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Education for independent living: methods, tools, experiences

Abstract

Empowering persons with disabilities to choose an independent living style, in terms of taking full control over their lives, and being informed and responsible consumers of assistive technology and support services required by their disabilities, is a key issue today. Personal motivation to be an active member of society, information on available options, and knowledge on how to make an intelligent use of them, are substantial components of such empowerment. Assistive technology, along with personal assistance services wherever needed, are often the key tools for such purpose.

This lecture addresses this topic by reporting on the experience of some programmes that have been running in Italy since some ten years:

- 1. The Independent Living Courses that are run yearly by an Italian association (Centro Studi Prisma), addressed towards adult people with severe motor disabilities with the twofold aim of improving their personal attitude to independent living, and also educating them to act as promoters and counsellors of other disabled in their path to independent living*
- 2. The Assistive Technology educational programme run by SIVA, addressed towards rehabilitation professionals*
- 3. The EUSTAT project, an international study carried out by SIVA with other 5 partner organisations within the EU Telematics Application Programme, aimed at developing methods and tools for transferring information and knowledge on assistive technology directly into the hands of the end-users.*

1. INTRODUCTION

I am deeply honoured to present some experiences from my Country, here in this beautiful Country, city, and people. I wish to thank both the local organization and prof. Annraoi De Paor, who invited me.

You may know Italy for its history and arts, as a place for holidays at the seaside or in the mountains, for cities like Roma, Florence or Venice. Here I will take you to Milano, where my Institute is located, and where I work with my team.

The focus of this lecture is empowerment of people with disabilities; more specifically, how information and education on assistive technology, and professional or peer counselling, can contribute to such a goal.

Being empowered to choose an independent living style, in terms of taking full control over one's own life, being informed and responsible consumers of assistive technology and supports services, is a key issue today. It is obviously a matter of rights to be ensured through affirmative legislation: but not only that, it is also a matter of information and knowledge, because knowledge means power.

Personal motivation to be active members of society; information on available options; knowledge on how to make intelligent use of them; all these are substantial components of such empowerment. Assistive technology, personal assistance services and other kinds of support, are key tools for empowerment.

To get the full benefit from a tool, this should be put fully in the hands of its end-user, and opportunities should be available for learning how to make the most efficient use of it. Such a training is often provided by good rehabilitation teams in the course of the rehabilitation process; it may be part of the approach of good community social workers; it may be embedded within an efficient service delivery system; it may be a matter of individual counselling, at professional or peer level. But not everywhere in Europe do persons with disabilities have the opportunity to easily access this knowledge.

The findings of Line C of the HEART Study (carried out within the TIDE programme of the European Commission) highlighted the importance of having not only the professionals, but also the end-users as active partners in the process that leads from the identification of a need to the implementation of a solution. End-users should be considered as major actors in the process, as opposed to regarding them as passive recipients of medical prescriptions: the HEART report "Recommendations for Service Delivery systems" issued a clear statement that a *good service delivery system is designed in a way that empowers users to make their own choices. This can be done by:*

a. educating professionals to have an attitude of equity towards users

b. providing information and consultation to enable users to make responsible choices.

Another European project, the EUSTAT which will be discussed later in this paper, adds a third method: *providing persons with disabilities with education on assistive technology.*

There is not much time here for a detailed discussion on all possible ways to pursue the empowerment objective: there is a number of experiences and models which can be looked at in the various Countries. I think the most effective thing I can do now is to bring examples, by outlining briefly the experience of our centre (SIVA), which has been serving for 15 years as a leading centre in our Country in the field of information on assistive technology, and an Italian association (Centro Studi Prisma) which I happened to serve as president for ten years.

2. OUTLINE OF SIVA

S.I.V.A., which stands for Assistive Technology Research and Information Centre, was established in 1981 by the Pro Juventute Foundation (the largest private non-profit Institution in the field of rehabilitation in Italy). Its initial aims were to create a nation-wide computerised information system, and an advice service concerning all technical aids which contribute to rehabilitation and independent living of the disabled persons.

SIVA's current activities include:

- a nation wide information system on assistive technology
- an information and advice service providing consultation on individual cases
- educational programmes addressed at rehabilitation professionals
- research programmes

The information system

The information system is composed of a database, updated on a daily basis, and published quarterly in a CdRom for distribution to all technical aids centres throughout Italy; an Internet www site; and a monthly bulletin. Running the database requires a normal PC.

