ENVIRONMENTAL CONTROL SYSTEMS
for
PEOPLE WITH SPINAL INJURIES

A Report on Research Undertaken by the
ABILITY RESEARCH CENTRE

And funded in part by the
MOTOR ACCIDENTS AUTHORITY OF NSW

September 1999

ABILITY RESEARCH CENTRE

Royal Rehabilitation Centre
600 Victoria Rd RYDE NSW 2112
Ph: 02-9809-7466 Fax: 02-9907-9599
www.abilitycorp.com.au

EXECUTIVE SUMMARY

BENEFITS AND USAGE

- Environmental control systems (ECS) increase the independence of people with spinal injury and this independence is highly valued by them.
- Most people use an environmental control system to control TV/video and lights. Control of a computer and the telephone are also very important to them, but new technologies have meant that people need not rely on an environmental control system for these functions.
- Environmental control systems can improve the quality of relationships with a user's family members and carers. They offer some flexibility in the duties required to be performed by a carer.
- There is no hard evidence to suggest that environmental control systems reduce the need for attendant care for people with spinal injuries at home; further work is needed in this area.

TYPES OF ENVIRONMENTAL CONTROL SYSTEMS

- As well as appliances, lights and infra red devices, environmental control systems can be used to control security systems, telephones, sprinklers, doors, curtains, electric beds and virtually any other device in a home that is electrically operated. They usually operate through infra red, X-10 or Radio Frequency (RF) technology.
- Some environmental control system must be operated from a fixed location. Some require line of sight for effective operation. Some newer systems can be operated from a person's wheelchair. Operation of an ECS from a person's bed can be a vital consideration for many.
- Sometimes an ECS can be controlled directly with a mouthstick. Some systems allow access via a switch in combination with a scanning system. Computer-based systems rely on whatever method the person uses to access their computer. Some systems can be controlled entirely by voice.
- Users require feedback that their commands have been enacted. This is sometimes provided by lights on a display panel, text on a screen or by audio feedback. More basic systems rely on user observation only.
- Systems vary considerably in the way data can be backed up in case of malfunction or power failure.

- There are systems that offer control over a comprehensive range of devices, from a variety of locations using a number of alternative access methods. These systems will be more likely to meet a user's changing needs and preferences.
- On the other hand we note that developments that link different technologies (such as infra red and X-10) allow the creation of much simpler environmental control systems that will be effective for a broad range of users.

USER EXPERIENCES

- Training for users and their carers is vital for the effective operation of an ECS. About 30% of users feel the training they received is not adequate.
- Reliability is a key user concern. Nearly half the users in our survey described their systems as "very unreliable" or "hardly satisfactory". Poor reliability is a major factor in technology abandonment.
- Support is vital, especially in the early stages when customisation and adjustments will often be required. In our study 45% of participants found the support they received to be "inadequate" or "barely adequate".
- Other reasons people cease using an ECS include a preference to have other people perform these tasks, a change in the user's functional capacities or a user's preference to use simpler technology.

RECOMMENDATIONS

- Opportunities should be provided for people to become aware of environmental control systems during their rehabilitation, to raise awareness and stimulate motivation. But the final selection of a system should wait until the person returns home and becomes familiar with patterns of care and gains some experience with their own limitations.
- To offer assistance in this regard therapists require greater knowledge of environmental control systems and training in their operation. The availability of a demonstration centre would greatly facilitate this process.
- The individual patient must be the centre of the process of selection throughout. Individual differences and preferences will have a strong influence on the ultimate patterns of usage of the ECS.
- Recommendations regarding environmental control systems need to take account of future needs, training requirements, and compatibility of an ECS with other equipment. Information on equipment long term reliability, support and supplier performance are generally not available; steps should be taken to generate this information, in cooperation with suppliers in this sector.

- In spite of all care being taken, a person may still end up with a system not matched to their needs. For this reason a system should be created, in cooperation with the industry, for users to be able to trial (rent) an ECS over a certain cost for one year before confirming their purchase.

INTRODUCTION

This study aims to ascertain the role of environmental control systems (ECS) in the lives of people with spinal cord injuries. There have been three main components of this research:

1. An exploration of the experiences of current users of an ECS through a telephone survey (see Appendix A).
2. An evaluation of other contemporary research in this area.
3. An investigation of some practical aspects of ECS usage through on-site testing undertaken at the Moorong Spinal Unit at the Royal Rehabilitation Centre, Sydney.

This report is presented as follows:

PART A: Benefits of Environmental Control Systems

An analysis of the needs and aspirations of people with disabilities regarding domestic independence, as well as an examination of the literature regarding benefits of environmental control systems to users and to those who fund such systems.

PART B: Types of Environmental Control Systems

An outline of available ECS and the development of a typology of ECS to facilitate comparisons.

PART C: Users' Experiences with Environmental Control Systems

The results of our survey and other studies regarding the experience of people in using ECS. This will include the results of our testing at Moorong.

PART D: Key Issues

Implications of this study for the prescription and provision of environmental control systems.

PART A: BENEFITS OF ENVIRONMENTAL CONTROL SYSTEMS

One of the major consequences of spinal injury is a loss of independence. This loss is felt in many areas of the person's life, including mobility, written communication, the management of personal affairs (such as finance, appointments, completing forms), personal care and domestic independence. Loss of independence at the personal level affects the individual in a number of ways. Depending on the level of the spinal injury, the person will face varying limitations in aspects of personal care (dressing, washing, bowel and bladder management, food preparation and eating). Similarly they will to varying degrees depend on others for such domestic activities as opening doors, turning on lights and lamps, using the telephone, and controlling TV, video and other appliances. Van Laere and Duyvejonck note that "in the early stages the patient considers himself useless, and a burden to his environment".[1]

Environmental control systems[2] operate at the level of domestic independence.[3] They seek to give users greater control over domestic appliances. They can be used to control an extensive range of domestic appliances and facilities. These include lights, lamps, heaters, air conditioners, radios, televisions, hi-fi systems, electric doors and beds, security systems and other appliances[4]. According to Dickey, one of the first environmental control systems on the market was the POSSUM, designed primarily for polio victims in the 1950s and 1960s in the UK.[5]

While most definitions of environmental control systems are descriptive, Graf has sought to widen the concept to include "anything that remotely controls electric items in the environment" such as "the door at the grocery store that can be opened or closed via a pressure switch in the floor".[6] However this makes the control of the system incidental rather than purposeful, and removes the ECS beyond the boundaries of meaningful analysis.

---

[1] Van Laere M. and Duyvejonck R., "Environmental control and social integration of a high-lesion tetraplegic patient: Case report" Paraplegia 24 (1986) p. 322

[2] The term 'environmental control system' (ECS) is preferred to the more common 'environmental control unit' (ECU). The latter is an outdated term that was relevant when single control boxes were the basis of these systems. Modern systems involve a range of interactive elements. Thus 'system' is a more appropriate description than 'unit'.

[3] Environmental control systems could also be used at the workplace, although such an application is rare in Australia. See Flippo K. et al., Assistive Technology — A Resource for School, Work and Community, Paul Brooks Publishing, Baltimore, 1995, p. 177. They can also be used in hospital; see Cook A. and Hussey S., Assistive Technology — Principles and Practice, Mosby, St Louis, 1995, pp. 608-609

[4] See McDonald D., Boyle M. & Schumann T., "Environmental control unit utilization by high-level spinal cord injured patients", Archives of Physical Medicine and Rehabilitation, Vol 70, 1989 p. 621. In their study 93% of users perceived the ECS as increasing their independence.

