Provision of environmental control systems in the North West of England

Paula McDonald and Selwyn St Leger

Abstract

Background Environmental control systems (ECS) enhance the independence of housebound severely physically disabled people and offer them the prospect of a greater quality of life. A Department of Health scheme has provided ECS to severely disabled people. Provision and quality of provision in the North West were examined.

Methods Audit of five years’ prescriptions within the North West of England was carried out. Postal questionnaires were sent to 41 voluntary and self-help groups. Additional qualitative data were collected by contacting manufacturers and voluntary group advisors.

Results Eighty per cent of people referred for assessment received an ECS. However, there was geographical variation in referral rates and a bias toward younger people. There were unexplained variations among the assessors. The commonest diagnoses resulting in referral were multiple sclerosis, motor neurone disease and muscular dystrophy. Many other conditions, such as stroke and arthritis, for which an ECS might produce benefit were under-represented.

There were some problems with the quality of the service, especially with the timescale of provision.

Conclusion It is concluded that doctors and other professionals need a heightened awareness of the categories of person who can benefit from an ECS. Clarification of criteria and training are required if assessors are to be more consistent. Moreover, the mechanism of provision needs review. Public health physicians should re-evaluate their roles in provision, and should concentrate on commissioning an appropriate and good quality service rather than on co-ordination of the scheme.

Keywords: health needs assessment; environmental control systems; physical disability; medical devices

Introduction

Environmental Control Systems (ECS) are electronic switching devices which allow severely disabled people to control their environment by remotely operating equipment. They can increase quality of life, and provide security by controlling access to premises and allowing people to summon help in an emergency. They have been shown to lead to cost savings in institutions.1 Possible cost savings in the community have not been examined, but it seems likely that ECS could reduce care costs for some people, and might help to maintain others in the community. As Mandelstam2 and Platts and Andrews3 have pointed out, they cannot replace human contact.

Very severely disabled people are currently loaned ECS through a scheme set up by the Department of Health. Some less severely disabled people are provided with ECS by social services departments and some housing associations.

How the Department of Health scheme works

Most public health physicians will be aware of the rather complex Department of Health scheme for provision of ECS, which involves nine stages to be gone through before provision (see Fig. 1). Referrals are made to a co-ordinator at the Health Authority, assessments are made by a specially delegated consultant assessor, a case conference is held in the patient’s home, and the equipment is ordered through the NHS Supplies Authority.

Until recently, the Regional Director of Public Health was responsible for deciding whether to provide a particular system. This responsibility was usually delegated to District Directors of Public Health, who in turn often delegated it to a co-ordinator. The equipment, the assessor’s fee, and continuing maintenance and repair costs were met by the Department of Health. Installation costs and some peripherals are paid for by West Pennine Health Authority, Westhulme Avenue, Oldham OL1 2PL.

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social services departments. The budget for the DH scheme was devolved to Regional Health Authorities in 1995, and to District Health Authorities on 1 April 1996. Lead purchasers for ECS have been appointed in most, but not all Regions. The British Society of Rehabilitation Medicine (BSRM) has recommended a service led by consultants in rehabilitation medicine and an expanded co-ordinator role, including training and follow-up. The Medical Devices Agency has recently published an evaluation of eight systems. The objective of this study was to examine current provision and look for inequalities and areas where quality needs to be improved. This was accomplished by an examination of policy and practice in the North West of England. The findings may help Health Authorities to plan future services.

**Method**

Data from all new referrals accepted by the two Regional Assessors in post in the North West between 1985 and 1991 were extracted from the assessors’ records. Some additional data on the dates of case conferences and dates of installation were obtained from the NHS Supplies Authority. Data were not collected after 1991, as there were major changes in the system: one assessor retired, another changed his areas of responsibility, and five new assessors were appointed.

One assessor changed his base in 1985. The records from his previous district were checked to see if any had been left behind. ECS co-ordinator records for two districts were cross-checked against assessors’ files to see if any additional records were found. As none were found, this was not extended to other districts.