The SIVA CdRom is mainly addressed at rehabilitation services and resource Centres, where experts are expected to be prepared to act as professional counsellors towards clients with disabilities. Its contents covers technical aids available on the Italian market (some 8000), each of them described by a picture and an extensive technical record with all available versions; it also covers manufacturers, national suppliers or local dealers, non-commercial organisations involved in disability matters (including voluntary associations), legislation and literature. When used within an information centre, the CdRom includes also a special software utility that keeps record of all consultations provided to clients.

On the basis of our experience in developing and using information systems in daily practice, SIVA acted as the national data collection centre for the European multilingual database known as Handynet, within the HELIOS programme of the European Commission. The Handynet CdRom was also regularly distributed to the technical aids information centres network, in parallel with the SIVA CdRom.

The information service

Over the years, the information and advice service has provided over 15000 consultations to persons with disabilities, families with disabled members, rehabilitation & health care professionals, teachers, architects, health authorities and even to manufacturers. The service is open every morning upon appointment, with an average of 15 clients a week. Simpler questions are sometimes dealt with also by mail or on the phone. The team is composed of one occupational therapist, two physiotherapists, one computer technician, one psychologist and one secretary. Basic tools for the information service team are the SIVA information system, a library, and a permanent exhibition of technical aids. It is divided into environments (mobility, communication, kitchen, bathroom, etc...) which represent the most common situations of independence in daily life.

Each consultation is carried out by one or two SIVA experts together with the client himself or herself, and generally involves the following steps:

- discussion of the client's problems, expectations and goals
- functional assessment and task analysis
- trials in the exhibition of technical aids
- searching in the information system for appropriate solutions
- recommendation of the most suitable technical aids and of personalisations.
- information on suppliers who are able to provide such devices, and on funding possibilities.

Education

Each year SIVA carries out an extensive programme of In-Service Courses and Continuous Education Workshops, mainly addressed at rehabilitation professionals and also other people who aim at qualifying as assistive technology counsellors. The features of such courses are explained later on.

The Courses provide a basic "horizontal" education encompassing the whole domain of assistive technology: the complete curriculum is composed of three modules with an overall duration of 120 hours. Agreements are in progress between our Foundation and the Milano Catholic University for qualifying such a curriculum as a Post-Graduate Master, by adding 80 hours practical experiences and a final examination. Another Master's course is also being planned, addressed at educational technology for school integration of disabled children.

The Continuous Education Workshops take place monthly and last one full day. Each of them addresses a specific "hot-issue" of assistive technology: it is composed of a scientific session, and a demonstration session where products available on the market and relevant to the topic of the day, are presented and discussed with the manufacturers.

Research

Another aspect of SIVA activity is Research. A variety of research programmes are ongoing. Within the Pro Juventute Foundation, SIVA is in charge of all research activities falling under the heading of "technologies for social integration and for public health". Some projects address technological topics, like information systems development and technical aids testing; other projects address clinical issues, like the experimental set up of a seating clinic; and, finally, social or economic topics, like cost-outcome analysis of assistive technology and educational models for end-users.

3. ISSUES IN ASSISTIVE TECHNOLOGY EDUCATION

Before reporting in more detail on our experiences, I wish to discuss briefly the educational needs of both professionals and end-users concerning assistive technology.

Today there is more awareness than in the past about the key role of assistive technology. This is due to factors such as:

- the fast pace of technological developments in this field
- the rising assertiveness of people with disability and their associations
- the increasing awareness of the problem-solving role of technical aids
- the increasing demand for good-quality products
- the need to establish good-quality prescription/provision processes
- the need to make efficient use of resources
- the financial constraints which are currently faced by many Countries.

As yet, there are not so many educational initiatives in the field throughout Europe. In the HEART study, carried out within the TIDE programme of the European Commission, a comparative analysis of experiences of AT education for professionals was performed. Components for developing training curricula were identified and guidelines were issued for their implementation. Despite the fact that the variety of national contexts would make it impossible to achieve a common standard curriculum applicable everywhere, this study was able to identify educational components that can be assembled in different ways and at different levels depending on the professional profile to be trained.

Traditionally, almost all educational activities in the field focus on professionals. But what about the end-user? Is she or he just the user of something decided by other experts "who know what is the best for me?". Today many people think, and also public documents like some reports of the European HELIOS programme recommend, that the so-called "medical prescription" model has to give way to a "consumer-provider" model, where the end-user makes the choice of what he or she wants, and controls the quality of what he or she gets. A kind of partnership is foreseen between professionals and clients for achieving effective and responsible choices.

