terms of technology and inquiries for new AT solutions is provided by the caregivers at his apartment and his peers at work.

6. Outcomes and reflections on the process

Throughout the process of assessment and review Dirk has expressed strong views and ideas about what he needs and from what he will benefit. This assertiveness is perhaps unusual. Dirk has had a close relationships with technology from a young age and has demonstrated considerable initiative in his use of AT. Nevertheless, he has sought advice and training regarding his personal autonomy in the light of his changing needs and with the development of new technology. Consequently, Dirk has improved his working efficiency, the level of responsibility at work, and the recognition and respect of his peers as an independent person.

Altogether there were 13 contacts for the first assessment involving three people from the advice centre and a caregiver from the residential home. In the context of the second review there were nine contacts involving two people from the advice centre (advisor, information scientist), one caregiver and a welfare worker from the rehabilitation centre.



1. Personal details

Name: Federica ☺

Gender: Female

Date of birth: 1990

First Assessment Contact: February 1997

Primary Disability: Arthrogyposis multiplex congenita

2. Background and context

Almost immediately after her birth Federica was observed to have severe difficulty moving her foot and backbone joints and severe reduction in her muscle tone. At two months a regional Rehabilitation Centre saw her and a diagnosis of Arthrogyposis Multiplex Congenita was made.

The severe nature of her difficulties meant that she received a significant level of early support involving many sessions of rehabilitation (once a day) each week. She attended regular classes at the Rehabilitation Nursery School, which allowed staff of the Rehabilitation Centre and the school to establish close working relations. Since starting at the Rehabilitation Nursery School Federica has also received psychomotor support, and occupational therapy. She has been encouraged and supported to participate in group activities and building peer relationships. She was also helped to reach out for, and experiment with, materials and objects. Following psychomotor and occupational therapy intervention Federica has gained adequate head support and movement such that she is able to use a headstick. In her pre-school years Federica developed speech and verbal communication skills and demonstrated an ability to make her own decisions and follow her own interests.

On entry to primary school, however, she experienced persistent and severe difficulties with physical tasks. For instance she was unable to walk or take and hold objects. She required assistance with many activities of daily life and continued to receive support from rehabilitation services. At present, Federica lives with her parents and an older sister in a ground floor flat. The flat is located on a steep hill. To support Federica's access to the flat her parents initiated the building of a wheelchair ramp. She currently attends first grade junior high school. The school is located at a Rehabilitation Centre.

Here she is able to move freely and independently between classrooms using a powered wheelchair. She attends school six days a week, returning home each day late in the afternoon. Consequently, her leisure time is limited and principally involves watching TV or using her personal computer (PC). On rare trips out of the house she is accompanied by her father, mother or sister. Usually Federica is pushed around in an old pram. She is not involved in any of the social events organised within her local community.

Federica's persistent physical condition means that she still lacks significant movement in her body other than her head and neck. Unsupported sitting is possible for only short periods with severe joint and muscle contractures soon causing stiffness and rigid posture. Despite recent



surgery to correct a severe scoliosis, pelvis obliquity and left lateral flexion are still evident. Federica requires assistance in all activities of daily living (for example, eating, drinking, getting dressed, etc.).

Our previous intervention

While Federica was attending primary school, she received rehabilitation support regularly. This intervention was aimed at improving her:

- cognitive skills
- visual scanning ability
- task execution strategies, involving the development of critical thinking and problem-solving.

To this end, rehabilitation providers usually make use of software and are generally quite successful **but need advice in setting up access to a PC**. The first request for our support concerned exploring options for access to a PC. Use of a PC was seen primarily as a valuable tool to rehabilitation. Supporting access to her school work, promotion of organisational skills, facilitation of Federica's participation in PC based play activities and general promotion of independence were seen as important additional benefits to PC access.



Until 1997 Federica had been using a headstick.

Assessment supported our initial contention that the headstick was the most appropriate method of access to a PC. At that time Federica was familiar with it and skilled in its use. When she was positioned appropriately, taking into account her pattern and range of head movements and visual fields, Federica was able

to type using a standard keyboard. The problem of desktop navigation and pointer control was overcome using a trackball, which was positioned under her chin. Large left and right click buttons, covering the entire left and right side of the trackball, allowed Federica to activate the click function with her chin over a large surface area (see photo 2). Use of the pointer was improved by activating a facility whereby she could drag icons without having to hold the button pressed while dragging (as in standard applications). The chosen mounting system for the trackball and pointer allowed quick and easy alterations to positioning.





Federica used this access equipment during her rehabilitation sessions and at school. This system was used throughout primary school. During this time her PC access was monitored regularly.

3. Starting a process: the demand

In June 2001, Federica underwent corrective surgery to alleviate respiratory difficulties caused by backbone deformity. However, following surgery she complained of pain in her backbone and shoulders when maintaining a sitting position for more than 20 minutes.

Federica was now 11 years old. She had grown taller and gained weight, which posed increasing problems for her parents, for example, when required to lift her into bed. The Rehabilitation Service asked Centro Ausili (La Nostra Famiglia) to explore further options aimed at increasing her independence, including the use of environmental control.

4. The search for a solution

It soon became clear that sitting was a crucial issue. If a comfortable position could not be found, Federica would be required to lie down. Besides pain, annoyance and irritation, which impacted on Federica's willingness to collaborate, Centro Ausili had to consider how lying and sitting would influence the type and positioning of the user interface and control systems used. For instance, it was possible that different devices would have to be used for each position. Because the appropriate solution depended strongly on the decisions concerning Federica's posture it was decided to collaborate with the physiotherapist from the Rehabilitation Centre. This professional was responsible for choosing mobility equipment and could provide a suitable expert opinion.

The wheelchair

This was a chin-controlled electric wheelchair provided by the Local Health Agency in 1997. The wheelchair control was secured to the backrest and could be positioned at various heights. It was considered rather bulky and did not allow the user full, unobstructed vision when moving. Federica's excellent head control allowed her to make use of a joystick. However, the available device was not adequately sensitive to small movements, forcing Federica to make larger and more frequent head movements. This activity tired her quickly and caused cervical pain, further



reducing her movement and motivation.

The wheelchair she was using was not suitable for use outdoors. It was slow and tiring to use, particularly when travelling uphill and Federica often required assistance to push her wheelchair.



Postural system.

Federica was also seated on an old high chair that had been modified and placed on the electric wheelchair. The backrest and the seating had a planar surface, made of foam rubber, with a cover of washable material. The seat/back angle was fixed at approximately 90°.

A suitable solution was required taking into account the following:

- The apparatus for chin-control had to be small and sensitive allowing effective control with minimal range and strength of chin movement in use.
- Support had to be stable and compact but also easy to remove to allow non-expert assistants to change Federica's position easily and reset the chin-controlled device appropriately.
- Federica had to be able to use the same controls for the wheelchair and the PC. A highly effective and flexible device was required, and one that could replicate high-speed PC navigation and would be available to Federica via her chin operated trackerball.
- It was important to ensure that the various types of pressure exerted on loading surfaces, in particular the hip, were distributed as evenly as possible to prevent decubitus ulcer. Federica's comfort could thus be improved and she could maintain the seating posture for longer. Further, it was important to support her trunk in an asymmetrical position that would maximise the benefits of her surgery.
- The performance of powered wheelchairs. Ideally, Federica would require a powered wheelchair that would allow her to drive both indoors and out, particularly up steep slopes and across uneven ground.

The assessment was unable to test the validity of different supportive seating strategies. This was because the introduction of new positioning typically reduced Federica's pain at the time of assessment but this pain re-emerged later. A comparison of supportive seating solutions was extremely difficult because of this. In addition to Federica's own perceptions of discomfort, feedback generated from tactile force sensing technology was based on a sensor matrix. This

system is used to measure forces between opposing surfaces, typically between the hip and a supporting surface. It was discovered that by modifying the seat/back angle of the seating the impact of body weight on the hip could be changed. By tilting the seat/back angle towards Federica's backbone and, at the same time, decreasing trunk muscular fatigue Federica would feel less tired.

It was agreed that a new powered wheelchair, which could be programmed easily, was needed. The assessment tested a "Rabbit" wheelchair with the following features:

- a modular seating system, made of an aluminium cover and soft rubber material, which allowed adjustment in the backrest to match the anatomical shape of the hip and the lumbar tract. Lateral supports for the trunk should be adjustable to suitable height, width and depth.
- a cushion made of soft foam and transpiring fabric providing optimal pelvic support including fluid gel to reduce pressure peaks, distribute pressure and absorb shock.
- a small chin-controlled joystick allowing good vision. The wheelchair would be driven with minimal application of strength and minimal range of movement. It would employ a gradual and progressive analogic command, which could be freely customised to meet the user's needs.
- a *graphical display* allowing the user to view the single cells of an iconic menu.
- a control panel and environmental control which would permit use of almost all analogic and digital commands. In addition, this system would permit the user to turn the wheelchair on and off, access menus and seat/back angle control, and use environmental control - that is use all the appliances (TV, Hi-Fi sets, lights, and doors) normally be controlled by infrared systems.

