Technical Assistance for Motor- and Multiple Disabled Children – Some Long Term Experiences

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Abstract. This paper describes the application of a Technical Assistance system developed by the Vienna University of Technology. Main focus has been to provide new means for severely and multiple disabled children in order to support the children's development and to give them more independence and autonomy while exploring their material and social environment. The concept of the system and the experiences collected in practical application of the system in a smart room of an Austrian Support Centre for disabled children are outlined. Based on the encouraging results the system now is also being used in other institutions, in private homes and in higher education in order to enhance independent living of profoundly disabled persons.

1 Introduction and Aim

One of the main reasons for severe motor- and multiple impairments in childhood is cerebral palsy. Here different brain regions can be affected resulting in random combinations of disabilities (motor, cognitive, communication, intellectual etc.). Up from a certain degree of impairment motor- and multiple disabled children rarely are able to use conventional environmental control (ECS) and augmentative and alternative communication (AAC) systems. To attain this ability, in many cases customer tailored user-interfaces plus a long-time training process is necessary. Even learning the relation between reason and effect and experiencing self-effectiveness (being able to make something happen in the environment) is the first big challenge and often an entire new experience. Hence, a technical system capable to meet the needs of these users has to fulfil three criteria: (1) give optimal support to the training-process; (2) support the facilitators with a tool to easily adapt the system to the rapidly changing user needs; (3) be capable to grow from first experiencing self-effectiveness up to a multifunctional multi-purpose technical aid.

The paper discusses an innovative Technical Assistance system developed at the Vienna University of Technology which especially has regard to the needs of motor

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and multiple impaired children and to the training-process. After introducing the concept of the Technical Assistance system and pointing out its special features experiences from practical application of the system are described.

2 Methods

For nearly 10 years now our research group has been involved in the development and field-testing of a combined ECS and AAC system we named AUTONOMY [4], [5], [6], [18]. It is based on a PC hardware platform (notebook or a handheld computer) and on the MS-Windows operation system. The input/output hardware can be chosen from a wide range of standard and special devices to meet the specific needs of the disabled user. A set of peripheral hardware components links the system to the physical environment.

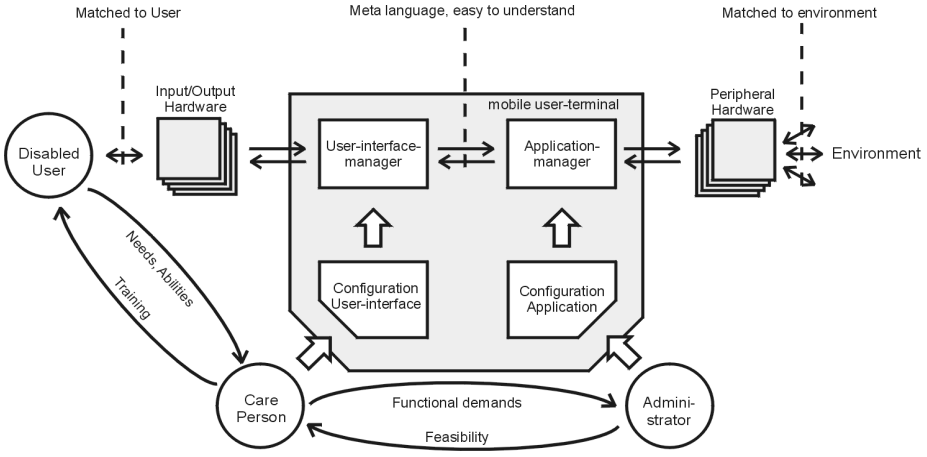

Fig. 1. Block diagram of AUTONOMY system [6], [18] showing interaction between system components and user groups

As a main innovation AUTONOMY offers three different user-interfaces for the three distinctive user groups working with the system (a) The end-user (the person with special needs, who is using the assistance system), (b) the facilitator (e.g. a therapist, pedagogue or family member) responsible for the configuration and adaptation of the user-interface and (c) the integrator carrying out the technical set-up of the system. The cooperation between these three groups of users is essential for optimisation and successful use of the system. The three interfaces/tools (user-interface, configuration tool and set-up/test tool) are tailored to the very specific needs and abilities of the three different user groups according to the specific roles they play in setting up, configuring and operating the entire system.

Fig. 1 shows the interaction between the system components and how the different user groups utilize dedicated user-interfaces. The user-interface-manager and the ap-

plication-manager are internally linked with one another by an easy to understand meta language. This ensures that after the integrator (= system administrator) has set up the application configuration and the peripheral hardware the facilitator (= care person) can refer to non-cryptic (non-technical) terms when configuring the user-interface. The task of the facilitator is to enable the disabled child to discover and exploit new areas of self-determination and independence. He/she will need a versatile and easy-to-use tool which enables him/her to create not only various user interfaces but also creative procedures for working with the communication and environmental control functions in a didactic and therapeutic manner.