That is in fact what we experience daily at SIVA in our information service. We like to define this approach as "assistive technology counselling". To be clear on the concept of "counselling", IRTAC (the International Round Table for the Advancement of Counselling) defines it as "*a method or a process of relating to other persons and responding to them so as to help them to achieve more rich and resourceful life perspectives*". Counselling can be carried out on the basis of a specific professional expertise (in this case being described as "professional counselling") or on the basis of a personal experience of the client's problem ("peer counselling").

If we assume that end-users (and often also other members of the primary network like eg. the spouse or the parents) are partners in the process, they should have the opportunity to be educated to actually act as partners. Knowledge leads to informed and responsible decisions on whether to use a technical aid, when and how: the person with disabilities has to live with that solution, not the professional prescribing it. Of course the degree of involvement in the decision may depend on the technology considered: devices addressed at replacing functions (like prostheses and orthoses) may require

mainly clinical evaluations and thus decisions may be left substantially to professional experts; devices aimed at assisting independence in specific daily life tasks (e.g. moving around in the workplace) may be effective only if the user takes decisions in full freedom. In many Countries (see eg the HEART reports) experience confirms that the more knowledgeable the end-user, the more effective is the delivery of assistive technology.

Within the professional community it is often argued that a percentage of people with a disability is not able to be really active in the choice of their assistive technology: this may depend on factors like age, cultural level, psychological barriers towards the acceptance of an assistive device during the early onset of disability, unfamiliarity with technology, etc... However, it is not always clear to what extent such difficulty is a cause or rather a result of traditional organisation models in the provision of rehabilitation services. Difficulties should not be underestimated: it may be true that many disabled persons or elderly persons with a disability will be unwilling anyway to act as "full partners" in the choice of assistive technology; but it is also true that more efforts towards empowering the end-user can decrease such a percentage of unsuccessful cases.

In fact even the HEART study felt the need to have a look into the end-users: after analysing the training needs of the various categories of professionals, some experiences of end-user education were reported. It recognises that end-users education deserves the same attention as the education of professionals. And concerning the professionals it said: *...The first characteristic of a European curriculum is user focus. User focus means that in all training programmes and courses in assistive technology, the ultimate objective is to enable the elderly and the people with disabilities to reach the optimum level of capability by, for instance, reducing the demands of the environment through assistive devices. User focus also means that all demands of different groups of disabled and elderly should be taken in account when planning training in assistive technology. Users should also participate in training programmes and courses giving lectures, and sharing their knowledge and experiences with the participants...*

Who is the actual decision-maker when considering the opportunity to adopt a technical aid? Who is taking part in such process ? How much knowledge should be transferred to each actor in the process?

Italian legislation states clearly that the end-user has the right to decide. But the ability to decide must be supported by knowledge: that can be attained through either a basic education or a professional advice provided by knowledgeable professionals. The ideal situation of a disabled person with high motivation, deep knowledge in rehabilitation technology, a wallet fat with money, is quite exceptional. Many persons know little about technical aids, have to be motivated, face cultural barriers or financial constraints; some persons just rely so much on their doctor or therapist that they feel comfortable with their decision and give up any thinking. In such cases the freedom to decide is just a sentence written on paper, hiding the fact that decisions will be actually taken by the physician or the therapist, or ... the commercial supplier.

In conclusion, the end user should be educated, and there is also a large variety of professionals who have a role in encouraging, addressing or guiding the user. A comprehensive approach to assistive technology education should therefore address many targets.

The first targets are obviously the medical doctors involved in rehabilitation, who carry the responsibility of the rehabilitation process, including the prescription of technical aids provided by the National Health Service.

The lack of occupational therapists and rehabilitation engineers, who in most other countries have the key role in the provision of assistive technology, is one of the main difficulties in Italy, and brings about the need for a substantial involvement of the physiotherapists, much more than is usual in other Countries.

Nurses and home carers are in close contact with the disabled person in his/her daily life, thus being in a privileged position to identify the needs and to guess aspects which might benefit from assistive technology.

Social workers also have the opportunity of a good insight into the person's life, family and community. An adequate but basic education on AT can greatly help them in identifying needs, exploring whether technological tools may improve the situation, making links and influencing the barriers which exist in the community.

Teachers and school professionals have a specific expertise concerning educational needs and related aspects (accessing the school, moving around, communicating etc...) and may have a tremendous role in educating for independence. This is particularly true for the supporting teachers, i.e. the additional teachers who in Italy support the integration of disabled pupils into the mainstream school.