The assessment team calibrated the positions of the joystick and the graphic display, and trained Federica to use these devices. Happily, Federica was able to access and use the new joystick. However, she expressed concern that she would be unable to use the graphic menu display and control the new options available to her. This apprehension was overcome after her carer demonstrated how to select the functions individually and she was able to explore the functions herself. In particular, Federica enjoyed using this system to adjust her seating herself, which she could not do before. Training in system use was extended for a further week to allow Federica to learn how to use her new equipment for maximum functionality and verify the validity of the proposed solutions. Federica's enthusiasm for the new system confirmed the teams' decision to recommend the new system.

5. Living with AT

Use of Assistive Technology is an essential, long-term, requirement in supporting Federica's interaction with her environment. Federica is able to access a PC with a headstick and a chin-controlled trackerball. She controls an electric wheelchair through a chin-controlled joystick.

Importantly, Federica has been active in assessing the value of new AT. She is unambiguous in her opinions, clearly demonstrating approval, disapproval, agreement and disagreement with AT options. Despite the fatigue that she sometimes experienced in evaluating assistive technology, Federica has shown great surprise and delight at what she is able to achieve with the new



system, and has been keen to explore new software functions and accessibility options.

The months preceding surgery had been particularly frustrating for her. She experienced physical pain and was unable to move along her head-hip axis while sitting in the wheelchair or when lying in bed. Later she was unable to use the PC or wheelchair, compounding her feelings of frustration. Importantly, the AT solutions proposed provided new opportunities and motivation for independent living. Federica showed that she was able to control the equipment provided. Of particular value to Federica was the ability to alter her posture independently. The introduction of customised AT solutions improved her autonomy and subsequently improved her general state of well-being at a particularly difficult time.

6. Outcomes and reflections on the process

AT is playing a crucial and central role in Federica's life. Tailoring AT provision to improve efficiency in computer access is an obvious advantage for her in terms of functional abilities but has also impacted on other areas of her life, for example her sense of initiative, collaboration, curiosity and general physiological well-being as an active participant in her world. Indeed, Federica had a good track record in using AT solutions and her own expectations and those of her parents and the rehabilitation team were high. In this case close, constant and timely collaboration between Centro Ausili and the Rehabilitation Centre afforded time to explore the most effective solutions for her particular needs, and the teams were able to react promptly to difficulties and explore new options. It is recognised that this collaboration resulted as a consequence of the skills and sensitivity of all the professionals working with Federica.

The estimated cost of the new equipment was about Euro 15.000, which was more than double the amount made available by the National Health Service. The economic resources of the family were such that they were unable to provide the additional funds required. Following detailed discussion with staff at the Rehabilitation Centre to which Federica had been referred, it was decided to apply for additional funding.

It was agreed that the recommendation for the new equipment would be issued by the Rehabilitation Centre upon submission of a report, in support of the application, from Centro Ausili detailing Federica's AT requirements. Subsequently, the application for funding made reference legislation that, in particular circumstances, allows the Local Health Agency to authorise purchase of equipment when estimated costs exceed the funding resources available. However, there was no guarantee that the application for additional funding would be successful.



1. Personal details

Name: Juan ☺

Gender: Male

Date of birth: 1986

First Assessment Contact: 1991

Primary Disability: Quadriplegic dystonic-spastic cerebral palsy

Associated Disabilities: Severe dysarthria

2. Background and context

Juan is a boy with quadriplegic (dystonic-spastic) cerebral palsy. Despite receiving speech and language therapy from the age of three he continues to experience profound difficulties in generating intelligible speech. He currently communicates through use of his own portable computer equipped with synthesised voice, which he accesses via a switch that he operates with the left hand. At home his family interpret his speech, (despite its low level of intelligibility) and/or use a process of elimination mediated through yes/no questions to clarify the meaning of his speech. Juan is able to move independently using a powered wheelchair. In 2000 he moved to a house with a layout that allows him to move about more freely. Juan has great difficulty handling objects and requires assistance with self-care activities. Juan's IQ, assessed when he was 4.5, was found to be between 95-113. Juan has attended an Early Intervention Centre for physiotherapy from the age of six months. Juan also went to a mainstream nursery and then a mainstream state primary school. He now attends a mainstream secondary school.

In addition to providing an alternative means of communication and access to the school curriculum, Juan's computer has become an essential leisure activity in its own right, in that he uses it to access Internet services in pursuit of his hobbies. For instance, he, and his best friend and neighbour, browse the Internet exploring sites concerned with cars (his main interest), football and music.

3. Starting a process: the demand

Juan came to the Augmentative Communication Techniques Unit (UTAC) for the first time in 1991, when he was five, having been referred by professionals at the Early Intervention Centre "for advice regarding the advisability of mainstream education and to determine the technical support necessary for access to the curriculum". The physiotherapist, speech and language therapist, psychologist and Juan's parents thought it would be a good idea for him to attend a mainstream school as long as appropriate resources were put in place. These included the backup from specialist professionals and the necessary technical devices to support Juan in realising his learning potential. However, the professionals were concerned that a mainstream school might not have the resources and skills required to include Juan effectively. In the end it was decided that, despite these reservations, Juan should be enrolled in the local authority mainstream school.



UTAC sent them a comprehensive report containing the results of the assessment including the following recommendations. An orthopaedic chair and a table with a U-shaped cut-out were recommended to support Juan's seating and positioning in class. Concerning computer access, Juan was capable of using an on-screen scanning system by operating a switch located vertically on his left side. In this way, Juan coped successfully with many learning activities such as matching pictures and various cognitive games. He also demonstrated a high level of active interest in computer access. Subsequently, UTAC recommended that Juan should use a computer as a central route to curriculum access, and that development of literacy skills was a high priority learning objective. A recommendation was also made to introduce a symbol board to Juan to support his communication and language development. It was envisaged that letters would gradually replace the symbols and the written word as his spelling and reading developed.

It was agreed that a member of the Psycho-pedagogic Consultation Team (EAP) would assume the job of co-ordinating the educational plan and that UTAC would continue to provide advice to professionals in the school as necessary. In addition, the Education Department provided Juan with a full-time teaching assistant.

However, the funding arrangements presented some difficulties. At that time UTAC was a privately run service, subsidised by a 50% grant from the Social Welfare Department of the Catalan Autonomous Government (Generalitat de Catalunya). The school was unable to secure financial resources to afford the remaining 50% of the cost.

Juan was again referred to UTAC in 1996 when he was 10 years old. At that time he was in the fourth year of primary school and reported to be doing very well although highly dependent on his teaching assistant. He had an alphabet board for communicating and a computer with a keyboard and keyguard, provided by the Education Department, which he accessed directly using a headstick. He still did not have a powered wheelchair. The referral was made by the psychologists of EAP to seek advice in improving Juan's access to the school curriculum. Their main concern was that Juan's communication system and computer access system was inefficient. They reported that he tired quickly and had become demotivated. The psychologists of EAP also reported that Juan's reading and writing skills were below those expected of a child of his age and they were concerned that he might begin to fall behind his full learning potential as he progressed through education. However, by this time the outlook for funding recommendations had improved. UTAC services had become independent and the Welfare Department offered grants for the provision of technical devices.

4. The search for a solution

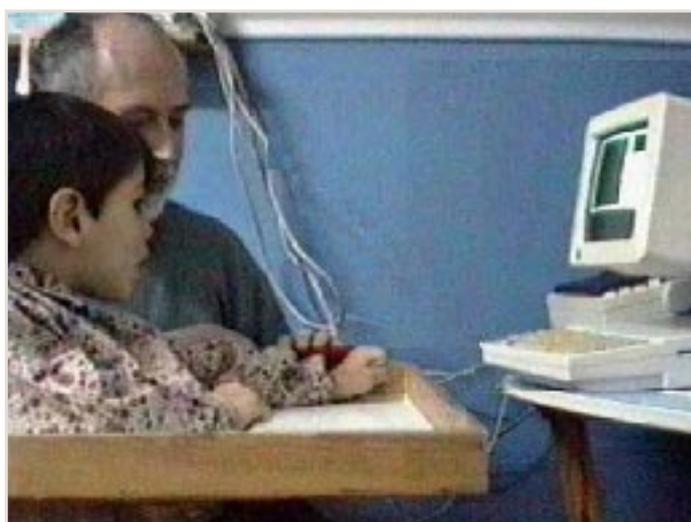
In the course of the assessment, training and follow-up, close collaboration was established between the educational psychologist, an engineer specialising in assistive technology (AT), the teachers, the physiotherapist, the speech and language therapist, the EAP psychologist, the teaching assistant, Juan's parents and Juan. An auxiliary teacher soon replaced the teaching



assistant. She has subsequently supported Juan and the assessment and implementation process throughout Juan's schooling. Indeed the auxiliary teacher became a "key person" in ensuring the continuity of support. Exceptionally, the Education Department supported the auxiliary teacher, who was trained as a primary school teacher, to move with Juan from primary to secondary school. Although she no longer supports Juan on a full-time basis, the EAP psychologist provides guidance once a fortnight, and co-ordinates all the professionals including the link with UTAC.