[5] Dickey R. & Shealey S., "Using technology to control the environment" American Journal of Occupational Therapy 1987 (41/11) p. 717. See also Holme S. et al., "The use of environmental control units by occupational therapists in spinal cord injury and disease services", American Journal of Occupational Therapy 1997 (51/1) p. 43

[6] Graf M. Et al., "Environmental control unit considerations for the person with high-level tetraplegia", Topics in Spinal Cord Injury Rehabilitation Winter 1997 pp. 30-31.

Independence

The role of an ECS in increasing the independence of users is a major emphasis in the literature. A study by McDonald et al found that of 29 persons with high level spinal injury who used an ECS for at least one year, 27 reported that it increased their independence.[7] Holme et al comment that "ECUs provide a way for persons with severe disabilities to participate in life activities that would otherwise not be possible, giving them greater independence and enhanced quality of life".[8] Platts and Fraser note that, in relation to environmental control systems, "maximisation of independence through technology is the route for optimal quality of life."[9] In the research by Symington et al one of the main benefits of an ECS was "a heightened sense of independence on the part of the disabled people".[10] Efthimiou found that ECS users "performed more activities independently" than did non users.[11]

Our study endorsed these findings:

- *85% of participants stated that their ECS had given them greater independence.*
- *80% of participants believed their ECS had made a positive difference to their lives.*
  (55% said it made a big difference while 25% said it had helped a little).

Efthimiou's early study of the impact of an ECS on the quality of life for spinal patients noted that the lives of users demonstrated a different activity pattern from those of non-users. He found that "users more frequently participated in educational activities, traveling and phone calls" and "engaged more frequently in social activities". By contrast, non-users were more likely to engage in passive recreational activities.[12] However the study failed to find any statistically significant differences in psychological adjustment. Symington also found that "while the documented comments of the participants reflected a favourable change in their sense of well-being, the statistical analysis revealed no change."[13]

Individual preferences

While environmental control systems can be used to control a variety of household appliances, **it cannot be presumed that all patients will desire to exercise the full available range of control**. Studies suggest that people have priorities — that some

[7] McDonald et al op cit., p. 621
[8] Holme et al op cit. p. 42
[9] Platts R. and Fraser M., "Assistive technology in the rehabilitation of patients with high spinal cord lesions", Paraplegia Vol 31 (1993) p. 286
[10] Symington D. and MacLean J., "Environmental control systems in chronic care nursing homes", Archives of Physical Medicine and Rehabilitation (1986) Vol 67 p. 322
[11] Efthimiou et al, "Electronic assistive devices: Their impact on the quality of life a high level quadriplegic persons", Archives of Physical Medicine and Rehabilitation 62 (1981) p. 133
[12] ibid.
[13] Symington op. cit p. 325

appliances and functions are more important to them than others. The study of these priorities can be approached in one of two ways. The first is to ask users of environmental control systems what functions are most important for them. This may however include a resignation effect — people adjust their priorities to what they are currently able to do. Previous ambitions may diminish in importance because they are no longer seen as "realistic". A study by McDonald et al. determined that operation of the telephone was the most important function (61%), followed by control of the television (21%). Other functions (lights, radio, emergency signal, door and computer) were much lower[14].

The second approach is to ask people what appliances are most important to them, whether they can control them or not. While answers to this question may still be coloured by what a person is able to do, it gives some scope for comparing aspirations with capabilities. This is the approach used in our study. We found that the most important items for the person to control were as follows:

Computer (80%)
TV/video (75%)
Telephone (65%)

When we asked people in our study what they used the environmental control system for, the responses were as follows:

TABLE: Appliances Controlled by Environmental Control Systems

Functions	**Those Using %**
TV/video	80%
Lights	70%
Telephone	45%
Air conditioner	45%
Stereo	45%
Lamps	30%
Bed	20%
Computer	15%
Security System	10%

N=20

[14] McDonald D., Boyle M. & Schumann T., op. cit

Computers

These results are not surprising. The role of computers has increased dramatically over the past 10 years but computers are not usually or necessarily controlled by an environmental control system. They have their own regime of control. These include alternative keyboards, trackballs, joysticks, switches, rate enhancement software, on-screen keyboards, touch pads and voice recognition systems. An environmental control system could be used to switch on the computer, although many computers can be powered up from the keyboard. Also many computers now have a sleep mode that allows them to be left on indefinitely.

Telephones

Access by people with disabilities to telephone technology has also increased significantly over the past decade, with greater availability of hands-free telephones and automatic dialling systems. Many people with spinal injury use a mouth stick in combination with speed dialling and a speaker phone to achieve desired outcomes. Some use a computer modem to dial a hands-free phone. The emergence of operator connection services such as Telstra's *Call Connect* (which is free for people whose disabilities prevent them from using a standard telephone) has also been beneficial. A company in Melbourne has developed a phone that gives the user single switch access to *Call Connect.*

TS Phone by Technical Solutions

Another phone has been developed by Rehabilitation Engineering in South Australia. This phone is based on an adapted voice modem.

The imperative to use an environmental control system to control a fixed phone has diminished in recent years in the light of these developments.[15]

Using a telephone from bed, a wheelchair or when outside the home is still a major concern for people with spinal injuries. Recent developments in mobile phone technology have been beneficial for people with disabilities. Features such as auto-answer and hands-free kits have been helpful. Voice (hands-free) dialling has made a comeback, after a false start several years ago. The *Ericsson T18* for example permits voice dialling and voice answer. Up to 10 different phone numbers can be dialled using your voice. You can respond to an incoming call by saying "Answer" or "Busy".

Relationships with Family Members and Carers

Not only is the control provided by environmental control systems seen as increasing the independence of the user (which is something of value in its own right), but it also serves to improve the quality of relationships with family members and carers. Platts and Fraser[16] argue that "maximum independence is desirable to free the carer from minute by minute tasks such as turning pages, switching lights, TV, etc. This not only frees the carer for other tasks, making the caring task more bearable (and thus easier to recruit carers) but also vastly improves the morale of the disabled person."[17] Symington's study found that "analysis of attendants' feelings indicated a significant improvement in their attitude toward the patients".[18] In our survey 50% of participants felt their ECS had made a positive difference to the family relationships.

Reduced Need for Care?

The question of whether or not an ECS should reduce the need for support from carers is a difficult one. Some studies have suggested possible cost savings from environmental control systems due to reductions in care. Sometimes this is expressed more as an expectation than an empirical fact. Thus the assertion by Bell and Hinojosa: "With the proficient use of assistive devices, personal and public financial savings can be realized with a decreased need for attendant care."[19]

Symington attempted to quantify the savings, and found that the ECS was used to replace "approximately one hour of nursing service per day".[20] However savings in a hospital setting, with easy access to emergency support if needed, and with large numbers of staff who have readily available alternative duties to perform, may not translate easily into a home setting. Also Symington's study does not take into

---

[15] Those with profound disabilities still suffer a significant disadvantage in access to the telephone. Special data commissioned by Ability from the ABS showed that although over 95% of persons with a disability can use a telephone, only 76.3% of those with profound disabilities were able to use a standard telephone. The elderly are highly represented in this group.

[16] Platts R. and Fraser M., op cit. pp. 280-287.

[17] ibid, p. 280. See also Ford J. and Pitt S., "New Directions in Environmental Control", Third Australian Conference on Technology for People with Disabilities — Proceedings (ARATA, 1997) pp. 16-18

[18] Symington op cit. p. 325

[19] Bell P. and Hinojosa J., "Perception of the Impact of Assistive Devices on Daily Life of Three Individuals with Quadriplegia", Assistive Technology 1995 (7) p. 87

[20] Symington op cit., p. 325

account some of the practical difficulties and hidden costs of having an ECS in a hospital. Some of these surfaced in a study by Woods and Jones, who found ECS use in a hospital was thwarted by turnover of trained staff, conflicts between nursing staff and technical staff, and the need to integrate new devices brought in by relatives and friends.[21] The broader issue of patient readiness for an ECS while in hospital will be discussed in Part D of this report.