Architects and building designers have a key role in providing a suitable environment for the integration of the disabled in the community: a barrierfree design can result in substantial reduction of the need of technological tools for mobility, navigation and communication.

Technicians dealing with prosthetic appliances or technical aids need a comprehensive education in rehabilitation technology.

Although SIVA is mainly working with rehabilitation professionals, we have relationships with more or less all the above professional profiles, and therefore we have had the opportunity to initiate training activities for most of them. In addition to that, the SIVA information system played a catalytic role in promoting throughout Italy a network of Technical Aids Information and Counselling Centres. Most Centres are inside Rehabilitation Units, other are stand-alone resource centres able to provide qualified consultation to disabled people and professionals. That led to a new professional task that can be called "assistive technology counsellor", that in our network is most often carried out by a therapist or medical doctor inside a rehabilitation unit, but in many cases also by people with disability with previous experiences as peer counsellors.

4. THE EDUCATIONAL MODEL FOR PROFESSIONAL COUNSELLORS

The SIVA Educational programme is mainly aimed at training assistive technology counsellors: however, it has proved quite effective also in meeting the educational demands of the other target groups. For this reason a modular structure was designed that includes three separate modules.

The **first module** (72 hours) provides the basics of assistive technology. It covers the following topics:

general topics

- * general concepts of assistive technology and accessibility
- * Italian legislation relevant to disability

technical topics

- * the home and basic activities of daily life
- * personal care
- * mobility (wheelchairs, walking aids and orthoses, cars and other vehicles)
- * leisure and sport
- * computer access
- * telecommunication and environmental control
- * aids for the blind
- * aids for the deaf
- * augmentative communication
- * computer applications for rehabilitation, learning and school integration

methodological topics

- * client assessment for selection of technical aids
- * elements of cost-outcomes analysis
- * counselling techniques
- * practical experiences on case studies

The **second module** (24 hours) focuses on the use of information systems for the selection of assistive technology. It provides extensive training on the SIVA CdRom, on the Handynet CdRom, and on discovering information resources on the Internet.

The **third module** (24 hours) addresses accessibility issues. It requires the first module as a prerequisite. The following topics are covered:

- * accessibility legislation
- * barrier-free design for the home and interiors
- * accessibility to public services
- * access to transportation
- * environmental comfort

5. THE EDUCATIONAL MODEL FOR END-USERS AND PEER COUNSELLORS

The term "independent living" is quite widespread today. It is used as a keyword by many Organisations of people with disability that advocate equal opportunities, social integration and active participation in Society.

To avoid misunderstanding, such a concept needs clarification. Independence, as several authors state, should not be regarded as just the ability to perform all tasks alone: such "utopia" might be the achievement of a just a few disabled persons, also because all people in Society, disabled or able-bodied, are inter-dependent on each other. Within the so-called "Independent Living Movement" the concept of "independence" is described in more realistic terms, as the ability to plan one's own life and to address it towards the desired achievements of life quality, work, relationships, social participation. Any human or technological help that may be needed for such goal does not conflict with the idea of "independence": on the contrary, it has to be seen as a support to independence.

A person with disabilities has direct experience of disability, and in consequence of that a specific competence. Based on that, the idea that disabled persons can act as counsellors, helpers or trainers of other disabled persons has been put into practice in a number of Countries. Self-help groups, peer-counselling services, independent living resource Centres managed by disabled persons are not yet numerous in Europe, but also they are not so rare.

"Education for Independent Living" is the title of an educational programme for persons with disabilities. It has been running every summer in Italy since 1985, on the initiative of an Association known as "Centro Studi Prisma". Centro Studi Prisma defines itself as "an interdisciplinary association for the advancement of information on technical and social resources which promote the integration of the disabled persons into society".

Based on the belief that the disabled person is the leading actor in her/his rehabilitation and social integration, the Course is addressed towards physically disabled persons and is led mainly by disabled experts. It is composed of two modules, called the First Level and the Second Level, each lasting one week (6 days) and both held in a fully accessible holiday resort located in the heart of the Dolomite Mountains (Belluno, Northern Italy).

The First level focuses on education for the personal dimension of independent living; in other words it provides the basic education on rehabilitation technology and aims at shaping the person's attitude

to take responsible control over his/her life. The programme is arranged so as to cover two main aspects:

- the technical aspects, by providing state-of-the-art knowledge of the available technical aids, of the criteria for accessibility, of the legislation concerned with their implementation;
- the personal growth aspect, by investigating the concept of independent living and by exercising the participants to take initiative in designing concrete solutions to the daily life problems.