Three assessment meetings were held in 1996. As a result, a round switch (Big Red switch from Able-Net), the keyboard emulator Switch Access to Windows (SAW), a CD-ROM player, the text-to-speech software (PARLADOR) and a light pointer were recommended. These technologies were subsequently purchased with a grant from the Social Welfare Department. In the following year, 1997, UTAC conducted three staff training sessions targeting educational strategies in the support of children using assistive technologies. For example, a 15-hour training course was staged for the local professionals in the use of SAW. In addition, a home visit was carried out to adapt the home computer in line with the recommendations.

In 1998, six follow-up sessions were held in the school, and an application was made for a powered wheelchair and an electronic communication device. The grants for electronic communication equipment incorporate dedicated communication systems and portable computers using communication software. Although UTAC had recommended a portable computer, the parents, on the advice of an orthopaedic appliance shop, acquired a Canon Communicator, (a small text based device that produces speech and paper based written output). Unfortunately, this device proved inadequate for Juan's communication needs.



First assessment – Juan is operating a switch located vertically on his left side.

In the following year a successful application was made for a new computer for use at home. Three further sessions aimed at monitoring Juan's progress were carried out, two at his school, and one at home. By January 2000, Juan had a powered wheelchair and had obtained a portable computer from the Education Department. The computer was adapted for use as a communicator with synthesised voice output.

Subsequently, seven follow-up sessions were held at school and two at home. The physiotherapist from UTAC also made a visit to the school, together with Juan's physiotherapist and the auxiliary teacher, to improve his postural control.

The areas addressed during the course of the assessment and intervention process included the following:

Seating, positioning and mobility

An appropriate chair and table with an U-shaped cut-out provided appropriate early postural control. Juan was able to control his powered wheel chair using a standard joystick. Initially, he was able to use his wheelchair without additional support. However, after complaining of backache a joint visit was made by UTAC and Juan's physiotherapists, who made modifications to the backrest and the position of the portable computer mounted on the wheelchair tray.

The computer and other curriculum access resources

Juan's computer access to standard applications improved with the use of an on-screen keyboard scanning system and mouse emulator provided by SAW rather than the head stick he had been using. Assessment after the second referral confirmed that switch access was achieved best through a sideways movement of his left arm when supported on the wheelchair table.



On-going monitoring of computer and curriculum access proved valuable in adapting SAW to the changing demands of the curriculum and in incorporating Juan's own ideas and those of the professionals that supported him. In addition, repeated

monitoring and training was seen to empower local staff in adapting SAW and exploring new educational strategies for including Juan in school activities. Juan is now able to access and use Microsoft Word for word-processing and its Equation Editor. He can also access a range of other software including the Windows calculator, a spreadsheet application, drawing programs, multimedia applications on CD-ROM, the Internet and a number of recreational games. Using a scanner and their imagination, Juan's teachers adapt all the paper-based exercises and tests for his computer. A light pointer is used to point to materials such as objects, maps or books.

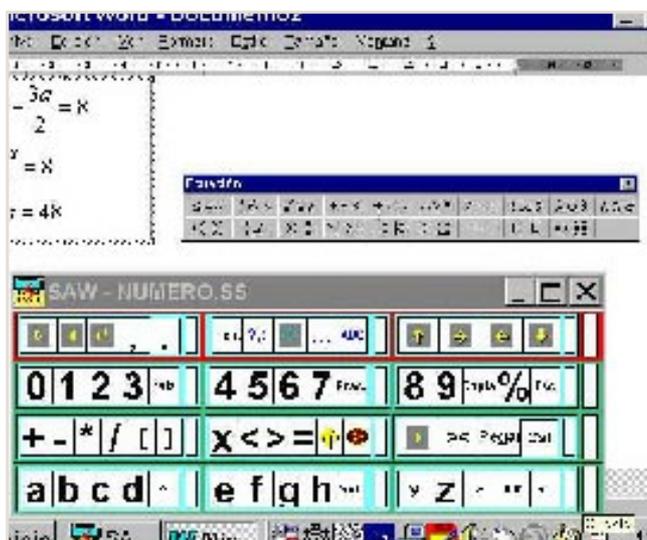


Communication

Social communication has been rather difficult for Juan. Initially, recommendations explored the use of a communication chart with large pictographic signs accessed by hand-pointing. However, this proved unsuccessful. Later the pictograms were replaced by letters and access supported via a headstick. Once again, this task proved too tiring for Juan and he made little use of it. However, these problems were not overcome by the purchase of the Canon Communicator. The scanning facility on this particular device was not suited to his needs and Juan subsequently discarded this device too.

Use of the portable computer, equipped with a voice synthesiser ("El Parlador", designed by UTAC), provided more suitable and flexible options for communication support.

Using a system based exclusively on spelling with a switch proved too slow. This difficulty was overcome by using SAW to customise on-screen arrays of words and stock phrases - a combination of SAW word lists with Parlador's word prediction. Interestingly, one of the first things Juan used his new synthesised voice to



say was "*¡Que te calles, Carmele!*" ("*Shut up, Carmele!*"), a catch phrase from a television show that his classmates kept repeating! In addition, access to and use of email became another major stepping stone in developing Juan's social communication. He has a long list of addresses that he uses frequently.

5. Living with Assistive Technology (AT)

Juan finds having a powered wheelchair "*quite good, because it's given me freedom and mobility*". He manages to do school work with the computer for "*they write the texts and the questions, then I read the texts and answer the questions*". About his classmates he says: "*I have a very good relationship with them and we hit it off quite well together*". He gets on at home "*very well because if I get bored I start doing my homework or playing with the console*." Tellingly, Juan requests that technical devices be "*quicker*" and government funding agencies "*to give more money*".



6. Outcomes and reflections on the process

Despite early reservations about the introduction of AT, it is apparent that the devotion of time, effort and imagination from all the professionals concerned, Juan's parents and Juan himself has positively influenced the process and outcomes of this particular stage of intervention. It is also recognised that the initial reservations articulated by a number of professionals, and the fear expressed by Juan's parents, are fully justified. Inclusion in mainstream schooling for people with disabilities is an unquestionable right, but should be recognised as a multifaceted and complicated process. Nevertheless, it would appear that inclusion is beneficial when adequately supported. Juan's auxiliary teacher and the EAP psychologist have played a crucial role in ensuring collaboration among the professionals and maintaining continuity of intervention over time.

The EAP psychologist says: *"Juan has managed to make some of his dreams come true regarding his possibilities for autonomy and spontaneity. He is now able to access school work, exercises and tests autonomously. In this way he is capable of expressing his interests and goals more clearly, which allows greater personal development and growth of his self-esteem, which enhances his prospects for a better future as an adult. As a result of the AT, Juan has undergone a change in his relationship with his class. Previously, they often adopted a protective attitude towards him; now he takes part just like the rest, making his contribution, which enriches the group, for example, with data taken from computerised encyclopaedias, games, etc."* (1999, Aguilar, A. and Saumell, C. "Comunicación y Pedagogía") And the teacher describes a particular instance: *"Before we went on the trip to Soria, he made an incredible dossier for us. He found addresses via Yahoo and Olé and other search engines, compiled historical and tourist material, captured photos, printed it all out and gave it to the whole class"* (1999, Silvia Pineda, "Diari de Sabadell").

The UTAC engineer adds: *"Attention should also be drawn to the extent to which the precision of the movement he uses to operate the switch has developed with practice. It has gone from being gross and forced to being brief and controlled, which allows him to press the switch more often within the same time interval and therefore to be more efficient in using the computer. Juan has gone from having a scan time (the time each item capable of being selected is highlighted) of 2 seconds to one of 0.8 seconds and a time of 0.5 seconds is being tried out satisfactorily"*.

These same professionals consider that he uses the Parlador program for communicating very effectively and regard the fully independent mobility he enjoys with the powered wheelchair as extremely positive. They conclude that the assessment, provision and training in AT has required a great deal of time, effort and commitment by professionals and Juan. It is true that Juan's schooling has entailed a big investment in money and human resources. People with disability unconditionally deserve this effort made by society on their behalf. In Juan's case, however, those of us who know and love him are convinced that he will become an adult ready to enter the world of work and that he will return with interest what society has invested in him. We are proud in anticipating that hope he will achieve this!



1. Personal details

Name: Paul ☺

Gender: Male

Date of birth: 1952

First Assessment Contact: 1994 aged 42

Primary Disability: Expressive dysphasia (damaged language processing)

Associated Disabilities: hemiplegia, dyspraxia, and receptive dysphasia

2. Background and context

Paul was born in 1952. He is married with one daughter who has recently left university. Paul had a successful career in electronic engineering as a logistics systems analyst. He worked on computer memory at a major university in the 1970s and, subsequently, in other demanding and responsible jobs that involved teamwork and leadership. Paul was the primary wage earner in the family, working full-time, while his wife only worked part-time. He had a responsibility at home for doing many of the practical jobs around the house, and described himself as an energetic and gregarious person, enjoying a busy social life with his family and friends.

In January 1992, when Paul was forty, he was diagnosed with an aneurysm (the ballooning of an artery) and underwent remedial surgery. Tragically, as a direct consequence of this operation, Paul had a brain haemorrhage. The bleeding caused a right-sided hemiplegia, right hemianopia, epilepsy and severe communication difficulties including expressive dysphasia and articulatory dyspraxia.