One Australian study demonstrated cost savings in the home setting. Doessel[22] describes a process whereby people with cerebral palsy with high support needs were assisted to move "from the 24 hour care of an institution to a house or unit where the majority have no rostered night staff and no staff for some 3 to 5 hour periods each week during the day".[23] Use of effective environmental control systems was integral to the apparent success of this project.

However the medical needs of those with cerebral palsy may differ from those with high level spinal injuries. In the case of the latter group the presence of an ECS may alter the mix of activities performed by the carer without altering the basic requirement for their presence. Each case would need to be determined on its merits.

Nevertheless it does appear that the scope for individuals with spinal injuries to live independently in the community, with the assistance of environmental control systems, varies considerably among the States. In Queensland, where more progress in this direction appears to have been made, the choice to live independently has been assisted by an active public housing program, together with accommodation and equipment funding linked to de-institutionalisation. Those who have chosen to live independently have had to make do with only 35 hours of support per week. The individual's right to choose to accept a certain amount of risk in their living situation has been supported.

In this process the role of environmental control systems has been central, in particular the link between the ECS and emergency call systems such as *Vitalcall.* This link would need to be customised for each individual and would need to be completely reliable. Issues such as battery backup also become more prominent for those living on their own.

While this issue has not been addressed properly in the literature, the survey by McDonald et al did make a contribution. They found that the presence of an ECS led to a perception by those with spinal cord injuries that they would be more comfortable for a longer period without an attendant present.[24] The results are summarised in the following table. For example, 51.8% of those with an ECS said they would be comfortable without an attendant for 4 hours, whereas only 25.9% of those without an ECS made such a claim.

[21] Woods B. and Jones R., "Environmental control systems in a spinal injuries unit: A review of 10 years' experience" International Disability Studies 1990 (12/4) p. 139
[22] Doessel S., "Depending on it — Environmental Control When You're Out There on Your Own" Second Australian Conference on Technology for People with Disabilities — Proceedings ARATA 1995 pp. 191-193, and Dickson J. and Doessel S., "Beyond Group Homes" Second Australian Conference on Technology for People with Disabilities — Proceedings ARATA 1995 pp. 185-187
[23] Doessel S., (1995) op cit., p. 191
[24] McDonald et al op cit., pp. 622-3

TABLE: Hours Perceived to be Comfortable without an Attendant (%)

Hours	With an ECS	Without an ECS
0	15.5	29.6
1	14.5	25.9
2	3.7	7.4
3	14.5	11.1
4	51.8	25.9
Total	100.0	100.0

There was no attempt in McDonald's study to correlate these perceptions with level of spinal injury. Nevertheless these results do raise the possibility that the quantum of carer presence, as well as their range of duties, could be influenced by an ECS.

Others argue that the benefits for the user in terms of greater independence justify the use of an ECS, even when no cost savings apply. Platts and Fraser argue that "the necessary presence of a carer near to hand should not deter the use of assistive technology to increase independence"[25]. Graf et al note that "With a caregiver available, it may not be necessary to have a piece of equipment to control various items in the environment. Some individuals are able to identify specific times they will be alone, or specific functions they wish to perform in order to enhance their independence. Even with 24-hour care, it may be very important for self-esteem and empowerment to control one's environment."[26]

Conclusion

The benefits of environmental control systems are consistently reported in the studies. Greater independence is the most common benefit identified. There are also benefits in terms of the quality of relationships with family members and carers.

Strong individual differences and preferences are evident in our study and other studies. These suggest that most users will mainly use an ECS to control a lesser range of appliances and functions than the ECS is capable of controlling.

It is possible that the presence of an ECS may, in certain circumstances, reduce the need for attendant care. However this has yet to be established in studies involving patients with spinal injuries.

[25] Platts R. and Fraser M., op cit.
[26] Graf et al., op cit., p. 38

PART B: TYPES OF ENVIRONMENTAL CONTROL SYSTEMS

The range of environmental control systems is expanding rapidly. Technological developments continue to open up new opportunities for people with disabilities to control their environment. Concurrent developments in areas such as home automation have served to stimulate innovation as well as reduce costs.

For the purposes of this study a typology has been developed to facilitate comparisons between environmental control systems. It seeks to highlight salient features of these systems.

- **RANGE OF CONTROL**

  This tells us what devices and appliances the user is able to control with the environmental control system. Is it limited to infra red devices? Is it limited to X-10 devices? Can it do both? Can it control the telephone? Can it control specialised devices such as electric beds and electric doors? Can it operate appliances in other parts of the house?

- **BASE OF CONTROL**

  Can the system be operated from a variety of locations or just one? Can it be operated from bed? Can it be operated from a wheelchair?

- **METHOD OF CONTROL**

  How does the user control the system? Do they use a control panel? Do they use a computer? Do they use a switch (direct or with scanning)? Is the system controlled by voice? Can some processes be automated, for example, through timers?

- **FEEDBACK**

  How does the user know that their command has been implemented? Is feedback given by direct observation? Or is feedback given through sound or visual feedback?

- **BACKUP**

  How can the user backup settings? What backup is provided in the event of power failure?

These factors are not the only ones relevant for evaluating environmental control systems. Ease of use, and the quality of training and support are also vital considerations. These will be explored in Part C when we examine the results of our user survey. The aim in this section is to show the range of environmental control

systems available and their main features. General comments are made in this section; more detailed technical information on specific systems is included in Appendix B.

Range of Control

Technologies for the control of appliances and devices in the home are usually based on infra red, X-10 type systems[27] or RF (radio frequency).

Infra red enables control of appliances such as the television, video and late model stereo systems. Usually an infra red controller (such as the ubiquitous television remote control) is used. The unique codes of different controllers can be incorporated into a single device that "learns" the codes from other infra red controllers. Infra red offers the advantages of portability and low installation costs. It also allows graduated control functions (such as volume control) rather than just on-off. One limitation is that usually the controlling device must broadly be pointing at the appliance to be controlled, although some relay devices are available to transfer signals to another room. The *PowerMid Transmitter* for example converts infra red signals to RF and sends them to the *PowerMid Receiver*, which converts them back into infra red.

Infra Red Controller

X-10 technology is based on the X-10 Power Line Carrier (PLC) signalling "language" that enables control signals to be transmitted anywhere in your house over existing 220/240v electrical lines. X-10 has been a de facto standard for sending commands over existing electrical wiring. It was developed initially by Pico Engineering in Scotland as a system of remote control for stereo equipment. The basic protocol is built around the standard binary bit string giving 256 address capability. To make it easier to understand, Pico Engineering divided up the addresses into 16

[27] The term 'X-10 type' refers to systems based on wiring or cabling.

letters, each with 16 numbers. Individual appliances are plugged into X-10 receivers. These can be set to a unique address. Activation of the appliance is achieved through X-10 controllers. These controllers can be computer interfaces, control panels, telephones and remote controls (RF).

X-10 Appliance Module (receiver)

While X-10 still dominates the systems based on control over existing electrical wiring, some alternative standards have emerged. CEBus (Consumer Electronics Bus) is a communications standard for in home networks developed by the Electronics Industry Association (EIA) and the Consumer Electronics Manufacturers Association. It was in development for over a decade and approved in 1992. CEBus is an open standard that means anyone can develop products using this communications protocol. The disadvantages of CEBus are the relatively few products currently available and the very high cost of those products.

Radiofrequency transmission (RF) is another method of controlling components of an environmental control system. This system is already used in homes to control garage doors and portable phones. It has a greater range than infra red and does not require line of sight between devices. Signal strength and interference can be a problem in some settings.

