

Assistive Technology Education for end-users: The GIHP and ANLH cases

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Context

Since 1979, **GIHP** Aquitaine (Groupement pour l'Insertion des Personnes Handicapées Physiques), an association of disabled people based in Bordeaux (France), has been running individual courses for people with disabilities who were seeking to increase autonomy in daily life. The first course was addressed to visually impaired people, and then temporary accommodation and home support services were created for people with motor impairment. Over the past few years, an accessible lodging service and a computer training service have also been added.

In order to ensure that these services were properly run, the association hired a team of skilled professionals in social and employment integration. Thanks to the impetus of the founding members, these professionals (an occupational therapist, a social worker, a psychologist, an educationalist, and an instructor in locomotion, Braille and daily living) developed considerable experience in supporting people in their daily life environment. This support has always taken into account the various complementary aspects of autonomy: psychological aspects related to either the individual or the family, socio-economic aspects, and technical aspects related to increasing autonomy in daily activities. This last element relates directly to the use of AT as a tool for autonomy. GIHP's activities have mainly been organised around individual work focusing on individual needs and based on a co-ordinated multidisciplinary approach.

In 1998, at the behest of the EUSTAT project, GIHP Aquitaine decided to organise a course on technical aids for a group of persons with disabilities. This was a fairly novel experience for the association, joining professionals and users together in a common process.

In a similar context, **ANLH** (Association Nationale pour le Logement des personnes handicapées) in Brussels also undertook the organisation of a new educational initiative for end-users in Belgium. The main mission of ANLH (the National Association for the Lodging of People with Disability) is to promote the social integration of people with physical disability by providing lodging and a living environment adapted to their needs. With this aim in view, ANLH established a set of services called AVJ (Daily Life Activities), whereby persons with severe physical can opt for an autonomous lifestyle in their private lodging, supported by a personal assistance service that is on call round the clock seven days a week.

In 1998, following a request from several AVJ services, ANLH launched a training initiative for both users and staff. This had a twofold aim: to provide the knowledge and know-how that disabled persons need in order to find their own

way towards independent living, both in daily life and work; and to train personal assistants in how best to support an independent lifestyle. Named *EPIL*, this training project received funding from the European Commission within the framework of the DG5 Employment / Horizon programme. The topics covered related to disability in general, centring on five key subjects:

- AT and accessibility
- Communication issues
- AVJ services and activities of daily life
- Legislation
- Employment.

It was decided to spread the training over five monographic *seminars*, each lasting one or two or three days to be repeated for three different regions: Brussels, Wallonie and Flanders. This meant that the AT module, designed on the basis of the EUSTAT model, would consist of a *one-day seminar* to be held in three different locations for three different groups of trainees, and in two different languages (French and Dutch). The title chosen was "*From Technical Aids to Decision*".

Design and set-up

GIHP

GIHP decided to dedicate this initiative solely to persons with disabilities, although it had initially been argued that it would also be useful for many others such as families, helpers and professionals, with a fruitful and enriching exchange occurring among the four groups.

A letter was sent out to 900 people who had benefited from GIHP services in the past. The letter contained the project presentation, a phone number for further information and a registration form to send back before the deadline. Applicants were also called on to specify the personal motivations for attending the seminars, so as to assess the spontaneous response to such an innovative programme.

For pedagogical reasons, it was decided to limit the number of participants to twelve, as it was believed that work with a larger group would be less efficient, particularly where practical work, tutoring or exchange sessions were concerned. A register of the applicants' phone calls was compiled, including the kind of information asked and whether the candidate eventually registered. Two selection criteria were applied:

- personal motivation, and
- date on which the registration form arrived.

The training team included two occupational therapists, a social worker, a psychologist, two computer trainers, disabled persons and AT providers. The mix of professionals and end-users was felt necessary to ensure a range of views on AT. Some disabled persons were engaged as professionals, and others on the grounds of their role in the association. It was also felt that the contribution of the occupational therapists, the social worker and the psychologist would be indispensable, and that the computer technician was essential for computer support and the use of information and communication data. The organisers

considered that direct contact and dialogue with AT providers during live testing and exhibition of materials would be extremely useful.