After early rehabilitation Paul was left with a hemiparesis on his right hand side. However, he made progress in recovering the use of his right hand and some of his other gross motor skills. For example, he was able to carry out various day-to-day, physical tasks around the house such as gardening and light repair jobs. He also enjoyed attending woodwork classes as part of his rehabilitation and made an ornamental wheelbarrow for the family garden. However, he was unable to drive a car. Following the operation the couple sued the Health Authority and after many years of litigation received negligence compensation.

The quality of his life, and that of his family, changed dramatically after the trauma of Paul's failed operation. In the words of his wife, "It ruined our lives". Paul and his wife reported that friends who found it too difficult to communicate with Paul simply abandoned them. This loss of contact even extended to some family members who were described as feeling "awkward" about Paul. In the weeks and months following their trauma Paul and his wife described feeling isolated and lonely, rarely venturing out for social or recreational purposes. Paul's wife also felt that the radical change in family roles and identities following Paul's brain haemorrhage were particularly difficult to deal with. For example, she described personal difficulties in becoming the sole wage earner in the family.



Understanding Spoken Language

Following his traumatic brain injury Paul experienced receptive dysphasia. His understanding of spoken language was described as 'patchy'. For example, he had more difficulty understanding other people when he was tired or tense than when he was relaxed. Paul's understanding was also aided by clear contextual cues (for example, already knowing about the topic of an on-going conversation). He also lost many everyday survival skills that he had to re-learn, skills such as telling the time and dealing with simple money matters.

Understanding Written Language

Despite intensive practice, including the augmentative use of Voice Output Communication Aids (VOCAs) and other computer-based tools, Paul's ability to understand written instructions remained very impaired. He could only read small chunks of text and often needed some phonological support to read a word or phrase.

Speech

Paul also experienced severe articulatory dyspraxia that required him to concentrate hard on producing every element (letter sound or syllable) of a spoken word. This made speaking a frustrating and laboured task and his speech was described as hesitant, almost dysarthric. Paul was supported in producing speech by cued articulation. Cued articulation is the use of hand shapes associated with specific sounds to prompt their production.

Expressive language

Paul's traumatic brain injury left him with severe expressive dysphasia. This manifested itself particularly in the form of profound, word-finding difficulties. He was able to generate a limited range of single words and occasional two-word combinations. These he reinforced with animated facial expressions and head movements.

Reading

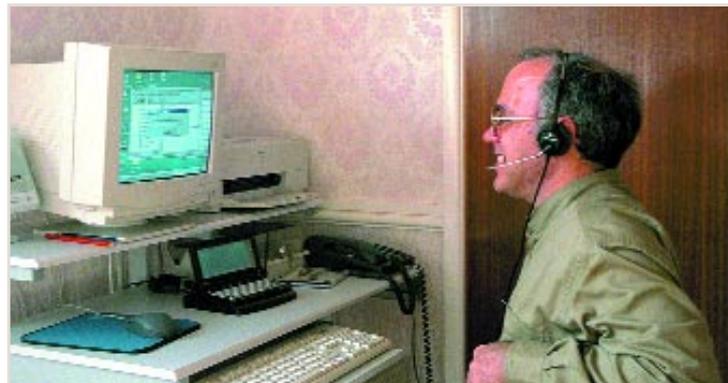
Paul's reading remained very slow and difficult and was best described as "telegrammatic", in that it was very disjointed, lacking both fluency and consistency of form. However, he was well motivated to read and the ability to read some text became an important component within the rehabilitation of his "total" communication system. Reading from wordlists or notes cued him into conversations and helped him maintain a conversation when it broke down. It also provided him with strategies for overcoming some of his profound word-finding problems.

Multimodal communication

Paul retained some important skills outside the specific domain of spoken or written language. Primarily, these fell within a visual, non-verbal domain in that he had good visual memory and an excellent understanding of pictures. These enabled him to solve many problems and to understand and make good semantic connections.



Despite a marked tremor Paul could control a pencil using his left hand. He was able to write individual letters, single words, and produce simple communicative drawings and narrative sketches. His narrative sketches took the form of a short sequence of elementary diagrams or drawings that told a story or described an event. The resultant combination of words and drawings were sufficiently legible for a conversation partner to read and interpret Paul's messages. When "writing to communicate" in face-to-face conversation, Paul restricted himself to names and nouns, rather than attempting to write syntactically.

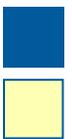


Paul using voice recognition to access his computer

Multimodal communication came naturally to Paul and he used it in various combinations to "get his message across" to the listener. In communicating with both familiar and unfamiliar conversation partners he used:

- Facial expression
- Gesturing and pointing
- Mime
- Some speech and vocalisation
- A little text
- Drawings (left-handed because of his hemiplegia)
- Narrative sketches
- Sounds
- Spelling out (either with a pencil and paper, or failing that using his index finger to 'write' invisible words and numbers on a convenient surface)
- Singing
- A communication device such as the Lightwriter or Portable Communication Aid for Dysphasics (PCAD)

Of these Paul was particularly imaginative when using drawing and narrative sketches to augment his communication. Drawings became a potent and natural means of communication for him. His communicative drawing also enabled other people to realise that much of his memory, experience, and knowledge, remained intact, even though he was unable to express himself verbally.



3. Starting a process: the demand

Following his return home, a local speech and language therapist, who identified several aspects of his communication requiring treatment, saw Paul. Initially Paul, his wife and his speech therapist agreed that the emphasis within his therapy should be on improving his spoken language and articulation. As a result, Paul received weekly individual speech and language therapy sessions that focussed on learning and practising speech articulation. This therapy involved the repetitive practice of speaking letters words, phrases, and numbers. It also included some reading practice. In addition to time with the speech and language therapist, Paul spent many hours replicating this form of therapy at home with the help of his wife. However, he soon reported that these therapy sessions exhausted him. He found that this constant "practice" was counter-productive to improving the quality of his speech and instead increased his fatigue. All in all this form of speech therapy did little to recover Paul's expressive language difficulties. Despite this lack of success, he persevered with his individual therapy sessions for four years and also attended a weekly communication group with five elderly dysphasic patients.

Augmentative and Alternative Communication (AAC) aids and strategies were never offered by Paul's local speech therapy services. Only as a result of a chance meeting at an exhibition with staff from the ACE Centre was this alternative avenue considered and an AAC assessment arranged. As a result of this first assessment in 1994 Paul borrowed a text-to-speech communication aid (a *Lightwriter*). Unfortunately, the speech therapist that organised the local communication group meetings actively discouraged him from using his *Lightwriter* at these meetings.

She argued that the emphasis of the group was to be on "real speech" and that the *Lightwriter's* synthesised voice was both intrusive and disruptive for the group. She remained uncooperative in support of the *Lightwriter* despite Paul's obvious progress.

Despite this hostility, Paul persisted in using his *Lightwriter* and working on the rehabilitation of his literacy skills. Twice a week he attended a local College of Further Education where he studied for, and passed, Level 1 computing exams - including the accomplished use of graphics, databases and spreadsheets. Once a week a support worker visited Paul at home for an hour to work on the specific development of his reading skills. Paul reported that he found this valuable support and his wife commented on how his reading improved during this period.

By early 1996 Paul had stopped attending the speech and language therapy communication group. Thereafter the only input to his communication rehabilitation came directly from the ACE Centre (this despite a distance of 200 kilometres!), with whom he remained in close contact until 2000.

4. The search for a solution

Staff at the ACE Centre recognised a need to support Paul in improving his self-confidence, and were keen to explore ways of enhancing Paul's existing strategies for communicating by introducing him to specific "high tech" communication aids. Paul's life-long interest in computers



and technology fuelled his motivation to explore suitable AAC options. In turn, positive experiences in the use of AAC contributed to improvement in his self-esteem. Between 1994 and 1997 Paul used a number of different communication devices, mainly for therapeutic and self-cueing purposes. By speaking a word or phrase first with a communication aid, he was then able to articulate the same word or phrase without it. He had his own *Lightwriter* and then borrowed a *Dynavox* with which he supported his literacy rehabilitation.

In 1997 Paul was asked by the ACE Centre to join the design and usability team within a European Telematics project. The project (Portable Communication Aid for Dysphasic - later renamed *TouchSpeak*) aimed to design and produce the first "bespoke" communication aid (*TouchSpeak*) for dysphasic users of AAC. It was a unique opportunity for the project consortium to involve Paul from the outset and to benefit from his insights and experience as a dysphasic AAC user with considerable experience of information technology.

To overcome the geographical barriers to Paul's involvement in the project, the ACE Centre were able to communicate with Paul via remote, computer-to-computer linkups and phone calls rather than by making frequent visits to his home. This innovative application of mainstream remote technologies proved to be very effective.

5. Living with Assistive Technology (AT)

Paul's individual profile of needs and abilities ensured that communicative drawing was integrated within the *TouchSpeak's* communication system and functioned in a way that was both useful and efficient for him. He helped to design a sketching tool that was both simple and flexible to use for communicative drawing. Indeed, the drawing tool became the most innovative aspect of the *TouchSpeak's* communication system and remains a unique feature in the field of AAC devices. In evaluating *TouchSpeak* Paul became skilled in its use and application. An example of this skill is illustrated below. On this occasion Paul drew a simple map of Europe and North America on his *TouchSpeak* and placed a dot in the Caribbean. In the context of a conversation about holidays, it soon became clear that he had spent a holiday in the Dominican Republic!