Table 1. Numbers of Configurations in relation to size of configurations. Total of 217 configurations in Autonomy Room at Elisabethinum Axams, data collected by December 2001

Amount of Icons (Command Icons and Menu Icons)	Number of Configurations
1-50	189
51-100	8
101-150	6
151-200	1
201-250	4
251-300	2
301-350	5
351-400	1
401-450	1
Total	217

In autumn 1995 AUTONOMY was installed in a Smart Room at a support centre for motor and multiple impaired children in Axams, Tyrol. By using the EIB (European Installation Bus) [8], [14] for the electric wiring and infrared remote control technology, all appliances in the room can be remotely controlled via the system. AUTONOMY usually is placed on a trolley. Thus the user can turn it to face any direction. The Smart Room covers four dedicated areas: living, working (PC with multimedia games, email, WWW, text processor), playing (e.g. electric toy train) and consumer electronic (TV, CD, VCR, ..).

1996 – 1997 several case studies were carried out in order to study the new possibilities provided by the AUTONOMY system [16], [19]. Data were collected by logbooks and project diaries in a close cooperation between therapists, teachers, researchers and disabled users. Some of the questions were: (a) What are the main problems for novice end-users and therapists? (b) How can severely disabled children best be trained to handle an environmental control and alternative and augmentative communication (AAC) system? (c) How do the facilitators accept and handle the configuration tool? (d) How can the cooperation between end-user and facilitator be augmented by a Technical Assistance system? (e) Which methods do the facilitators use to introduce and train the disabled children and how can this process best be supported by the system? (f) Is the system able to improve and accelerate the rehabilitation process?

The disabled children observed in the case-studies suffer from high-grade motor and/or cognitive impairments. It could be demonstrated that a Technical Assistance system can be used to improve the rehabilitation-process on a very basic level. Several case studies are reported in [16], [19].

3 Results

After a short time of training a very creative process was initiated by the teachers, therapists and care persons, providing feedback to the engineers to optimise the system and trying and developing new possibilities which a system like this offers. All the professionals found new applications for the AUTONOMY system and tried to adapt the system to match their special requirements. These applications were sometimes very different from the first scope of the system to be an environmental control system. One focus was to use AUTONOMY as communication aid especially with alternative augmentative communication using BLISS, PCS, ALADIN symbols or even photos.

Table 2. Used Input methods of total 217 configurations in Autonomy Room at Elisabethinum Axams, data collected by December 2001

Input Device	Number of Configurations	relative
Single Switch	76	35.02%
Two Switches	79	36.41%
Five Switches / Joystick	61	28.11%
Mouse	0	0.0%
Five Switches combined with Mouse	1	0.46%
Total	217	100.00%

Table 3. Distribution of Scanning Intervals of total 76 configurations in Autonomy Room at Elisabethinum Axams which are using single switch / automatic scanning, data collected by December 2001

Scanning Time	Number of Configurations	relative
0.5 – 3.0	43	56.58%
3.1 – 6.0	22	28.95%
6.1 – 9.0	4	5.26%
9.1 – 12.0	7	9.21%
Total	76	100.00%

The possibility to create very easily and quickly new configurations for a user accelerated this process. Simple configurations can be made by a carer in a few minutes, more complex ones in a few hours. Due to this fact the system was also used for

training, e.g. for novice users to get familiar with the operation of a computer with switches or special input devices and to recognize immediately the principle of action and reaction. When starting with communication via the computer with multiple impaired children the first step is to have only a *yes* and a *no* icon and to provide an acoustical feedback with synthesized or recorded speech. In cases where even that very simple yes/no communication fails the first step is to use environmental control functionality with few devices and acoustic feedback to teach the action reaction principle to the children.

The motivation of the children can be increased e.g. by controlling their favourite toys with the computer. Sometimes the users have already a communication book or something similar (using PCS, BLISS, ALADIN, …), in this cases an 'electronic copy' is built with the AUTONOMY system. An important feature is that almost every kind of picture material, e.g. photos of relatives, can be associated with an icon of a menu. Systems which offer only a restricted set of (often predefined) symbols fail very often if the user has very strong mentally impairments.