We also wrote to 41 voluntary and self-help groups, asking for information about ECS, how they would respond to a request for information from a potential user, and for comments on provision. Organizations were selected if (1) they provided advice to disabled

**FIGURE 1** Summary of Department of Health scheme for providing ECS.

TABLE 1 Characteristics of referrals in the North West Region 1987–1991 (percentages, with numbers given in parentheses)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>NW referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td></td>
</tr>
<tr>
<td>&lt;15</td>
<td>8.8 (29)</td>
</tr>
<tr>
<td>15–44</td>
<td>36.2 (119)</td>
</tr>
<tr>
<td>45–64</td>
<td>48 (129)</td>
</tr>
<tr>
<td>65+</td>
<td>16.8 (48)</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Males (all ages)</td>
<td>48.5 (163)</td>
</tr>
<tr>
<td>Males (under 65)</td>
<td>51.5 (148)</td>
</tr>
<tr>
<td>Main diagnosis</td>
<td></td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>30.1 (101)</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>16.1 (54)</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>10.1 (34)</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>7.4 (25)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>6.5 (22)</td>
</tr>
<tr>
<td>Spinal injury</td>
<td>5.1 (17)</td>
</tr>
<tr>
<td>Stroke</td>
<td>4.8 (16)</td>
</tr>
<tr>
<td>Spinal muscular atrophy</td>
<td>1.8 (6)</td>
</tr>
<tr>
<td>Head injury</td>
<td>1.5 (5)</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>1.5 (5)</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>0.9 (3)</td>
</tr>
<tr>
<td>&gt;1 diagnosis recorded</td>
<td>12.2 (30)</td>
</tr>
<tr>
<td>&gt;2 diagnosis recorded</td>
<td>0.4 (1)</td>
</tr>
</tbody>
</table>

Results

A total of 336 referrals were made to the two ECS assessors in the North West Region over the five-year period from 1987 to 1991. District referral rates, among the then 19 District Health Authorities, ranged from 0.8 to 2.5 per 100,000 per year (see Fig. 2). There was considerable variation in the proportion of referrals that were for people living in institutional care. Nine districts had no referrals for people living in institutions, but half the referrals in Stockport, and 40 per cent of those in Burnley came from institutions.

The age, sex, main diagnosis and number of diagnoses of referrals are shown in Table 1. Most referrals (84.2 per cent) were for people under the age of 65. There were slightly more referrals for women than men (51.5 per cent). The commonest causes of referral were degenerative neurological disorders. Most (87.4 per cent) people referred had a single diagnosis rather than a combination of disorders.

Referrals were most commonly made by general practitioners (GPs), who made a total of 173 referrals (59.9 per cent of recorded referral sources). Consultants made 83 requests (28.7 per cent). Adult and paediatric neurologists made up the bulk of these – a total of 57 requests (16.9 per cent of the total). Only one referral came from a consultant geriatrician. Other sources made 33 requests (11.4 per cent). The largest number of these (12; 3.6 per cent) came from occupational therapists. It was clear from the referral letters that many of the medical referrals had been instigated by someone else – often a manufacturer or an occupational therapist.

Time spent at home alone was recorded for 219 of the 282 people living in the community. Only 15 (7 per cent) were never left in the house alone: 58 lived alone, and 146 were left alone while their carer was out shopping or at work. Six people left their door unlocked, or left the key on a string inside the door. The rest were presumably locked in the house when alone. Many would have been unable to summon help in an emergency.

Most (79.5 per cent) assessments resulted in prescription of an ECS. The commonest reasons for non-prescription were that the patient could be helped by a simpler system (12.7 per cent of assessments) and not wanting an ECS (3.3 per cent of assessments). When those who did not want a system were excluded, the prescription rate was over 85 per cent. There were four cases where it was recommended that a simpler ECS should be purchased by the social services department, but it was not provided.

Provision of ECS was not statistically significantly related to diagnosis, sex, age or source of referral, but it was significantly related to assessor. The relative risk of being refused an ECS by assessor A was 4.9 times that of being refused by assessor B [95 per cent confidence interval (CI) 2.4–9.8]. If cases where the potential user or carer refused the ECS were excluded, the relative risk rose to 18.9 (95 per cent CI 2.6–137.2).

Provision of the more expensive and comprehensive Possum PSU6, which incorporates a communication device, was statistically significantly related to male sex [relative risk (RR) = 1.5, 95 per cent CI 1.1–2.1], age under 65 (RR = 2.4, 95 per cent CI 1.2–5.1), not living alone (RR = 1.8, 95 per cent CI 1.05–3.2) and assessment by assessor B (RR = 2.2, 95 per cent CI 1.6–3.1). There was no statistically significant relationship with the diagnoses shown in Table 1, including disorders such as motor neurone disease, which often lead to communication problems.
TABLE 2 Examples of problems with the referral system

A co-ordinator did not take any action on receiving the assessor’s report. This was not discovered until the neurologist who made the referral wrote seven months later to ask why the system had not been installed.

A GP referred a patient to Mersey Regional Health Authority, who passed the referral on to North West Regional Health Authority, who eventually passed the referral on to the correct District Health Authority.