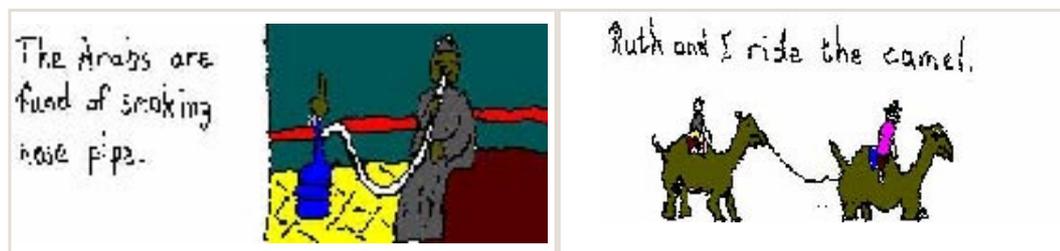


Dominican Republic

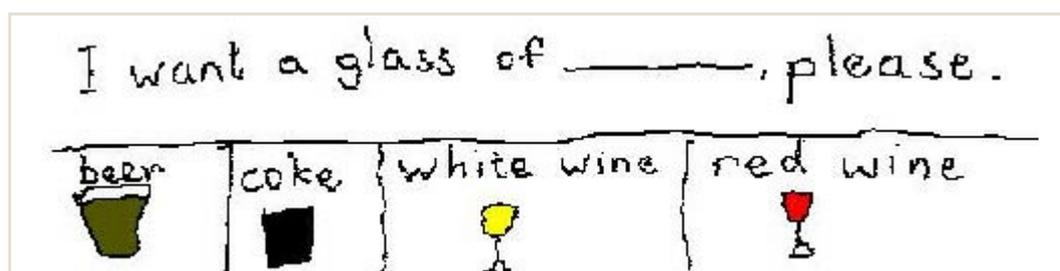


On another memorable occasion, Paul first used his hand-held *TouchSpeak* to order food and drinks for some friends in a bar. Then he returned to the table, switched the *TouchSpeak* into Sketch Mode, drew a map of Egypt and the Nile Valley, and typed in "L" for Luxor. Finally, he drew a detailed head of Tutankhamun to indicate that he had been to the Valley of the Kings, recalling the pleasures of a recent holiday in Egypt with his wife and daughter.

The Sketch tool and its related picture gallery were also used by Paul to develop a log of experiences and events (in effect a narrative) that he later used in conversation. There were many examples of this, often relating to his frequent and rather exotic holidays abroad. For example, the series of screendumps below refer to a holiday in Morocco. Here Paul combined drawing and annotation, something he often liked to do. The drawing always came first, and this in turn triggered some verbal recall, which was then followed by copying a written phrase or sentence. This sentence was pre-constructed either with the help of his wife or from words and phrases within his thematically structured communication aid. The annotation of his communicative drawing also provided him with a good strategy for improving the quality of interaction with his conversation partners.



Paul also used the communicative drawing tool in *TouchSpeak* to produce illustrated shopping lists that he used together with text-to-speech messages. These he created before setting off independently to the shops to make his various purchases.



Apart from shopping for clothes or groceries, he constructed a number of other scenario-based message hierarchies:

- To deposit and retrieve money from his bank
- To order food and drink in restaurants and bars
- To deliver a short speech about himself and the TouchSpeak project to Princess Anne, a member of the British Royal family, when she came to open the new ACE Centre in April 1999.



The index page of Paul's food & drink messages within TouchSpeak

6. Outcomes and reflections on the process

Paul's experience of local and regional AT service provision was rarely positive. Time and time again service providers failed to recognise his needs and his remarkable abilities, focusing instead on his disabilities. An insensitive and often inappropriate rehabilitation programme was offered that inevitably broke down with time. So often local services lack the knowledge and skills in the introduction and support of AAC options. However, it is unusual for service providers to display such extreme resistance and negative attitudes towards the exploration of AAC options for people with dysphasic communication difficulties. Despite this resistance, Paul demonstrated the value he placed on AAC as a communication tool.

Interestingly, a shift was also observed in his use of AAC systems. Initially, Paul chose to use his communication aids (the *Dynavox* & the *Lightwriter*) primarily for *augmenting* his other residual channels of communication (facial expression and mime, for example). Later, during the *TouchSpeak* project he began using AAC, as an *alternative* channel of communication - that is, as a social communication device per se, and thereby reducing unwanted pressure to use his voice to communicate.

TouchSpeak was particularly useful for communicative drawing and for preparing tailored vocabulary for specific communication situations and environments such as shopping or going on holiday. Finally, Paul also showed just how crucial the end user is at every stage of AT product evolution - user requirements, functional specification, implementation, and evaluation.

1. Personal details

Name: Rita ☺

Gender: Female

Date of birth: 1987

First Assessment Contact: 2000

Primary Disability: Blindness

Associated Disabilities: Learning disabilities; reduced tactile sensitivity

2. Background and context

Rita lives with her parents and her older sister in the suburb of a large city. Her parents describe her as a shy but attentive girl. From birth Rita has had the presence of an increased amount of cerebral spinal fluid around her brain. This has been managed by a small shunt draining the excess liquid. Rita also has some learning difficulties. A learning support teacher has supported her in a mainstream primary school, where she has developed skills in literacy and maths.

In 1999, at the age of 12, Rita started junior high school. Midway through the first school year, she experienced the sudden and severe onset of strong headaches, reduced vision, increased physical difficulties and decreased tactile sensitivity. Despite admission to hospital the trauma caused a significant reduction in physical and cognitive abilities. Rita became blind and experienced a decline in her physical abilities in all four limbs. This resulted in her having to use a wheelchair, the lowering of tactile sensitivity and a decline in her learning abilities.

On leaving hospital Rita was referred to a Rehabilitation Centre. She received a complete assessment of her physical and cognitive abilities, and a rehabilitation treatment plan was developed with the aim of gradually re-introducing Rita to school. The Rehabilitation Service provided support through on-going meetings, assessments, treatment and liaison with her teachers. Rita made some progress with physical, intellectual and tactile skills but her vision did not improve.

Subsequently, her support teacher contacted the Service for the Education of Blind Students for advice and guidance concerning the use of appropriate resources and strategies to continue her rehabilitation. In the meantime, Rita's family decided to look for a teacher who could teach her Braille in the afternoons.

3. Starting a process: the demand

Rita insisted in participating in all activities alongside her peers. She was able to do so orally but she was unable to read or write effectively. Although Rita had developed some early skills in writing with Braille, owing to her reduced tactile sensitivity and physical disabilities she experienced significant difficulties reading Braille, that is, reading her own work.

Soon after starting in the second grade (2000/2001 school year), her family and staff of the



Rehabilitation Centre agreed to refer Rita to Centro Ausili (La Nostra Famiglia) for advice concerning the provision of Assistive Technology in support of Rita's desire to read and write.

Local professionals and Rita's family were keen to pursue Rita's development of Braille but it was uncertain when she might develop such competence. Consequently, they wanted to explore solutions that would allow Rita to record her work independently in the short-term, while she developed skills in Braille in the long-term. In particular, they were keen to support Rita in doing homework where the learning support teacher could not support her. The Service for the Education of Blind Students was not directly involved with this referral but continued to meet with Rita's teachers and parents.

4. The search for a solution

In the first instance Centro Ausili gathered relevant clinical information from the most recent assessment at the Rehabilitation Service and school. The first meeting established that any recording system needed to match her recording needs. That is, given her learning difficulties and age, it was agreed that there was little desire for Rita to record long and complex written text.

In addition to single elements of information such as names, acronyms and Braille symbols, Rita demonstrated an ability to memorise and understand the main elements of a spoken language such as a story or description of a process.

The Need For Non-Standard Solutions

Standard methods for access to writing for blind people include use of Braille display or a standard keyboard (requiring ten fingered typing) with a screen reader and speech output. Unfortunately, Rita's reduced tactile sensation difficulties did not allow for the use of standard applications. Nor was voice recognition software for writing and computer control a suitable solution because training to use them would have required the reading of long texts. Also, Rita would have had no feedback on the accuracy of input, or on the quality of recognition of dictated words. Lastly, she had never used a PC before and did not really know how it worked.



Rita Tests The Validity Of Proposed Solutions

After many trials conducted at Centro Ausili, an unusual but nevertheless suitable solution was identified.



An adapted programmable membrane keyboard was used to produce a customised keyboard. A membrane keyboard consists of a flat surface subdivided into pressure activated cells. The active cell size can be customised by merging and dividing cell units, and cells can be programmed to function in a variety of ways. Different cell configurations can be saved and retrieved as required. In preparation of such keyboard the most taxing task was the generation of an overlay sheet demarcating the cell boundaries and contents.