ANLH

Analysis of training needs was the first step in operational planning. This consisted of a brainstorming session attended by AVJ co-ordinators, administrators and end-users, which confirmed that end-users:

- often had limited knowledge of workable technical possibilities;
- had difficulty in using the AT presented to them due to psychological reticence, technical difficulties or functional problems;
- did not know where to go for information, adaptations, maintenance and repairs.

As a result of this brainstorming session, a questionnaire was drawn up and sent out to every trainee, along with an invitation letter to attend the seminar. Returning the questionnaire was voluntary, and trainees were invited to share their personal experience so as to help complete needs analysis.

A set of specifications was then drafted, which identified the AT used and outlined the human environment and socio-economic elements to be covered in the seminar. This provided a guideline that the training officer could follow when planning the day's activities, and setting pedagogical aspects, content and expected results.

The preliminary estimate for attendance was 12 people per region but no limit was set on the number of registrations; if the number of applications proved to be higher a supplementary day would be organised. The trainees were persons with disabilities, most of whom were users of AVJ services in the three regions: Brussels, Wallonie and Flanders. The event was free of charge, and ANLH provided services such as transport and personal assistance in response to the needs expressed in a special coupon that each candidate had filled in and returned. Training was also open to AVJ assistants wishing to participate: agreements with their employers were made beforehand in order to decide whether and to what degree the training session was to be considered as working time.

In order to gather the required training expertise, three specialised centres in the local area were contacted: CRET (Centre de Réadaptation), SAPH (Service d'Aide aux Personnes Handicapées, an affiliate of the Red Cross) and the LBSP (Ligue Belge de la Sclérose en Plaques). The multidisciplinary nature of the training team, including AT users, was important in order to tackle various AT-related fields. It was absolutely essential for the training to be practical, since many trainees had described themselves as having little or no experience.

Trainees and Trainers

At the end of the selection process, the trainee group in the *GIHP* course comprised ten persons ranging in age from 35 to 60, some with visual impairments and the others motor disabilities. The teaching team consisted of an occupational therapist, a social worker, a psychologist, a computer trainer, and

some disabled persons and AT providers. The team was led by a training co-ordinator.

72 *trainees* were enrolled for the *ANLH* seminar: 51 persons with disabilities ranging in age from 20 to 60 with severe physical disabilities (such as tetraplegia, paraplegia, muscular dystrophy, polio and multiple sclerosis); and 21 personal assistants ranging in age from 18 to 40, all employees of AVJ services. The group of disabled persons comprised 21 from Brussels, 22 from Wallonie and eight from Flanders, while the group of personal assistants comprised nine people from Brussels, five from Wallonie and seven from Flanders. There were three *trainers* for each site: an educationalist and an occupational therapy from LBSP, and a service delivery expert from the Ministry of Health.

The programmes

The GIHP Course		
<i>Date</i>	<i>Session</i>	<i>Topic</i>
Friday 5/6/1998	Introduction	Trainer/trainee introduction; explanation of the motivations and objectives of the training programme; presentation of the EUSTAT project; self-evaluation questionnaire.
	Theory 1	General concepts; definition of handicap according to the WHO definition; AT as a support for handicap situations and for independent living.
	Theory 2	Definition of AT; ISO classification; standard classification (ten categories); AT research based on the classifications; information resources.
Friday 12/6/98	Theory 3	Choice of AT; individual needs; local resources enabling the individual to make decisions.
	Practice 1	Presentation, demo of computer aids adapted for different impairments.
	Practice 2	Presentation and practice with the Internet; HANDYBASE databank.
Friday 19/6/1998	Theory 4	Half-group session in flats adapted either for visual impairment or motor disabilities; psychological aspects of personal autonomy within community and society; difference between autonomy and dependence; acceptance of AT.
	Practice 3	Half-group session in flats adapted either for visual impairment or motor disabilities. Comparative testing of AT used during daily activities; manipulations; analysis of the differences between models.
Friday 26/6/1998	Theory 5	Socio-economic aspects of AT; costs of AT; financial and legal aspects; funding.
	Practice 4	Half-group session organised on the basis of visual impairment or motor disabilities. AT demo by a supplier
	Practice 5	Critical analysis of Practical Session 4
	Closing	Course evaluation; theoretical and practical competence acquired; analysis of course contents; tips for course improvement.