These systems of control can be combined to increase the range of control of an environmental control system. For example, products have emerged that enable infra red transmitters to control lights and appliances through X-10 technology. Devices are also available that enable RF remote control devices to control X-10 devices.

As well as appliances, lights and infra red devices, environmental control systems can be used to control security systems, telephones, sprinklers, doors, curtains, electric beds and virtually any other device in a home that is electrically operated.

The table below shows a list of household appliances and the most common ECS technologies used to control them.

TABLE: Methods of Control for Common Devices and Appliances

DEVICE/APPLIANCE	ECS METHODS OF CONTROL
Air conditioner	X-10 for on/off
Bed (electric)	X-10 with special module or specialised device
Computer	X-10 for on-off
Curtains (electric)	X-10 with special module
Doors (electric)	X-10 with special module
Fan	X-10 with on-off
Heater	X-10 with on-off
Lamps	X-10 with on-off and dimmer
Lights (fluorescent)	X-10 with on-off
Lights (incandescent)	X-10 with on-off and dimmer
Radio	X-10 with on-off or infra red
Security system	X-10 with special modules
Sprinkler systems	X-10 with special module
Stereo system	Infra red
Telephone	RF or modified device
Television	Infra red
Video	Infra red
Windows (electric)	X-10 with special module

Base of Control

Of considerable concern to people with spinal injury is their ability to control devices when their own mobility is limited, for example, when they are in bed. [28] Some environmental control systems do not meet this need because they require the user to be in front of a computer or control panel in order to control appliances and devices. Systems based on infra red generally require the user to be broadly in line with the receiver, and this can also be a limitation. Activation of a switch can be troublesome for many people with spinal injuries when they are in bed. Voice activated systems offer considerable flexibility.

[28] See Porter M. and Dean J., "Home Modifications for a High Level Quadriplegic — A Case Study", Third Australian Conference on Technology for People with Disabilities — Proceedings (ARATA, 1997) p. 12

> *"Of considerable concern to people with spinal injury is their ability to control devices when their own mobility is limited, for example, when they are in bed."*

The issue of **feedback** becomes important when a person seeks to control appliances from a fixed location. The person will need verification that their command has been executed.

Some new generation ECS offer control from a person's wheelchair. These operate through RF signals to a base unit. The *Simplicity* system, for example, has remote switch and remote microphone options. The *Sicare Pilot* uses a computer to train voice commands but can then be used to control both infrared and X-10 devices by voice. The Proteor *NEMO* is similar. All can be operated by switch or voice. All can be used to control the telephone as well. These are comprehensive systems but also the most expensive.

NEMO

Sicare Pilot

Method of Control

The available methods of control distinguish an ECS from generic home automation systems. The latter often rely on dexterity that is not available to a person with a high level spinal injury.

Cook and Hussey[29] consider the issue of 'control enhancement' for disabled users of technology. They distinguish between 'direct selection' methods and 'indirect selection'. For instance, a large remote control device is a control enhancer that gives a disabled user direct selection of ECS functions.

Big Remote

The *GEWA Prog* is a control enhancer that enables direct selection but also permits a system of scanning — a method of indirect selection. Other similar devices are the TASH *Relax* (and *Mini Relax*) and the *Scanning Director*.

GEWA Prog

[29] Cook and Hussey, op.cit., p. 328 ff

TASH Mini Relax

TASH Relax II

Scanning Director

Voice control

Of major interest to people with spinal injuries have been systems of environmental control that can be controlled by voice. Early systems of this type were generally unreliable and left a legacy of suspicion regarding this technology. Summers (1988) for example found that only 7 people from a group of 19 found a voice activated ECS to be effective: "Most found difficulty in getting the machine to 'wake up' despite repeated training. Misrecognition of appliance names frequently led to the wrong appliance being switched on or off. The need for frequent repetition of commands led to annoyance and frustration." Background noises (such as children, dogs, television and radio) interfered with the system.[30] Later systems such as *Simplicity*, *Mastervoice*, *Sicare Pilot*, *HAL 2000* and *NEMO* use more advanced technology, although poor training and/or setting up can still lead to user frustration with these systems.

[30] Summers G. and Cochrane G., "Evaluation of a voice activated environmental control system for disabled people" Clinical Rehabilitation 1988 (2) p. 235

Computer-based Systems

Some systems are available that are controlled by a computer. Most of these use the power of a PC to program the system for timed events or clusters of events. Timers can be especially useful as they completely automate the control process once they are set up. Once programmed the system does not require the PC to be on in order for the ECS to operate.

Because these systems rely on a PC they rely on the control systems the user already has in place for accessing the computer. The ECS in these cases is essentially a generic home automation system. Examples include *IBM Home Director*, *HomeBase*, *TotalHome, Jeeves* and *Active Home.* Some of these systems also allow control of functions through a telephone, either from within the house or from outside.

While computer based systems are limited in that they operate from a fixed location, they also have a number of advantages. They have a dynamic display with graphical interfaces, making them more intuitive to use. The process of backing up is greatly simplified. The computer, of course, can be used for many other purposes. An ECS based on a computer may suit a person who spends a lot of time in front of their computer.[31] The idea of using simple computer networks in the home to enable operation of a computer ECS from various locations has not yet been properly exploited.

Feedback

It is vital for the safe and effective operation of an environmental control system that the user receives adequate feedback on the result of commands issued through the system. Safety concerns can arise in the case of appliances such as heaters and security issues can arise with systems that allow control of the front door.

In some cases users are able to see directly the result of their commands, for example, when changing the channel on a television set or when a light is turned on or off. In other cases the user will rely on the feedback given through the environmental control system. This can be visual, through a display or a control panel with lights, or it can be through a system of audio feedback. Some environmental control systems offer both methods of feedback. Many display panels are LCD and can be difficult to read in poor light. They often use words rather than symbols, and this too could make them more difficult to use by people with poor vision.

"It is vital for the safe and effective operation of an environmental control system that the user receives adequate feedback on the result of commands issued through the system."

[31] Simpson R. et al., "A Computer-based environmental control system "RESNA 96 Proceedings, p. 124

Wards and Jones noted that "confusion of novice uses was also often apparent as a result of the same lights on the display panel being used to depict both the function status (i.e. on or off) and function selection during scanning. For example, if a number of consecutive functions were already switched on, it was easy to lose track of where the scanning was because the lights being scanned were already on."[32]

Backup

Backing up settings is important for users of environmental control systems, in the case of malfunction or power failure. Some systems (such as *Simplicity*) back up the settings internally, even when the power is off. Other systems (such as the *GEWA Prog*) allow settings to be backed up to a computer. Backing up to a computer allows a wide variety of data storage options.

The issue of power backup is a key concern for users who live alone for some of the time and especially for those who link their ECS to a system such as *Vitalcall*. Systems that are based on portable control devices rely on small batteries that must be replaced periodically. The *GEWA Prog*, for instance, has a battery with an estimated life of 12 months. For such units a careful regime of battery testing and replacement would guarantee continuous operation of the unit itself.

More complex systems have more demanding backup requirements. The *Simplicity* for example has only one hour battery backup. Those who rely on such systems for operating the telephone would be vulnerable should the power fail when they were asleep. For these systems a more extensive battery backup arrangement should be customised, especially for people living on their own.

There are advantages for those who do not rely on their ECS in order to control their telephone. As the telephone is usually preserved in most cases of power failure, these people would still have access to assistance via the telephone. Alternatively access to a mobile phone could also be set up for use in emergencies during power failure.

The issue of backup operation of critical functions during power failure will require specific customisation for each user.

Conclusion

Environmental control systems can vary considerably in the range of devices controlled, the base of control, the method of control available to the user, the feedback offered to the user, and the methods of backup provided. *These differences can be important in linking the ECS to a person's needs and capacities.*

We note that there are systems that offer control over a comprehensive range of devices, from a variety of locations using a number of alternative access methods.