Using familiar functions/letters/words in pre-set positions proved very useful for Rita. However, the issue remained how to adapt the overlays for Rita who was blind. A solution was identified in the use of a keyguard. A keyguard was made from a plate of *Plexiglas* and positioned over the overlay. Holes are made in the guard corresponding to cell positions. Raised reference markers were added to the keyguard to allow easy and fast identification of keys. This solution allowed Rita to identify by touch the position of letters, numbers, etc. easily from the grid of holes and reference marker.

Keyboard overlay. In order to assist Rita to grasp the concepts behind the keyboard overlays, a number were tested to identify the most intuitive for her. The keyboard overlay was designed using letters in alphabetical order, number keys and some basic type commands. Rita also used some function keys ("macros"), allowing her to perform complex operations (these normally require a series of commands) with a single button press. For the convenience of support staff a description of their function was included on each of the keys, (for example, "print", "close program", "close file", "read word"...).



Auditory feedback and "reading". To support Rita in monitoring her written work a flexible text-to-speech software application (*Intellitalk*) was used. This allowed Rita to read the text, letters, numbers etc. she produced.

Purchasing AT

Centro Ausili produced a detailed report documenting the assessment process and recommendations for equipment and software. These included:

- A standard multimedia PC
- An alternative keyboard with a keyguard
- Text-to-speech synthesis software

It was agreed that Centro Ausili would set up the keyboard and operating system and train Rita to use the PC. Afterwards local Social Services would take over responsibility for Rita's support.

The application for funding required authorisation from an ophthalmologist. Rita's parents had the job of collating estimates for the recommended equipment and presenting these to the ophthalmologist. After a few months Rita's parents were unable to identify suppliers of such specialist equipment. Consequently, the ophthalmologist had not authorised the funding application. Centro Ausili were able to gather suitable estimates and offered to meet with the ophthalmologist to discuss the recommendations. On receiving the appropriate documentation, including estimates, the ophthalmologist reported to the family that he did not understand the need for the recommendations for a blind child and would not authorise the application. Unfortunately, the ophthalmologist also declined to contact Centro Ausili. As a result, Centro Ausili agreed with the family that it should approach the ophthalmologist directly. Soon after the meeting the application was completed. Almost the entire funding was provided by the National Health System. By this time Rita had completed her second grade in junior high school.

5. Living with Assistive Technology (AT)

Customising AT and training in its use

Rita visited Centro Ausili for initial system set-up and training. Several hours were required to achieve this. During training Rita demonstrated that she remembered much of what she had learnt during the assessment some months earlier. Following training for both Rita and her parents the family returned home to practise using the system.

In the meantime Centro Ausili contacted the Service for the Education of Blind Students. They had continued following Rita both at home and at school. They were informed of the centre's plans. They were not familiar with the solution and had themselves planned to introduce Rita to a training course for the blind. Here she would learn how to use a standard keyboard as they contended that Rita had shown all the necessary pre-requisites for learning how to use a standard keyboard with speech synthesis software. A meeting of all the professionals working with Rita was convened to discuss a joint action plan.

In the following months, Rita held regular meetings with Centro Ausili to assess her improvement



in use of the PC and to continue her training. She became more confident and faster in the use of a PC. For example, on her own initiative, she wrote simple letters to her friends. However, it was noted that her family had not been able to provide support to Rita to allow her to practise regularly and frequently with her customised keyboard and that training in the use of a standard keyboard had progressed instead. Rita reported that she had had difficulty in mastering the standard keyboard. It was revealed that the Service for the Education of Blind Students recommended the support teacher help Rita practise with the standard keyboard at school, while at home she used her alternative keyboard. This was confusing for her!

Centro Ausili suggested a further meeting of the various professionals, an idea that Rita's family supported. Staff of Centro Ausili and others, including her support teacher, a typhologist and the physician from the Rehabilitation Centre, participated in the meeting. The meeting included a demonstration of the assistive technology that Rita was using at home and the viewing of a video clip in which Rita was seen practising her new skills. Rita's support teacher stated that the standard keyboard was not suitable for Rita, while she was satisfied with the solution proposed by Centro Ausili for homework as it was producing good results and kept her motivation high. The school thus decided to introduce the alternative keyboard during classes.

They purchased a PC with text-to-speech software and the alternative keyboard was transferred with Rita from home to school.

6. Outcomes and reflections on the process

When working with Rita, it was necessary to establish the aim of the AT and the context in which it was going to be used. Once this starting point was identified the teams involved had to remain flexible in order to adapt to new problems and issues. That said, flexibility requires detailed investigation and assessment of the efficacy of selected AT as well as a frank exchange of ideas and experiences between all the professionals, the family and the user. It became apparent that Rita's school was eager to collaborate in the process, to attempt to overcome their organisational difficulties and pave the way to a wider application of PC in school. For instance, the school IT coordinator contacted Centro Ausili to enquire about appropriate specifications to ensure compatibility between a particular PC and the alternative keyboard. Indeed, it is hoped that Rita's school will be able to purchase a similar keyboard soon. However, despite legislation documenting that schools are responsible for providing appropriate equipment for children with disabilities concerns have been raised about excessive bureaucracy and the availability of necessary funds.

Rita is now in her third year of junior high school. Next year she will start high school, and her environment will change completely: new building, new peers, new teachers and so on. Centro Ausili will need to review what progress has been made so far in collaboration with the school staff. However, centres such as Centro Ausili have no nationally or regionally recognised role in the provision and support of AT. The danger, therefore, exists that Rita will fail to maintain her level of progress in her new school. It is thus hoped that the Service for the Education of Blind Students will become involved in, and carry out, this intervention.



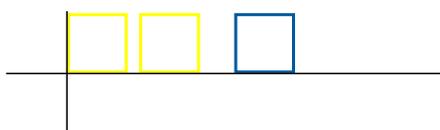


assistive
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In this case, establishing what the appropriate AT was for Rita only required relatively little time, but considerable time was taken in delivery of equipment and, above all, establishing a form of collaboration with the other service agencies involved with Rita.

Furthermore, a key period in the process was the time it took for the equipment to be delivered. In order to kick-start the use of AT Centro Ausili had to install and set-up the software, customise the keyboard and train the family and Rita in its use. The whole process involved four members of staff from Centro Ausili (social assistant, psycho-educationalist, and two occupational therapists) and took 40 hours, half of which were spent with Rita.

section 5





section

6

Cornerstones
for successful
AT policies



This chapter is concerned with key issues in AT Service Delivery and is informed by the shared experiences of the AT Centres in introducing AT into the lives of people with disabilities. The themes of this chapter are relevant to the experiences of professionals and service users across Europe.

Service delivery in AT - finding the right balance

THE DEMAND FOR AT in support of improved autonomy for people with disabilities is rising rapidly and those already using AT continue to present life-long changing needs. Developments in "state of the art technology" continue to accelerate, introducing powerful new solutions that were unthinkable only a decade ago. The potential exists for more people with disabilities to benefit from AT. Meeting this potential means investing in human resources, developing new skills among professionals, and identifying appropriate approaches that incorporate the best technical solutions in response to the emerging needs and demands. Professionals working in the field of AT in Europe are continuously asked to challenge their own practices and assumptions. Policy-makers throughout Europe need to find effective solutions to support the evolution of AT Service Delivery Systems (SDS).

Key principles in the development of SDS are the maximisation of *effectiveness* and *efficiency*. Effective services provide the best possible solutions to the largest number of people. Efficient services do so by using the available resources well without wasting money and time. It is, in part, the responsibility of policy-makers in Health, Social Services, Education and Employment to find the best possible balance between desired services and available resources.

Recognising people's rights

It is a fundamental right of all European citizens to live with dignity, to have opportunities for individual growth, and to take part in social, cultural and political life. AT is concerned with promoting these rights by facilitating the active participation of people with disabilities in all areas of life, whether it is school, work, leisure time or social life. AT can help people exercise their civil rights through freedom of speech, political participation and self development. That is, minimising discrimination and social exclusion. (Dirk) 😊

Recognising the complexity of each case

The provision of an AT solution is not in itself the whole solution. Rather it may be considered as a means to an end. In other words, it is a mistaken supposition that a *disabled person with an AT solution* equates to a *non-disabled person*. Such an assumption is a dangerous oversimplification of a complex reality and one that may lead to frustration for the disabled person and their carers. Effective and efficient AT interventions typically are long-term and multi-professional processes that must take into account factors central to the individual and their environment.



Information dissemination and awareness raising

AT SERVICE DELIVERY is a relatively new phenomenon, especially where AT is based on the application of electronics and microtechnology. Accurate information about the opportunities and limitations of AT is not widespread across Europe, either among public service professionals or among people with disability, who often remain isolated from events in AT development. Where reliable and independent information does exist, it is confined typically to too few specialist AT centres or European databases and websites.

New opportunities and developments in AT are of interest not only to specialist professionals working in the field. Users of AT, policy makers and a wider audience should have access to accurate, digestible and up-to-date information from researchers and professional service providers. Information dissemination and awareness-raising are essential in encouraging wider acceptance of inclusive policies and good practice.

European policy-makers can have an important role in promoting pragmatic and *inclusive* mechanisms for accurate and effective AT information dissemination.

The media

The media play an important role in creating stereotyped representations of AT. Often the attention of the media focuses on the miraculous healing potential of technology and not on the particular circumstances and complexity of each case.