A GP initially referred directly to the assessor for his district, and was asked to re-route his request through the co-ordinator. Three months elapsed before the referral reached the assessor through the official channels. At this point it was labelled ‘urgent’. The patient died before being assessed.

A hospital occupational therapist tried to obtain an ECS for a patient with advanced motor neurone disease by approaching the manufacturer directly. Two months elapsed before the representative visited the hospital and advised the therapist of the procedure for obtaining an ECS from the Department of Health.

A GP requested a home visit from a neurologist to assess the patient for an ECS. The neurologist visited, pronounced the patient suitable, and then asked the ECS assessor to visit to make another assessment.

An assessor requested urgent installation of an ECS. The patient had previously been seen and assessed by the following people:

1. Possum representative
2. Community occupational therapist
3. GP
4. Senior Clinical Medical Officer in Adult Health
5. ECS assessor

Patients waited an average of 142 days, or about five months, from referral to installation (range 56–276 days). There were many examples of delays caused by lack of knowledge of how to obtain access to the referral system, or by referrals being lost in the system (see Table 2).

Several voluntary organizations commented adversely on the problems caused by the long wait for installation; for example, ‘The process takes far too long and impedes rehabilitation.’ Five out of six patient advisors working for the Motor Neurone Disease Association who were contacted told us that the long wait for a DH system meant that it was not worth referring some patients: ‘To refer early enough to be hopeful of getting a system, people with MND are usually so early in their illness that it would be difficult to explain how a system would help. More usually, people with MND are too far in their illness, and one has to decide, is it worth the upheaval for them?’

Only seven (2.1 per cent) people were recorded as having seen or tried out an ECS before or during their assessment. Fifteen people (4.5 per cent of referrals) were subsequently revisited by their assessor, mainly because of problems with equipment.

Voluntary and self-help groups complained about the variability of instruction: ‘(It) is left to the goodwill of engineers. Some spend half a day running through it, others install the equipment and leave you to it.’ They also complained about breakdowns, and difficulty in getting repairs done. Voluntary advisors commented that they often found problems when they called to see users: ‘You ring the doorbell, and Radio 1 comes through the intercom!’

Lack of information about ECS was also seen as a problem: one voluntary organization called it ‘rationing by secrecy’. A small core of voluntary organizations appeared to be well informed about ECS and made lengthy comments about them. Other organizations appeared to be much less well informed, making comments such as: ‘They can only be purchased by people who have received substantial damages after accidents’. Some asked us if we could send them information. Fewer than half of the 26 organizations who responded to our questionnaire felt confident enough to deal with a request for information about ECS. Most of these relied on information from the Disabled Living Foundation and/or manufacturers. Only two organizations (The Arthritis and Rheumatism Research Council and the Motor Neurone Disease Association) produced information aimed at users.

Lack of knowledge amongst professionals was also raised as an issue. One voluntary group advisor commented: ‘There is not enough information/knowledge about systems in the community. I may suggest a system, but then GPs/OTs [occupational therapists] just don’t know how to make a referral. Neither do they understand the system, so they don’t appreciate the need for an immediate referral.’
TABLE 3 Department of Health criteria for provision of ECS

To qualify for provision of an ECS, the following must apply:
(1) the patient must be permanently so paralysed or so disabled by disease, injury or congenital defect that they are unable to carry out simple tasks such as ringing bells for attention and switching on lights,
(2) the patient must be able to derive some continuing measure of independence;
(3) the patient must have the will and the ability to use the apparatus;
(4) the patient cannot be assisted so effectively by simpler or cheaper means.
(5) An occasional wider interpretation of general eligibility is acceptable when there appears to be real clinical necessity; in particular, patients with deteriorating neurological conditions should be assessed with the future course of the illness in mind.

Discussion

This audit identified inequalities in provision of ECS. The reasons for geographical variations need to be explored, but it is possible that they may be caused by relative under-provision in some areas. ECS engineers report seeing clusters of referrals following an initial referral in one area (ECS engineers, personal communication, 1993) and this is indirect evidence for under-provision.

The prominence of younger people with single neurological diagnoses in the North West referrals may be because they are in contact with specialists and voluntary group advisors who know about ECS and raise the possibility with them. Referrals for people with muscular dystrophy have increased in the North West since specialist advisors in muscular dystrophy were appointed. Some common disorders such as arthritis and stroke, which are known to be important causes of very severe disability, especially in older people, appear to be under-represented in the referrals for ECS.