[32] Woods and Jones op cit. p. 137

These comprehensive systems (such as *Simplicity, Mastervoice, Sicare Pilot* and *Nemo*) will be more likely to meet a user's changing needs and preferences.

On the other hand we note that developments that link different technologies (such as infra red and X-10) allow the creation of much simpler environmental control systems that will be effective for a broad range of users.

PART C: USERS' EXPERIENCES WITH ENVIRONMENTAL CONTROL SYSTEMS

We have already noted that users of environmental control systems tend to use their systems to control a specific range of appliances. Prominent among these are the television, VCR and lights. Other devices such as the computer and the telephone are important to the independence of people with spinal injuries but do not necessarily require an environmental control system for their operation.

As with most technology, there can be a considerable gap between the technical capabilities of an environmental control system and its effective use by a person with a disability. Issues such as training, reliability and support are important in enabling an individual to use an environmental control system to its full potential. These are considered below.

Training

Environmental control systems are complex and users require adequate training in order to operate them effectively. The operation of many of these systems is far from intuitive. We must remember that people with spinal cord injury often confront technologies such as environmental control systems out of necessity rather than personal interest. Many of them have no natural inclination towards such devices. Proper training can well be decisive in shaping the user's future experience with these systems.

The need for training applies not just to users but also to family members and carers who will often be responsible for adjusting and maintaining the systems once they have been installed.

Even basic environmental control systems require training. Several basic systems involving infra red and X-10 devices were tested for several months at the Moorong Spinal Unit, at the Royal Rehabilitation Centre in Sydney. There were no patients with high level spinal injuries during this period, so all were able to use remote control devices either directly or with a switch. The *GEWA Prog* was the most popular device. However all users required training in the use of the device. Access to different levels of function with this device was not intuitive for patients or staff.

Studies suggest that often the training provided with environmental control systems is inadequate. *In our survey 80% of users were provided with training in the operation of their environmental control system, but nearly 1/3 of these described the training they received as "inadequate" or "barely adequate".* Other studies have produced similar findings. In the survey conducted by McDonald et al only 70% of respondents believe they had received sufficient training from the person who installed the environmental control system (sales representative or therapist). Only 64% of users

felt that their attendants understood how to operate the system.[33] Holmes' survey of occupational therapists asked respondents to nominate reasons why users of environmental control systems stopped using these systems. Improper training was the third most common reason for non-use.[34]

Reliability

An environmental control system that fails to operate reliably is much more than an inconvenience. It can cause intense frustration for the user. At worst it can be dangerous, when appliances fail to operate as required. *For those living on their own, reliability is essential.*

Yet it is difficult for those who recommend environmental control systems to incorporate equipment reliability into their recommendations. As with most assistive technology, there is a lack of firm data on the reliability of equipment.

In our survey:

- *55% of respondents said their environmental control systems were "very reliable" or "mostly reliable".*
- *35% described their systems as "hardly satisfactory"*
- *10% described their systems as "very unreliable".*

When asked what factors would make their system work better for them, 55% included "greater accuracy and reliability" as one of their nominated factors.

Of those who had ceased using their ECS, 60% gave "lack of reliability" as one of the reasons.

In the survey by Holme et al poor reliability was the second most common deterrent to consistent use of a person's environmental control system.[35] Poor device performance is a major factor in assistive technology abandonment in general.[36]

Clearly reliability is an important issue for environmental control system users, yet this issue has been bypassed by most of the studies and surveys mentioned in this report.

Support

[33] McDonald et al op cit., p. 623
[34] Holme et al op cit., p. 46
[35] ibid p.47
[36] Phillips B and Zhao H., "Predictors of Assistive Technology Abandonment" Assistive Technology 1993 (5) 36-45

Any technology can have problems once it is in the possession of the user. They are many reasons for this, including user errors, settings that are disturbed by family members or carers and equipment malfunction. Often the systems need to be fine-tuned or customised. For example, in our study half of the participants said their ECS required modifications to suit their specific needs. These types of problems tend to occur early in the user's experience with the system and it is at this time that adequate support is most essential.

Again this is an area overlooked by the published studies on environmental control systems. It was clear in our study that most users (85%) rely on the equipment suppliers for support. While 60% of respondents said they received as much support as they needed, or that they didn't require any support, the remaining 40% received very little or no support. *A total of 45% of respondents regarded their training and support as "inadequate" or "barely adequate"*. 35% of respondents nominated "better support" as a factor that would have made the system work better for them. *Of those who had abandoned using their ECS, 60% nominated "lack of support" as one of the reasons*. This is another important issue that is overlooked by those who prescribe environmental control systems for their clients.

> *"User frustration and poor ECS performance may result from a poor prescription in the first place."*

The above factors — training, reliability and support — are what we might call *intrinsic factors* affecting people's experience with environmental control systems. They are factors that relate to the ECS itself, the technology and support services that surround it.

Even here a word of caution is called for. User frustration and poor ECS performance may result from a poor prescription in the first place. This is not really an intrinsic factor but may manifest as one. None of the studies referred to in this report includes this as an explanation of a user's poor experience with an ECS, yet one suspects it must be relatively common, especially given the lack of knowledge about environmental control systems on the part of funding organisations. We return to this issue in Part D of the report.

We now turn to other factors, *extrinsic factors* that lead people to abandon use of an ECS. These are factors distinct from the technology itself.

User Prefers Another Person to do the Tasks of an ECS

This was the main factor reported for non-use of environmental control systems in the study by Holme et al.[37] Where care is available, the person may choose to make use of

[37] Holme at al op cit., p. 46

the services of this person, rather than use an ECS. There are many factors that may influence such a choice. Sometimes operation of an ECS is too physically draining. Sometimes pain and discomfort overpower the desire to be more independent through an ECS. The person with a spinal cord injury may be socially isolated and prefer the personal contact available through a carer to the impersonal operation of an ECS. Further research is required to identify and evaluate these factors.

For those without the availability of carers, the use of an ECS becomes more of a necessity.

Changes in the User's Functional Abilities

In some cases a person will cease using an ECS either because their capabilities have improved (so that they no longer need an ECS) or deteriorated (so that they can no longer use the ECS).

User Finds a Simpler Way

In some cases a user may abandon use of an ECS because they have found simpler ways of achieving the same results. This was the case with one of the participants in the study by Bell and Hinojosa, who abandoned an ECS in favour of a remote control and speaker phone accessed with a mouthstick.[38] They concluded that *"the simplicity and ease of using equipment proved to be a crucial factor in how often a device was used, or how useful it was perceived to be, and therefore, its impact on their daily lives."*[39]

In our testing of equipment at the Moorong Spinal Unit it appeared that users had a preference for the simplest method of achieving a task. They preferred using a remote control device rather than jumping to a high tech solution such as a voice activated system.

Other Factors

In our study we attempted to isolate factors that shaped a person's experience with their ECS. We did this by defining "successful users" as those who:

1. used their ECS at least daily;
2. stated that the ECS had made a positive difference to their lives; and
3. were able to nominate a specific area of benefit (such as independence).

[38] Bell P. and Hinojosa J., op cit., p.91
[39] ibid

On the basis of these criteria we identified five unsuccessful users (25%). Upon more detailed examination we confirmed that reliability of the ECS and the quality of the training and support received were the major factors in shaping a person's experience with their ECS. *There was no evidence in our research that people who paid for their own systems had any different experience from those whose systems were funded by insurance companies.* Eight participants had systems paid for by insurance companies; six of these (75%) were "successful" users, the same proportion as for the whole group. Nor did level of disability or period of disability have an influence.