The audience

This simplistic media representation can lead to unrealistic expectations for AT among disabled people and their families – expectations that are, all too often, disappointed. In the absence of independent and competent AT centres that are able to guide individuals, families and local professionals towards appropriate solutions, the risks of purchasing inappropriate and often expensive equipment are very high. Badly chosen solutions are quickly abandoned and can engender frustration, anger and dejection.

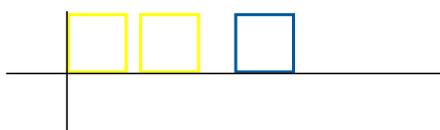




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The professionals

Typically, European professionals in health, education, rehabilitation, social services, and employment do not have the necessary training and experience to provide qualified opinions in the field of AT. Of course, professionals working with clients with a variety of complex needs cannot be experts at every level. However, they do need to be aware of the opportunities and limitations of AT, and maintain an open and flexible attitude and approach to its uses. Professionals should also take initiative in seeking support from independent AT services where they exist. Where they do not exist, support should be focused on their foundation. Those working in the field of AT recognise that the training of local professionals is a significant element of their work. This includes training aimed at improving the knowledge base of local professionals and the practice of initiating and supporting interdisciplinary interventions in the field of disability, independence and integration. (Paul) 😊



An holistic approach

ASSISTIVE TECHNOLOGY AIMS to create opportunities for the personal development and social participation of people with disabilities; that is, improving independence in everyday situations at home, work, school, in leisure activities and in mobility.

Human beings live and move in various social and physical contexts, interacting with many people and in many different environments. People with disabilities are disabled in their environments and by their environments. This means that AT intervention must consider *an overall view* of the person with a disability and their environment, their current needs, how these needs may change over time, and the current and changing perspectives and needs of all the significant individuals and organisations in their life.

Only AT solutions that result from an integrated and comprehensive approach to disability can really "make a difference". Therefore, any cost benefit analysis of AT intervention that wishes to have integrity and credibility must view the larger picture - a picture that embraces the end user of AT services, their family, and their physical, social, economic and cultural context.

Home and daily living

For many, the onset of disability is sudden and multifaceted. The person with a disability and their family will need to consider new approaches to activities that have been, until recently, taken for granted. These activities may include, for example, mobility, transport, communication, and environmental control. In these areas AT can play an important role in enhancing the quality of life of the person with a disability *and* their family. Carefully considered solutions that take account of the individual and their disabling environment are essential.

Work

The onset of disability is likely to impact greatly on the individual's work. Indeed, it may not be possible to return to work at all. Returning to work will often require significant adaptations to the workspace and the job description. For some, the use of AT in supporting a return to work is considered a simple case of finding an AT tool to fill the skill gap left by the disability. Such failure to acknowledge a broader spectrum of disabling factors in the workplace further hinders the person with a disability. (Carlo) 😊

School

Mainstream schools may be willing or unwilling to welcome children with special needs. Developing a truly inclusive classroom environment requires school staff to change ordinary practice. Inclusion of a disabled child in school is an opportunity for staff and classmates alike. A technological aid or a computer may become an important tool towards the inclusion of the child in the classroom, supporting access to the curriculum, opportunities to socialise with classmates, and acquiring "status". (Claire) 😊



Multi-professionalism

AN ESSENTIAL CORNERSTONE to the success of AT is the existence of an agreed and clear set of objectives and a multi-professional team capable of supporting their implementation. In addition to support from a specialist AT Centre, the assessment for and provision of AT demand the active participation of the person with a disability, their family, personal carers, and a multi-professional support team. Usually this team is made up of professionals from health, education, social services, rehabilitation and employment services, etc. The sheer number of people involved in this process may appear unwieldy or unnecessary. However, it is essential to consider the views of all the significant professionals involved with the individual, not least because each of these people needs to be aware of the objectives of AT intervention.

AT assessments and recommendations need to remain flexible, and team members - in particular the case manager or keyworker - should guard against the possibility of fuzzy objectives, potential confusion and unproductiveness. Coordinated and interdisciplinary intervention is a key factor for successful outcomes in AT service delivery.

The end user and their family

The disabled person is the single most important person in the whole process of AT service delivery. A clear and detailed understanding of their needs and goals is central to the success of the intervention. Users of AT and their families need to be supported in becoming as independent as possible in using the recommended equipment.

The professionals

The professionals working within the multi-professional team should be committed to an ethos of collaboration and mutual support. Genuine interdisciplinary collaboration between professions such as occupational therapists, speech and language therapists, educationalists, teachers, doctors, technicians and social workers requires professional teams to combine and mix their skills and knowledge in exploring AT solutions. This is not always easy to achieve where local professionals may feel vulnerable or lack experience in the field. AT professionals need to show sensitivity to the feelings and perceptions of staff from local teams. This in itself requires special skills and abilities. (Andrea) 😊

Case manager or key worker

Teams that work well are co-ordinated by a case manager or key worker. This individual is required to maintain a clear and objective view of the overall complexities of the case. They must co-ordinate the implementation of an agreed workplan making certain that the technical components go hand-in-hand with the psychological and emotional elements of intervention. This involves the monitoring of factors such as time, cost and resources. In this way the case manager or key worker is central in driving the AT intervention. This important role need not be profession specific, so a case manager or key worker might be appointed from any of the professional stakeholders.



Appropriate processes and solutions

THERE ARE NO off-the-shelf solutions in complex AT intervention. The era of "the quick fix" or "do it yourself" solution must be confined to history. Today's AT solutions need to be much more than adequate or sufficient. They need to be *efficient* and *effective*. To address the needs of most AT users takes months, sometimes even years of carefully planned intervention. Above all, then, solutions need to be *appropriate*. That is because appropriate solutions are personalised solutions. An appropriate solution is one that is within the everyday reach of the user and that is fundable, usable, and acceptable to the user across a range of environments. Unfortunately, only a few Europeans have access to customised AT services – services that provide assessment, the personalisation of equipment, training, long-term support and, if necessary, short term loans of equipment. Appropriate solutions not only benefit the end user but are also cost effective to society.

Strategies for the successful implementation of appropriate AT solutions need to be *concrete*, *incremental*, and *timely*. Pressure to find a one off "solution for ever" needs to be avoided so that AT intervention can be provided on an "as needs" and continuous basis. Finally, the timing of AT intervention is equally important in recognising and respecting the needs, capability and resources of the disabled person.

Personalisation

In almost every case of AT intervention solutions need to be personalised: software configured, computer peripherals (for example, special input devices) adapted, wheelchair control system built in, ergonomic workstation constructed. Often the individual will need a multifaceted and integrated system where various devices interact with each other. In extreme cases no existing device(s) can solve the problem and a new prototype has to be designed and constructed. (Rita) 😊

Training

The assessment phase of AT intervention should be followed by a period of support, during which the individual user and their facilitator(s) are trained to use the device(s). Where possible, training should take place in the individual's natural environment. Monitoring and evaluation of the training process is equally important, as significant changes can still be made during the support phase.

Loans

Wherever possible, opportunities should be available for trialing devices for a limited period of time. The decision to purchase an electronic aid will be much easier to make if the end user has already evaluated it. This applies particularly to European countries where AT devices are rarely subsidised and where families, therefore, have to make the final purchasing decision.



Appropriate funding opportunities

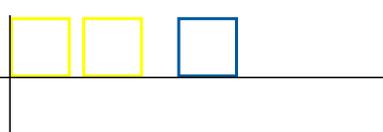
The funding of AT devices is a complex matter, but an important factor to consider. Many interventions in AT are under multiagency responsibility leading to personalised and complex solutions implemented through interagency funding. For a variety of reasons not all devices are fundable through institutional channels. The funding of human labour, personalisation and training is sometimes overlooked in drawing up a budget. Frequently the best possible solution is not the easiest to find funding for. The user and their family are not always able to contribute to funding equipment. (Federica) 😊

Long-term support

It is not enough to make sure that disabled citizens are supported in identifying the right technological aid. An adequate monitoring of the individual AT project over a longer period, which includes training and feedback from all stakeholders, is necessary to avoid the re-emergence of social exclusion where solutions become redundant or outdated. (Juan) 😊

Appropriate timing

Often valuable time is lost before the right support is found or funding is obtained. Delays in the introduction of AT for children can have a profound impact in restricting development during a critical time of life. Good AT service delivery is timed appropriately with early intervention recognised as a priority. (Claire) 😊





section

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Independent AT centres



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INDEPENDENT, NON-COMMERCIAL AT centres, supported by public institutions and agencies, can play a key role in responding to the individual needs of people with disabilities, particularly in supporting their inclusion in a variety of life contexts.

Experienced AT Centres have a role in mediating between the disabled person and their local professional team, especially where individuals' needs and expectations are not being met by current solutions. In this way an AT centre can become a central, unbiased point of reference for all those with a stakeholding in the process of long term support, proposing technological solutions and intervention approaches. However, AT centres should rarely provide the case managers or key workers, as users of AT are best served by their own local professionals. AT Centres provide people with disabilities and local health, social and educational authorities with accurate and up-to-date information on assistive technologies, devices and appropriate approaches to intervention. In addition they can assist policy-making agencies in developing realistic and effective models of service delivery in the field of AT.