This highlights a need for information and training. This needs to be directed particularly at the GPs, specialists in medical care of older people and therapists who are in touch with people with common disabling conditions (such as stroke and arthritis) and older people with a combination of disorders who are not currently being referred for assessment for ECS.

Many ECS are relatively inexpensive. Some potential users might wish to buy them for themselves, if they only knew about them. Advertisements or features in consumer magazines would give them the information to consider this.

The most important factor influencing the outcome of the assessments was which assessor carried out the assessment. ECS engineers comment that it is not unusual for assessors to have a preference for one system or another: 'You get one assessor who's known as a Possum man, and another who's known as a Steeper man' (ECS engineers, personal communication, 1993). Both of the North West assessors were very experienced consultants in rehabilitation medicine. The differences between them probably reflect the lack of common training for assessors and the rather general nature of the criteria for provision (Table 3). The BSRM has set up training for assessors. Clarification of the criteria for provision is also needed.

It could be queried whether consultant-level assessment is needed in all cases. Most referrals result in provision, many referrals are for people who are virtually immobile and clearly meet the criteria for provision, and the outcome of assessment in this audit was related to the assessor rather than the diagnosis. This is an expensive method of assessment, and some occupational therapists wonder why doctors are assessing patients for an aid to daily living.

The BSRM has recommended that all those referred for an ECS should have a full rehabilitation assessment. This would undoubtedly be helpful for some people. Others, for example those being discharged from spinal injury units, should already have been assessed: their priority is fast provision.

Timescale of provision is one of the important issues raised in this study. The current wait of about five months for provision of an NHS system compares unfavourably with the performance of some commercial companies, who claim to be able to assess a patient and install a modular system within 1–2 weeks of being contacted (RehabTeQ Ltd and Scientific Technical Developments Ltd, personal communication, 1996). In many cases in this study, it was evident that the potential user was deteriorating fast and great efforts were being made to expedite provision, but the shortest period from referral to installation of an NHS system was still 56 days. Although this may be acceptable to some patients, it is likely to cause major problems for those who need an ECS to survive in the community, and it forms a major part of the life expectancy of...
someone with motor neurone disease. Patients with motor neurone disease might be thought of as prime candidates for ECS, yet the MND Association produces a booklet for therapists advising the use of plug-in timers rather than trying to obtain a system through the DH scheme.

The modular systems recently introduced on the Department of Health contract should help speed up the process, as they do not need to be wired in. However, two-thirds of the wait in this audit occurred before the ECS was ordered. There is a need for a simpler, faster system of assessment. In particular, there is an urgent need for a 'fast track' assessment for those with fast-deteriorating conditions such as motor neurone disease, and those whose rehabilitation and/or discharge home would be impeded without an ECS.

One model for 'fast tracking' would be to institute assessment by a local occupational therapist, for those who meet certain pre-defined criteria. Ordering directly from the manufacturer or keeping modular ECS in stock for temporary loan would also speed up provision. Cross-cover for assessors when they are on holiday or on sick leave would prevent some delays.

Other quality issues include lack of user choice. Although most assessors will discuss options with the potential user, the only real choice users have is whether or not they accept the system recommended by the assessor. Many will not see a system until it arrives. They also have no choice of assessor, and there is no formal appeals mechanism to challenge the assessor's decision.

Resources have in the past been concentrated on assessment, with little being spent on training and follow-up. Many audits have found unused or under-used systems. Many districts are now improving their assessment, training and follow-up. This should lead to better use of equipment, and faster recycling of unused equipment. More user involvement in the assessment process and feedback from users, for example, via user groups (as suggested by Mandelstam) would also help to better direct resources. The Internet would provide a possible means of communication for a local or national group.

The role of public health doctors appears to consist, in practice, of administration and of responding reactively to requests for information about ECS. They did not attend assessments or case conferences, and there was no evidence that they had taken on other roles, such as publicity or audit of provision. There were no instances of them challenging the assessor's recommendations. It would be more efficient if administration was carried out by those involved in the assessment, i.e. the assessor or the local occupational therapy department. Resources might need to be provided to support this.

Conclusion

We conclude that there are inequalities in provision of ECS. Doctors and other professionals and information-givers need a heightened awareness of potential need for ECS. Clarification of criteria and training are required if assessors are to be more consistent. The current referral mechanism is too complex, and should be simplified and speeded up. There should be more user involvement in the process. Public health physicians should re-evaluate their roles in ECS provision. Coordination should be delegated to those dealing with assessment and follow-up, and public health physicians should concentrate on ensuring that there is an appropriate mechanism to meet needs and that there is a quality service.

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References


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