Table 4. Used Graphics in Autonomy Room Elisabethinum Axams, total amount of Autonomy configurations = 217, total number of available graphic files = 11,313, totally used graphics = 1,033. Data by December 2001. Used Libraries: *) Picture Communication Symbols, Mayer Johnson Co. US **) Blissymbolics Communication International, Canada ***) Bliss for Windows, Handicom, NL #) PuT – Pädagogik u. Technik GmbH, Germany +) TU Vienna, Austria

Type of Graphic Library	Available Graphics in this Library	Used Graphics	Relative to Graphics in this Library	Used relative to totally Used
PCS color *)	3,043	124	4%	12.00%
PCS b/w *)	2,983	179	6%	17.33%
BLISS **)	2,482	138	6%	13.36%
ISABLISS ***)	186	182	98%	17.62%
Aladin #)	1,321	80	6%	7.74%
Biblio +)	1,066	211	20%	20.43%
Others (individually created)	214	102	48%	9.87%
System Graphics +)	18	17	94%	1.65%
Total	11,313	1,033	9%	100.00%

Certainly one of the most important features of the AUTONOMY system is the very easy and comfortable handling. Out of the first smart training room at the beginning of the project became a system for every day life which is running on different computers in classrooms having a database of more than 250 configurations (ranging from configurations with only two icons and no menu structure up to configurations with more than 100 icons arranged in menus with a depth down to 7 menus) and image and sound file resources of hundreds of megabytes stored on a server.

The concept of AUTONOMY acknowledges and supports the immense importance of the rehabilitation experts (teachers and therapists) for the satisfactory implementation and use of a Technical Assistance system. It could be proven [16] that (a) the

technological concept satisfied all expectations of the users and facilitators and that essential drawbacks of existing systems could be avoided, (b) integrating a Technical Assistance system into the rehabilitation process (mainly in the areas independence, self-determination and development of residual functions) is a factor to speed-up rehabilitation and (c) these results are positively assessed by the disabled users themselves and lead towards an increase in quality of life.

4 Discussion

One of the main goals in developing AUTONOMY was to provide a configuration interface which enables even complete computer illiterate persons to create client tailored user interfaces and application. The concept received perfect acceptance from teachers and therapists and meanwhile several hundred different configurations were set-up at the test site. The extensive use of AUTONOMY at the support centre in Axams also showed that the system offers additional therapeutic benefits beyond pure AAC and ECS. Especially cognitive and motor impaired children encounter severe problems in experiencing the principle of reason and effect. As their possibilities to handle objects by themselves and perceive what will happen ("...will it drop to the floor and crash when I release it?") are restricted they encounter a deficit along these lines. The smart-room can help to teach these basic principles. Properly configured, accessing an icon by hitting a switch can cause to start fireworks of sound and light. It occurred that children needed such experiences to conceive the concept of reason and effect for their first time.

Table 5. Typical amounts of icons and hierarchical levels (menus) per configuration. Applications marked with *) or **) are being used outside Autonomy Room, application marked with **) is used by a non-speaking severely motor disabled student using Autonomy system for writing source code in Modula-2 programming language as part of his studies at Vienna University of Technology [2]

Application	Icons	Levels
starting	2-4	1
ECS	20-50	4-8
AAC (symbols)	40-90	5-13
AAC & ECS	80-150	10-20
AAC (BLISS)	350	17
Independent Living *)	190	24
Independent Living with Access to PC*)	250	16
High Performance Access to PC **)	3.600	115

A next step in therapy can be basic communication training for non-speaking children. The usage of an AAC system is often hard or impossible to explain to severely impaired children. The therapists at Axams, therefore, started to combine AAC with ECS. This has been easy to achieve, as AUTONOMY integrates both function in one platform and under the same user interface. Thus the intensity of feedback from the

environment is significantly increased and the child receives an additional multimodal stimulus.

Currently, (2002) some of the children who started to use AUTONOMY 6 years ago are preparing themselves to leave the support centre and to join a sheltered living community located in Innsbruck, Tyrol. There, Technical Assistance systems also shall provide them with helpful support in order to empower them to live a more independent and self determined life. Based on the successful application at Elisabethinum Axams the system was installed in other institutions, e.g. in 1998 in the Smart Room of a Viennese school, at several private homes for disabled adults, at rehabilitation centres. Since 2001 a disabled student of our Vienna University of Technology is using the system in automatic scanning mode for accessing a PC in order to write source code for his studies of informatics [2]. A commercial version [18] was released in 1999.

In December 2001 a seminar was organised to establish a network of users. Several Austrian institutions and individuals who are using the research prototype of the Technical Assistance system AUTONOMY or who already purchased the commercial version have followed the invitation to present their experiences and to report about their daily usage of the system. About 60 participants joined the seminar, 9 presentations were given to the audience. It is remarkable, that three out of nine contributions were delivered by non-speaking persons with the help of personal assistants or by using speech synthesizers [2]. Besides the dissemination of already collected experiences the seminar also allowed to establish personal contacts among different users and care persons of several institutions. This also can be expected to ease the exchange of ideas and the co-operation in future.

One of the remaining problems is that the system needs a personal computer (even desktop or notebook) this decreased the mobility of the user but there are also first trials to build a robust, mobile AUTONOMY system. The EU funded R&D project DE-4208 RESORT (Remote Service of Rehabilitation Technology) developed a tele-help system [13] dedicated for RT application. The AUTONOMY system served as one of the first demonstrators and is now downloadable as evaluation version with an integrated Tele-Help functionality [18], [20].

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