There is a hint in our data that females are more inclined to have unsuccessful experiences with an ECS than males, but the small number of females in the study (4) guards against firm conclusions in this regard.

Conclusion

There are a variety of reasons why a person's experience with an ECS will be terminated. Some factors, such as reliability, training and support, arise because of the quality of the system provided and of the necessary services associated with the supply of that system. From our research these appear to be major factors in shaping a person's experience with an ECS. If these factors were improved, then the person may have had a more successful experience with their ECS.

But there are other factors that are not related to the specific system. The person may prefer to forego greater independence for the sake of getting a carer to undertake domestic tasks. The person's functional capacities may have changed. The user may have found simpler ways of achieving the same ends.

PART D: KEY ISSUES

This report has shown that environmental control technology is available to enhance the independence and quality of life of people with spinal injury. It has also shown that there are many pitfalls in the processes of prescribing and supplying environmental control systems, to the extent that many users are frustrated and some abandon their systems.

It is also quite likely that inadequacies in the prescription process will manifest themselves as equipment or support problems, as the person experiences frustration with a system that is inappropriate to their needs and circumstances.

What follows is a suggested process for recommending and supplying environmental control systems. It draws together insights from the literature and our own research.

1. During Rehabilitation — Raising Awareness

There is an apparent controversy in the literature between those who believe environmental control systems should be provided early in the patient's rehabilitation and those who believe the ECS should only be prescribed when the patient returns home. Efthimiou argues for the early introduction of an ECS for patients: "Since the ECS and other adaptive devices have a positive impact on the lives of users, patients should be exposed to them as early as possible in their rehabilitation programs to promote their acceptance."[40] Platts and Fraser argue that "the importance of early introduction of technology to form the ground in which the seeds of motivation and rehabilitation will flourish cannot be over-emphasised"[41]. They argue that while it is true that a patient will often reject assistive technology until they have come to accept their circumstances, it is also true that "psychological rehabilitation will not evolve unless there is visible and tangible evidence of the possibilities of overcoming the physical limitations"[42]. Wood and Jones also argue in favour of "environmental control facilities in acute spinal injuries units", even though they note that "patients' initial response to environmental controls varies widely".[43]

> *"the importance of early introduction of technology to form the ground in which the seeds of motivation and rehabilitation will flourish cannot be over-emphasised"*
>
> *— Platts and Fraser*

[40] Efthimiou op cit., p. 131
[41] Platts R. and Fraser M., op cit., p. 285
[42] ibid
[43] Woods and Jones op cit., p. 139

Others such as Bell and Hinojosa argue that an ECS should be prescribed "with the home environment in mind" and that "the therapist must observe the devices being used in the home". They point out that "the performance with a device as an inpatient may be very different from performance at home".[44]

Graf takes an approach that balances these two positions. She acknowledges that people with recent injuries may be overwhelmed by the range of lifestyle changes confronting them, and that this may restrict their capacity or interest in exploring environmental control systems. However she notes that *"the initial rehabilitation program may be the only opportunity to introduce these ECU systems to individuals with high tetraplegia"*.[45] She therefore recommends a two-stage process. First, the patient "should be evaluated for an ECU during the initial rehabilitation program by a team who is well versed in the technology available". They should "define an ECU, educate the consumer as to how different ECUs operate, and explain the variety of tasks and operations ECUs can perform".[46]

Second, "rather than prescribe an ECU during the initial rehabilitation program, it is most often recommended that consumers return home, gain experience with their new limitations, home environment, attendant care, and so forth, and return at a later date with a specific list of their wants and needs".[47]

The emphasis then, during the rehabilitation phase, should be placed on making patients aware of environmental control systems and their capabilities. They should not be locked into a system at this stage. Even an initial assessment of access methods should be regarded as conditional at this time, because the patient's functional status can alter in the early stages. Also there may be a variety of access methods available, depending on what environmental control system is ultimately chosen.

DURING THE ACUTE REHABILITATION PHASE

- ***Evaluate***
- ***Educate***
- ***Demonstrate***

There is another reason why environmental control systems should not be prescribed during the rehabilitation phase. An important element of the secondary rehabilitation process is to train the person to undertake as many normal activities as possible, with

[44] Bell and Hinojosa op cit p. 92
[45] Graf op cit., p. 37
[46] ibid p. 40
[47] ibid

minimum assistance. In this process the lowest level of technology available will often be preferred. For example, training a person to use properly positioned large-button light switches may in many cases be preferred to an environmental control system that performs this task. An occupational therapist may prefer a person to use what hand function they have remaining rather than adopting technology that gives the person a more efficient method of achieving desired outcomes. For example, the therapist may prefer the patient to persevere with handwriting, even though this may be slow and uncomfortable; a rehabilitation consultant may prefer the person to use computerised voice recognition, so that they can keep up with college essays. Some describe this as a difference between augmentative technology and alternative technology.[48]

The different opinions of those who emphasise a person regaining physical function and those who emphasise a person achieving efficient outcomes is a necessary one. The priority of one perspective or the other will depend on individual circumstances. But its presence guards any hasty adoption of environmental control devices at this early stage.

Expertise and Availability of Equipment

The successful implementation of this step requires therapists who are aware of and competent in using environmental control systems, as well as the availability of demonstration ECS equipment. Neither of these factors applies in Australia. In common with their counterparts elsewhere, Australian occupational therapists are generally not trained in the use of environmental control systems.

Holme's survey of over 100 occupational therapists in the USA found that "few respondents were knowledgeable of the variety of ECUs available for evaluation and recommendation to clients". She proposes a checklist of what occupational therapists need to know in order to properly evaluate and recommend environmental control systems: [49]

CHECKLIST — WHAT A THERAPIST NEEDS TO KNOW

- *what devices are available and appropriate for client needs;*
- *where the devices can be purchased;*
- *how to get funding for the devices;*
- *how to evaluate and train clients in using the devices;*
- *what follow-up to pursue after acquiring the devices;*

[48] Cook A. and Hussey S., op. cit, p. 576
[49] Holme et al op cit., p.43

- *how to document the need of equipment, its installation and training in its use.*

Without this knowledge therapists may refrain from recommending an ECS, prescribe what worked for their last client or what someone else has prescribed. They will be at the mercy of sales representatives.

The issue of availability of demonstration equipment is not unrelated to the need for therapists to become familiar with ECS equipment. To my knowledge *there is no location in Sydney where one can go and see a variety of environmental control systems in operation in a simulated home setting.* Costs preclude individual rehabilitation centres having their own range of ECS equipment. While this situation exists people will continue to make inappropriate recommendations.

2. Start with the Person

It is not appropriate merely to link a person's functional capacities to the available technology. *The process must begin with the individual, and the individual must remain its central focus throughout.* [50] As Bell points out, "it is the individual with the disability who decides whether to use a device".[51] Phillips' study established that "when users' opinions are considered in the selection process, devices are more likely to be retained… consumer involvement in planning and decision-making enhances the likelihood of a successful outcome".[52]

"It is not appropriate merely to link a person's functional capacities to the available technology. The process must begin with the individual, and the individual must remain its central focus throughout."