The technical aspects are dealt with through lessons given by experts, most of them disabled. Expertise and quality of presentation are given high concern in selecting the teachers. The personal growth aspects are tackled through team works, by dividing the participants into groups, each composed by 8-9 persons and led by a disabled expert.

Since the Course is held outside any medical or nursing facility, every participant who needs personal assistance comes with his/her personal attendant (a relative, a friend or a carer). The attendants take part in the lessons together with the disabled participants. Teamwork is performed separately: generally 3 groups of disabled and 2 groups of attendants are formed, each led by a disabled leader.

Participation to the Course is open to 25-30 participants with disability plus their personal attendants. Due to the restricted number, selection of applicants is necessary. A number of criteria are adopted: priority is given to the most severely disabled; then care is taken in having a variety of pathologies among the participants, thus helping them to broaden their concept of disability; finally, a personal talk is required in order to ensure that the applicant really wishes to take steps towards independent living and not just spend a holiday week in a wonderful natural environment as the seat of the course is.

The second level Course aims at encouraging disabled persons to act as promoters of independent living. Here the focus is not mainly on rehabilitation technology but on aspects like the appropriate use of the mass-media, group dynamics, organisational skills, educational skills (e.g. how to speak to children about disability).

Up to now 300 disabled persons have taken part in the First Level Courses. Some 20 of them came from abroad (Spain, Greece, England, Portugal, Nicaragua and Argentina); the others from all over Italy. About 120 took part also in the Second Level Courses. The experience is really satisfactory and admits of promising developments.

A number of participants got motivation, after such courses, to undertake professional roles in technical aids/accessibility information or advice centres, and currently professional assistive technology counsellors. Some others have initiated peer counselling programmes on independent living in their local communities. Of course this is not the main objective of the course, but it points out its potential.

For most participants the courses result in a substantial improvement in their attitude to cope with the challenges of independent living and to play active roles in society: this is the actual objective.

6. THE EUSTAT PROJECT: A EUROPEAN PERSPECTIVE

Recently a new study started within the TELEMATIC Applications Programme of the European Commission. It is called "EUSTAT", an acronym which stands for "Empowering users through Assistive Technology".

Again, the project stems from the idea that end-users empowerment to the choice of assistive devices is a key factor for the success of assistive technology; its potential is fully exploited if also the end-user is directly provided with specific education.

EUSTAT aims at contributing to meet this need by working out guidelines and educational material at European level. Its main concern is the education of persons with disabilities in assistive technology for independent living, by providing them with knowledge and methodological elements for solving their personal problems, and helping other disabled persons to solve their problems.

Its main achievements will consist of:

- a) an analysis of critical factors related to transferring knowledge on assistive technology directly to the end users;
- b) an inventory of existing experiences (in the EU and in North America) with examples of good practice of user empowerment through education in AT;
- c) a set of guidelines able to assist all over Europe:
 - the design of courses for end-users
 - the integration of assistive technology within more comprehensive educational initiatives.
- d) a basic educational material package, consistent with the above guidelines, for user education in AT.

The guidelines and the educational package will be experienced and validated in three pilot training initiatives in Italy, Belgium and France.

The primary targets of the project are adult disabled persons with moderate to severe motor or visual impairments (congenital or acquired) of any kind. The elderly with a disability will be also considered. The findings will be of interest also for families and primary networks (personal assistants, friends, colleagues) of people with disabilities, and for their trainers (peer counsellors or rehabilitation professionals). It is expected that the results will be very useful also for rehabilitation professionals who are responsible for prescribing assistive devices to the end users.

SIVA is the project leader. The other partners are:

- * ANLH - Association Nationale pour le Logement des personnes handicapés, Belgium
- * GIPH Aquitaine, France
- * Centro Studi Prisma, Italy
- * Danish Centre for Technical Aids, Denmark
- * Instituto Superior Tecnico, Portugal

This study will be a unique opportunity for discovering and networking ongoing experiences in the field, capturing tokens of wisdom from each of them, identifying good practice and possible common approaches. The know-how already developed by the HELIOS and the HEART programmes will be a substantial starting point for that. The EUSTAT web site (www.siva.it/eustat) will be soon in place for those who wish to be kept informed.

7. CONCLUSION

Ladies and gentlemen, I hope to have been able to communicate our experiences, offer a comprehensive overview of this topic, and outline the many issues involved. I hope you found it useful. Now I would most appreciate sharing with you ideas and experiences.