The ANLH Seminar		
Time	Session	Topics
10.00	Introduction	<ul style="list-style-type: none"> · Presentation of the EUSTAT and EPIL programs. · Presentation of the EUSTAT User Manual.
11.00	Lecture	<ul style="list-style-type: none"> · Presentation of a counselling service. · The different types of professionals and when they intervene. · Legislative and financial aspects. · Traps to avoid and handy tricks. · How can end users make autonomous choices?

12.00	Discussion	Questions & answers
14.00	Examples	Two users presented their own experience in AT: history of the choice; why they chose an assistive device; problems, people and specialists encountered; finance; uses of AT; improvements gained from AT; training in AT use; whether the users would make the same decisions if they had to choose again.
15.00	Discussion	Discussion of user testimony.
16.00	Discussion	Seminar evaluation.

Running the courses

Being a short initiative, the ANLH seminar is sufficiently self-explained by the programme above, but further information concerning the GIHP course might prove useful.

The GIHP programme comprised three types of sessions:

- theoretical: definitions, key words, classification, information sources, psychological and socio-economic aspects, choice procedures;
- practical: comparative tests, materials exhibition, adapted computer and introduction to the Internet;
- discussion: roundtables, case studies.

The sessions were spread over a month in order to allow trainers and trainees time for elaboration. The range of topics could have been extended with more lectures, but GIHP wished to give priority to practical sessions so as to maximise interactivity and to involve everybody actively in the work.

It was felt necessary to tackle fundamental aspects of disability definition (such as ICIDH and ICIDH-2) and to relate disability to the human, physical and community environment. AT was approached in conjunction with the concept of autonomy; AT use and the various existing classifications, especially the ISO classification, were discussed.

These concepts were also explored in hands-on sessions for various AT categories. Comparative tests were done to foster reflection about the value of each characteristic. Trainees also attended a commercial exhibition of AT tools, and discussed their relative advantages, drawbacks, limits, and appropriate use contexts. This was followed by discussion of the relationship between providers and end-users.

AT was also studied in relation to individual psychological facets, and the difficulties inherent in the process of prescription, acceptance and use of AT were highlighted. At the same time, stress was placed on how an open, tolerant and well-informed community (including the community of professionals) could foster the acceptance and use of the AT.

A large part of the GIHP course was devoted to the socio-economic dimension, involving law, costs and procedures for AT acceptance. This made it possible to discuss the economic dimensions of AT, to exchange views on the inadequacies of current systems, and to understand the differences between the existing system (thinking about the best way to use it) and what would be the most appropriate

system. One of the objectives of this approach was to help trainees stick to reality and be constructive.

By associating this basic knowledge with the use of available tools, trainers and trainees built a dynamic research process. It was particularly important to identify a procedure grounded on individual, needs-based initiative that would lead to satisfactory and confident use of AT. This raised fundamental questions like:

- What are the different steps in this procedure and what are their characteristics?
- What tools can ensure a good result?

The process involved human aspects of problem solving: starting with a precise need; assessing the situation; searching for information; meeting somebody and establishing a relationship; carrying out tests and investigations; and making decisions. An inventory of existing resources was drawn up, featuring: professional know-how; user organisations; and information sources such as magazines, articles, Information & Communication Technology (ICT) and exhibitions). In addition, practice was gained in the use of information sources, especially the Internet, and through some small role-plays and simulation of real cases.

The teaching aids and educational material used during the course included whiteboard, overhead projector, videos, publications and handouts. Various methods were used to transmit knowledge on AT to disabled persons. Stress was also placed on creating a dynamic and constructive exchange so that positive effects would be produced in daily life after training. The contributions of some disabled persons who are both professionals and daily AT users contributed to get across this message. Group work appeared to be more suitable and useful than the individual work adopted in the previous training initiatives. Consequently, this course was not designed just for solving the individual's problems, but rather to help participants situate themselves in a "meta" position in relation to AT and its daily support of autonomy. Personal testimony made a major contribution in this direction.

At the end of the course, participants were asked for their views about the course, the quality of teaching, and their personal contribution. It was interesting to see how this experience influenced individual and collective perspectives. Further evaluation was planned in the form of another meeting held six months after the course ended.