The individual's acceptance and use of a device will depend on a variety of factors, including such basic concerns as appearance and image. Individual tolerances and preferences regarding technology vary: some relish all the latest technology, while others may be prepared to trade-off outcomes for the greater sense of control that comes with simpler technology. Bell's study showed that "simplicity and ease of

[50] See Porter M. and Dean J. op cit., p. 12, and Cook A. and Hussey S., op cit., p. 602.
[51] Bell op cit., p. 87
[52] Phillips op cit., p. 42

using equipment proved to be a crucial factor in how often a device was used, or in how useful it was perceived to be, and therefore, its impact on their daily lives".[53]

It is most likely that the individual will not know their own mind on such matters until they have returned home for a period. Only then will they truly understand how their functional limitations translate into their home environment. In time they will have a greater understanding regarding patterns of attendant care, their daily routines and their own preferences and aspirations. Some of the issues the individual needs to consider at this point are listed by Graf[54]:

CHECKLIST — ISSUES FOR THE INDIVIDUAL TO CONSIDER

- *Will the person be alone for periods of time throughout the day?*
- *Will the person be in the home environment only, or be attending work or school?*
- *What are the person's avocational interests (music, TV, movies, going outside, etc.)?*
- *How will the person enter and exit the house?*
- *How will the person access the phone?*
- *How will the person alert someone in case of emergency?*
- *Will the person need to operate devices from both bed and wheelchair?*

The role of the therapist at this stage is to listen carefully. They can raise issues for the individual to consider, but ultimately they are assisting the person to come to their own mind on these issues.

3. Make Comprehensive Recommendations

The time comes for the therapist, armed with information about the individual's preferences, to prescribe an ECS for the person involved. While every effort should be made to consult with the individual throughout the process, there comes a time when the most appropriate system needs to be nominated and recommendations made to those who will fund such a purchase.

Some of the issues that the therapist will need to consider are shown below:

ISSUES FOR THE THERAPIST TO CONSIDER

[53] See Bell op cit., p. 91.
[54] Graf op cit., p. 38

- *What is the person's best means of access for controlling the system? This will need to take account of the person's muscle strength, range of motion, endurance, sensation capabilities, visual/aural/perceptual status, gross and fine motor coordination, and their cognitive status.*
- *What are the client's likely future needs? Will their functional status change? Is an expandable system required?*
- *How would the proposed system integrate with existing equipment, such as wheelchair and computer?*
- *Is the system of feedback provided by the ECS adequate for this person?*
- *How will this system operate in the event of power failure?*
- *What type and amount of training will this person require? What training will the person's carers require?*

Issues of Reliability

There is an additional set of information ideally required for a sound prescription of an ECS for an individual. This concerns the following:

- *reliability of the particular item*
- *amount and quality of support offered by the supplier*
- *procedures for repair and replacement of faulty components*
- *procedures for future updates and upgrades*
- *future viability of the supplier.*

Such information is not currently available to consumers, therapists, funding bodies or insurance companies. They must rely on anecdotal information and accumulate experience based on small numbers of clients.

I would propose two initiatives to overcome this problem. First, *steps should be taken to monitor and evaluate people's experiences with environmental control systems* (and other assistive technology for that matter). This could be done in a number of ways. Insurance companies and perhaps other funding bodies should arrange for an independent organisation (such as the Independent Living Centre) to obtain confidential information from consumers regarding their use of their environmental control system, the reliability of the system, and the quality of the support and training they have received. This information should be collated periodically and made available to those who prescribe such systems. Systems or suppliers with chronic poor performance should be excluded from future funding.

Second, all parties to this process should meet together to work out a *service charter* to operate in this sector. Those who supply environmental control systems should agree to meet some minimum standards regarding training, support (including reasonable accessibility by phone), upgrades and the availability of demonstration equipment. This would take some of the guesswork out of the therapist's role in prescribing systems.

4. The Need to Trial Equipment

Even with all reasonable precautions taken, it is still possible that a person may end up with an ECS that is not appropriate to their needs. This is most likely to occur during the first year. Phillips' study of assistive technology abandonment found that abandonment rates are relatively high in the first year of device use. She suggested that equipment could be loaned or rented during this time.[55]

It serves no one's interests to have expensive equipment sitting in cupboards. It would make sense in my view to rent environmental control systems above a certain cost during the first year of use. Arrangements would need to be made with suppliers for this to occur. Such a process should enable a closer match between the user and available technology. It should also result in cost savings to insurance companies and other funding institutions.

SUMMARY OF NEEDS AND RECOMMENDATIONS

1. *During the acute rehabilitation phase the emphasis should be placed on educating the individual and demonstrating ECS options. An ECS should not be prescribed until the individual has returned home for a period.*

[55] Phillips and Zhao op cit., p.43

2. *Knowledge about ECS options should be included in occupational therapy courses.*
3. *A facility is required where therapists and others could examine a variety of ECS options in a simulated home setting.*

4. *The individual must remain the central focus of the process of prescribing an ECS. Individual preferences must be respected.*

5. *A process should be established for independent monitoring and evaluation of people's experiences with their ECS. Those who fund the purchase of an ECS should act on these experiences in their future purchasing decisions.*
6. *A charter of service standards should be established in this area for those who supply environmental control systems. This should be done in collaboration with suppliers.*
7. *Provision should be made for people to trial or rent expensive environmental control systems for 12 months prior to purchase.*

A concluding word…

The quality of life at home for these individuals with quadriplegia is profoundly influenced by their ability to use assistive technology to achieve and optimise function. Because of the severe physical limitations, the ability to perform a task with any degree of independence is based upon the " fit" between the device and the user, the environment in which the equipment is used, and the appropriateness of training the user with the device.

Bell P. and Hinojosa J., op cit p.93

Graeme Smith

Director
Ability Research Centre

APPENDIX A: TELEPHONE SURVEY

Participants from the study were drawn from a number of sources. Leaflet inserts were placed in several disability magazines. Insurance companies and rehabilitation organisations were contacted. The study was promoted through various listservs.

We also made a direct approach to suppliers. We did not ask for names to be supplied to us. Instead we arranged for an officer of the Australian Quadriplegic Association to act as an intermediary. He received the names and invited people to participate; only the names of those who agreed to participate were passed on to us.

A total of 20 participants agreed to participate in the study.

The study proceeded by way of a telephone survey of participants.

SURVEY QUESTIONS

Section A: Personal Background

1.	AGE	What is your current age?
2.	GENDER	What is your sex?
3.	COUNTRY	In what country were you born?
4.	LANGUAGE	What language do you speak at home?
5.	POSTCODE	What is the postcode of your home address?
6.	EDUCATION	What is your highest level of education?
7.	WORK BEFORE	What job did you have before your injury?
8.	WORK NOW	Are you employed now?
9.	INDUSTRY NOW	If so, in what industry do you work?
10.	HOME BEFORE	What were your living circumstances before your disability?
11.	HOME AFTER	Where were you discharged from hospital?
12.	HOME NOW	What are your living circumstances now?

Section B: Disability Details

13. DISABILITY — What is your major disability?

14. LEVEL — If you have a spinal cord injury, which level is it at?

15. COMPLETE — Is your injury:
    a) complete
    b) incomplete

16. PERIOD DISABLED — How long have you been disabled?

Section C: Home Context and Capacities

17. APPLIANCES — Which of these items do you have at your home?
    a) lights
    b) lamps
    c) telephone
    d) television/video
    e) electric bed
    f) security system
    g) air conditioner/heater
    h) front door
    i) stereo
    j) computer
    k) other (specify)

18. CONTROL WITHOUT ECS — Which of these items can you control independently?
    a) lights
    b) lamps
    c) telephone
    d) television/video
    e) bed
    f) security system
    g) air conditioner/heater
    h) front door
    i) stereo
    j) computer
    k) other (specify)
    l) none

19. IMPORTANCE — Which 3 of these items are most important to you?
    a) lights
    b) lamps
    c) telephone
    d) television/video
    e) bed
    f) security system
    g) air conditioner/heater
    h) front door
    i) stereo
    j) computer
    k) other (specify)

20. WHO HELPS Who controlled the above appliances for you prior to your ECS?
    a) Partner
    b) Family member
    c) Carer
    d) Friend
    e) Other
    f) No one