ESSENTIAL CHARACTERISTICS OF INDEPENDENT AT CENTRES

AT CENTRES DO NOT necessarily have to share all the same characteristics. A Centre could specialise in specific areas of AT such as environmental control or communication aids or in specific age groups. However, they do share the following characteristics:

Non-commercial ethos

A non-commercial ethos means the disassociation from all commercial and vested interests, for example the production and sale of AT aids. This is an important issue in that it guarantees an independent advisory service.

Assessments with multidisciplinary teams

A competent and independent AT Centre is multi-disciplinary in nature, able to assess and recommend AT that is appropriate to the needs and expectations of the end user and their local support team. Customised solutions may be developed in collaboration with end users and local teams, and evaluated over time.

Training, loaning

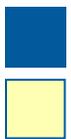
Many AT Centres train those using AT and other professionals. Some centres loan equipment for a limited period as an extension of their assessment. This facilitates testing and evaluation.

Research and development

An AT Centre is the natural place to identify relevant research questions reflecting the needs of disabled people and the professionals that serve them. Development work aims to fill gaps in technology, through the development of prototypes, involving disabled people in the design and development of new hardware and software. As a result AT centres have become valuable "centres of expertise" for designers and developers of AT devices.

Networking

AT Centres should work together in local, regional, national and international networks to share expertise and to co-ordinate interventions. Examples of such networks are available in Europe. For instance, the G.L.I.C. network in Italy unifies all major non-commercial AT centres. The members exchange information and expertise, and work together for a wider recognition of the role of AT in fighting social exclusion.





section

8

Conclusions



*Inclusiveness is not a privilege,
it is a right.*

BRIDGE Assistive technology is a powerful ally in the battle against social exclusion. In many cases it can bridge the gap between people with disabilities and mainstream society.

BRIDGE In order for people with disabilities to benefit from the advantages assistive technology can provide, mainstream society needs to implement inclusive policies. Such policies should aim at the elimination of physical and mental barriers, through a profound and on-going reflection on current everyday practice in all realms of life.

BRIDGE AT intervention is, by definition, a complex and long-term process, involving many stakeholders. The outcomes of intervention, in terms of changes in the quality of life or improvements in social inclusion, for people with disabilities are difficult to measure. However, any cost benefit analysis needs to include an evaluation of such long-term benefits in order to reflect accurately the value of intervention.

BRIDGE Independent AT Centres are important resources for many people with disabilities, local professionals, and agencies with formal responsibility in health, education, and employment. Nevertheless, many European citizens do not have access to AT centres. This is because the role of independent AT centres is not yet recognised in every country or region of Europe. Consequently, the provision of AT service provision to European citizens is geographically uneven.

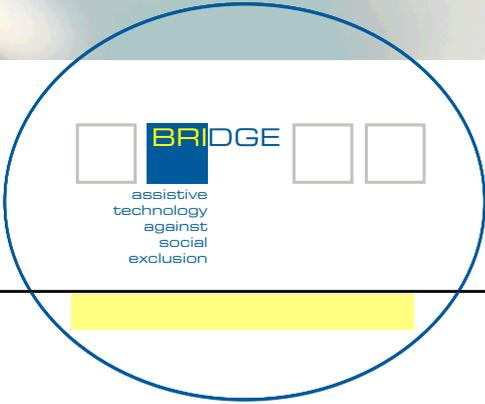
BRIDGE Commonly, different European countries and/or regions provide different models of AT service delivery. Although most do demonstrate good practice within the context of their funding arrangements, it is rare to find services providing for the global needs of people with disabilities throughout life. Many could have the expertise, but limited or short-term financial support restricts their development.

BRIDGE Policies aiming at supporting the development of AT for the benefit of people with disabilities should:

- Promote the development of technologies according to the principle of "design for all"
- Create models of service delivery capable of offering concrete and adequate answers through the integration of public and private resources
- Promote the provision of accurate, up-to-date information and the life-long training of professionals
- Promote the development of an approach to intervention based on the recognition of individual needs in a life-long perspective
- Promote multiple and transparent funding opportunities for equipment and services
- Favour the growth of an open and well-developed European market for AT devices
- Advance the development of a well-distributed network of independent AT Centres
- Support research and development activities aimed at improving technological aids, adapt existing devices for pan-European compatibility, and explore the impact of service delivery and AT equipment on the life experiences of people with disabilities
- Involve people with disabilities and their organisations in all stages of decision making and policy evaluation.



centres



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AT centres
promoting
the BRIDGE project



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exclusion



AUSILIOTECA is the AT centre of AIAS Bologna onlus, a non-profit making association of disabled people and their families. The centre is supported by the local health service of Bologna and the region Emilia Romagna as a specialised service provider in the field of Assistive Technology, focussing on technical aids for communication, play, environmental

control, mobility and daily living. For people with disabilities, their carers, and professionals from health, education and social services the centre is a national reference point. The centre practises a multidisciplinary approach to assessing individual needs, working with people with disabilities of all ages and in all areas of life: school, work, home, rehabilitation, etc. In addition, and wherever possible, staff of the centre support users of AT and their local teams in introducing AT devices into life-long projects. The provision of information, training, equipment loans and research are among the other activities of the Ausilioteca staff. The centre collaborates closely with other similar centres across Italy and is a coordinating member of the Italian network of AT centres specialising in the field of technological aids (GLIC).

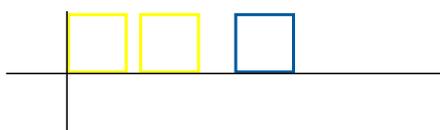
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The **ACE CENTRE ADVISORY TRUST** is an independent charity whose role is to be a centre of information, support and training for parents and professionals in the use of Assistive Technology (AT) for young people in education who have communication or accessing difficulties in speaking and/or writing. We are funded by central government, by The Gatsby Charitable Foundation, by European Union project grants, and by general fund-raising activities.

The staff comprises teachers, speech and language therapists, occupational therapists and technical experts with extensive experience in working with the application of computer technology including alternative and augmentative communication (AAC). The centre maintains a wide variety of services in addition to the core activities of independent assessment and training. We are involved in a number of national and international research projects; we lobby on behalf of those with communication difficulties; and we act as a dissemination centre for an extensive range of AT information. Much of the work we do also contributes to our software development and publications material.

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UTAC is a Communication Centre supporting people with motor disabilities who need augmentative and alternative communication (AAC) as well as assistive technology for play, mobility and computer access. UTAC provides assessment, intervention and life-long support to the users, their families, carers and professionals. Staff training, dissemination of information and research are also activities of the UTAC team. Increasing access to mainstream education and improving curriculum access for all school-aged children are among our main goals, which UTAC tries to attain in close cooperation with the school staff and the educational psychology teams (EAP). Collaboration has also been established with health and social services throughout Catalonia (early intervention centres, hospitals, residential and work settings, etc.). This helps professionals build their competence as interaction partners for the AAC users, and as rehabilitation trainers for people of all ages who need assistive technology to participate and to enjoy life.

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FORSCHUNGSINSTITUT TECHNOLOGIE-BEHINDERTENHILFE (FTB)

is part of Evangelische Stiftung Volmarstein (ESV), a large rehabilitation centre for physically disabled people, and a scientific institute at the University of Hagen. FTB is organised in three areas of responsibility: information, development and the test centre.

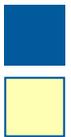
Within the scope of R&D, FTB is concerned with themes like telework/ teleservice, human-machine interaction, wheelchair control, rehabilitation robotics, augmented communication, environmental control, integrated home systems, and "design for all" at a national and European level.

As a centre of excellence in "design for" all FTB is a national reference point for this matter and advises the German Federal Government within the European initiative "eAccessibility".

One main field of work is the information and advice service on AT and home adaptations for people with disabilities, elderly people, as well as rehabilitation professionals. For this purpose FTB runs a permanent exhibition of technical aids including a specially adapted apartment that can be used for demonstrations and short periods of user trial.

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CENTRO AUSILI is the AT Centre of Association "La Nostra Famiglia".

Association "La Nostra Famiglia" is

a non-profit making organisation with many branches in Italy and abroad, and a network of Rehabilitation Centres and hospitals providing diagnostic services and treatment for physical and psychological disabilities, especially in childhood and adolescence.

Centro Ausili provides services to people with disability, their families, voluntary workers, carers and professionals who may or may not work for the Association.

The aim of Centro Ausili is to provide specialist counselling to help people with disability achieve the highest possible independence by:

- Using AT equipment;
- Improving accessibility to different environments such as work and education;
- Integrating equipment into rehabilitation and/or educational plans;
- Using software for rehabilitation and educational purposes.

Centro Ausili has a multidisciplinary team, with professionals coming from many different (social, rehabilitation, psycho-educational, engineering and design) backgrounds.

The many services and activities provided by Centro Ausili can be grouped into four main sectors: information provision, counselling and support, research and training, system projects and layouts.

The Centre focuses closely on new technologies and is a coordinating member of the Italian network of AT centres specialising in the field of technological aids (G.L.I.C.).

CENTRO AUSILI

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