Section D: Environmental Control System Usage Now

21. ECS TYPE Which ECS do you use?
    a) X10s command unit
    b) X10 Powerhouse
    c) Mastervoice
    d) Simplicity Voice
    e) Simplicity Switch
    f) Jeeves
    g) Envicon
    h) Butler in a Box
    i) Other

22. CONTROL HOW How do you control your ECS?
    a) Voice
    b) Direct Switch
    c) Switch and scanning
    d) Voice and switch
    e) KeyPad
    f) Telephone
    g) Computer
    h) motion sensor
    i) timer
    j) other

23. CONTROL WHERE From where do you control your ECS?
    a) bed
    b) wheelchair
    c) front door
    d) study
    e) living room
    f) other

24. CONTROL WHAT What do you control with your ECS?
    a) lights
    b) lamps
    c) telephone
    d) television/video
    e) bed
    f) security system
    g) air conditioner/heater
    h) stereo
    i) other (specify)

25. SUPPLIER — Who paid for your ECS?
    a) Self
    b) family/friends
    c) charity group
    d) insurance company
    e) other
    f) no answer

26. START USING — When did you start using your ECS?
    a) Up to one year after disability
    b) 1 - 2 years after disability
    c) 3 - 4 years after disability
    d) 5 - 10 years after disability
    e) over 10 years after disability

27. HOW OFTEN — How often do you use your ECS?
    a) Many times a day
    b) 2 - 3 times a day
    c) Once a day
    d) 2 - 3 times a week
    e) rarely
    f) never

28. USE MOST FOR — What do you use your ECS most for?
    a) telephone
    b) lights
    c) television
    d) bed
    e) security
    f) stereo
    g) other

Section E: ECS Experience

29. SUPPORT — What support did you receive when you started using your ECS?
    a) None
    b) very little
    c) as much as I needed; didn't need any
    d) other
    e) no answer

30. SUPPORT FROM — From who did you receive support?
    a) supplier
    b) family
    c) friends
    d) therapist
    e) other

31. MODIFICATIONS — Were modifications required to the system to meet your individual needs?
    a) Yes (specify)
    b) No

32. TRAINING — Was training provided?
    a) Yes
    b) No

33. HOW MUCH TRAINING — If yes, how much training did you receive?

34. TRAINING ADEQ — Looking back, what do you feel about the training and support you received?
    a) It was inadequate
    b) It was barely adequate
    c) It was adequate
    d) It was very good
    e) No answer

35. RELIABILITY — From your experience, is your ECS reliable?
    a) Yes, very reliable
    b) Mostly reliable
    c) Hardly satisfactory
    d) Very unreliable
    e) No answer

36. IMPROVE — From your experience, what factors would make the system work better for you?
    a) More training
    b) better support
    c) different method of control
    d) more flexible system
    e) greater accuracy/reliability
    f) no improvement necessary
    g) other
    h) no answer

37. STILL USING — Are you still using your ECS?
    a) Yes
    b) no

38. IF NOT, WHY? — If not, why?
    a) lack of reliability, frustration
    b) lack of support
    c) technical problems
    d) change in physical status
    e) inappropriate control method/access
    f) too difficult to use
    g) other
    h) no answer

39. EXPECTATIONS — Did the ECS work as well as you expected it to?
    a) yes
    b) no
    c) no expectations
    d) no answer

40. MADE A DIFFERENCE — Has your ECS made a positive difference in these areas of your life (can select more than one)?

a) independence
b) self esteem
c) privacy
d) family relationships
e) less reliance on community support
f) other

41. OVERALL — Do you feel that the ECS has made a big difference in your life?

a) yes, it has made a big difference
b) yes, it has helped a little
c) not made much difference
d) a waste of time
e) no answer

APPENDIX B: INFORMATION ON SPECIFIC ENVIRONMENTAL CONTROL SYSTEMS

More detailed information on various environmental control systems is shown in the attached brochures and Web pages. This information covers the following systems:

- GEWA Prog III
- Sicare Pilot
- Simplicity
- NEMO
- Cintex3
- TASH Relax II and Mini Relax
- Deuce and Scanning Director II
- TSPhone
- Plato for Windows
- PROXi
- IBM Home Director
- TotalHome
- Jeeves
- HAL 2000 Voice Control System

In addition some information on a typical simple system is included. The basic components of this system are outlined in the Technical Solutions web page, included with the above information.

Other requirements

In addition to the above controllers, the ECS will need to have X-10 or similar modules, modules and switches for specific appliances (such as door or beds) and devices such as motion detectors and timers.

BIBLIOGRAPHY

Bell P. and Hinojosa J., "Perception of the Impact of Assistive Devices on Daily Life of Three Individuals with Quadriplegia", Assistive Technology 1995 (7), pp.87-94.

Cook A. and Hussey S., Assistive Technology — Principles and Practice, Mosby, St Louis, 1995.

Dickey R. & Shealey S., "Using technology to control the environment" American Journal of Occupational Therapy 1987 (41/11), pp. 717-721

Dickson J. and Doessel S., "Beyond Group Homes" Second Australian Conference on Technology for People with Disabilities — Proceedings ARATA 1995 pp. 185-187

Doessel S., "Depending on it — Environmental Control When You're Out There on Your Own" Second Australian Conference on Technology for People with Disabilities — Proceedings ARATA 1995 pp. 191-193

Efthimiou et al, "Electronic assistive devices: Their impact on the quality of life a high level quadriplegic persons", Archives of Physical Medicine and Rehabilitation 62 (1981) pp. 131-134

Flippo K. et al., Assistive Technology — A Resource for School, Work and Community, Paul Brooks Publishing, Baltimore, 1995.

Ford J. and Pitt S., "New Directions in Environmental Control", Third Australian Conference on Technology for People with Disabilities — Proceedings (ARATA, 1997) pp. 16-18.

Graf M. Et al., "Environmental control unit considerations for the person with high-level tetraplegia", Topics in Spinal Cord Injury Rehabilitation Winter 1997, pp. 30-40.

Holme S. et al., "The use of environmental control units by occupational therapists in spinal cord injury and disease services", American Journal of Occupational Therapy 1997 (51/1), pp.42-48.

Lange M., "ECUs 101", OT Practice 1996 1 (12) pp. 27-31

McDonald D., Boyle M. & Schumann T., "Environmental control unit utilization by high-level spinal cord injured patients", Archives of Physical Medicine and Rehabilitation, Vol 70, 1989, pp. 621-623

Phillips B and Zhao H., "Predictors of Assistive Technology Abandonment" Assistive Technology 1993 (5) pp. 36-45

Platts R. and Fraser M., "Assistive technology in the rehabilitation of patients with high spinal cord lesions", Paraplegia Vol 31 (1993), pp. 280-287

Porter M. and Dean J., "Home Modifications for a High Level Quadriplegic — A Case Study", Third Australian Conference on Technology for People with Disabilities — Proceedings (ARATA, 1997) pp. 12-15.

Seplowitz C., "Technology and occupational therapy in the rehabilitation of the bedridden quadriplegic", American Journal of Occupational Therapy, (1984) Vol. 38(11) pp. 743-747

Simpson R. et al., "A Computer-based environmental control system "RESNA 96 Proceedings, (4p).

Summers G. and Cochrane G., "Evaluation of a voice activated environmental control system for disabled people" Clinical Rehabilitation 1988 (2) pp. 231-239.

Symington D. and MacLean J., "Environmental control systems in chronic care nursing homes", Archives of Physical Medicine and Rehabilitation (1986) Vol 67, pp. 322-325.

Van Laere M. and Duyvejonck R., "Environmental control and social integration of a high-lesion tetraplegic patient: Case report" Paraplegia 24 (1986) pp. 322-325.

Woods B. and Jones R., "Environmental control systems in a spinal injuries unit: A review of 10 years' experience" International Disability Studies 1990 (12/4) pp. 137-140.