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Needs and Opportunities in Rehabilitation

Aids and the environment

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Aids

"Logistics is part of rehabilitation," a consultant said to me—"getting the right thing to the right person or place at the right time."¹ Many people are providing this kind of service; but I have heard much about failures in all these aspects. In particular, delays in the supply of aids and in making adaptations may run into months or even years. Meanwhile the need may have changed or passed, or the patient may have found some unsatisfactory solution.^{1a}

The need for an aid may not be identified in the first place because the right questions are not asked or no professional looks at the patient's home and life, or no one knows of the existence of the relevant aid. Some aids moreover are incorrectly prescribed or supplied or are not the best possible; while others are not used to the best advantage, perhaps through lack of demonstration and discussion or because they are not simple enough solutions to the problem. The aids to concentrate on are those that are crucial to the patient, not the ones someone else thinks he or she should have, like the stair hoist installed for a woman who turned out to sleep downstairs. Aids that are not used are commonplace.² In a survey of 500 people with aids by Page *et al* half of all the aids were not being used.³ Apart from deficiencies in the items prescribed, in some cases an aid was not an acceptable solution—what was needed was personal help. Better aids, these authors conclude, better information about the aids, and better matching of aids to people are called for. The need for instruction in use and follow up visits by occupational therapists emerges from studies in Leeds of bath and toilet aids.^{4,5} Staff shortages are the difficulty here, but expensive problems later could be prevented.

A guide to aids and adaptations is provided in *Coping and Disability*⁶ and a summary of the types of aids and appliances is given in *Rehabilitation Today in Great Britain*⁷; sources of aids and information on them are listed in a DHSS booklet.⁸ Two series of detailed information about different categories of aids are published (see last article, 12 January, p 132). One off devices to meet special needs are produced by REMAP (box). Aids centres (figure),^{8,9} of which the Disabled Living Foundation was the first, are spreading: there are now 17, most supported by statutory services; but they cannot be accessible to everyone, and the client usually must get the equipment elsewhere. Mini displays in hospitals would be a possi-

REMAP

One off aids for people with special needs are produced by Rehabilitation Engineering Movement Advisory Panels (REMAP—part of the Royal Association for Disability). These groups of engineers, doctors, remedial therapists, and social workers give their time freely and the work is done in members' homes and sometimes educational establishments, etc. No charge is made except occasionally for materials. Requests are mainly from social service departments and health authorities. Apart from aids to daily living of many kinds, a lot of imaginative items have been produced to cater for special interests, such as wheelchair binoculars on a gantry for an arthritic bird watcher, a camera fixed to a wheelchair for a one handed person, arm supports for archery and for a violinist, a holder for a mouth organ, a stool on wheels for table tennis, a fishing aid for use after a stroke, and periscopes for use on a wheelchair and for a housebound person who had had an amputation.

bility, given adequate space, since manufacturers may loan or donate their wares, though costs are making this increasingly difficult for expensive items. Some hospitals should be able to provide certain aids out of their own stock to avoid the delays inherent in ordering through social service departments, and then have the cost reimbursed by social services; but this is not as straightforward as it sounds. There are about 20 joint schemes for supplying aids—that is, funded both by health authorities and by social service departments—and these are said to have resulted in a quicker and more effective service. A survey to assess problems and benefits is thought by some to be needed. An important point is the role of general practitioners: the time will come, it is hoped, when they will make more use of both occupational therapists and aids centres.

A rehabilitation department I visited itself provides aids on occasion; more often patients are encouraged to buy small things for themselves. A mail order catalogue of inexpensive products for the disabled should surely be kept in every GP's surgery and every day centre, together with a list of local and national information

resources for patients to consult. Some ordinary shops now stock items such as furniture and toilet aids for the handicapped and elderly. There should, however, be a member of staff with at least some training who can explain how to use the items. More importantly, it is thought that it would be a retrograde step if people could buy aids in general without having seen an experienced occupational therapist or been to an aids centre. Wolff has put forward the helpful idea of aids and technology for the disabled and frail as just one end of the spectrum of "tools for living" that we all increasingly use.¹⁰ Clearly many ordinary labour saving devices are eminently suitable for a lot of disabled people. Emphasising the enhancement of capability rather than disability, a firm called Ways and Means, supplying "capability centres," opened in Michigan in November 1984 (information from Institute of Bioengineering, Brunel University). An overview of technology in the service of disabled people is provided in a book based on two conferences held by the Commission of the European Communities.³

Chairs are a good example of the need for informed choice, and the Arthritis and Rheumatism Council's booklet *Are You Sitting Comfortably?* is helpful. There are simple requirements that make a large difference. Rising from a chair without arms may produce knee joint and muscle forces nearly eight times body weight but from a chair with arms less than three times body weight, and a high seat also greatly reduces the forces.¹¹ All professionals could give advice on this basis.

Requirements for wheelchairs (and other appliances) are discussed by Bossingham.¹² A 1973 survey recommended that more home visits should be made in connection with wheelchairs and more instruction given.¹³ These needs remain. Some hospitals have "wheelchair clinics" run usually by occupational therapists, and I visited an aids centre that had groups for users and their relatives; but in general many wheelchairs are prescribed that are not the most appropriate and users are too often then left to their own devices. In its evidence to the working party reviewing the work of the DHSS artificial limb and appliance centres (ALACs) the Royal Association for Disability and Rehabilitation recommended improvements in the wheelchair services, including home visits and more training for users and for staff.¹⁴

Several people I have met have talked warmly about the value of a rehabilitation engineer—or about the lack of one in their centres. Though not a substitute for a service on the spot, a national network of rehabilitation engineering centres within the NHS has been proposed to cater not only for orthoses, prostheses, and wheelchairs but also for the more expensive and specialised aids for daily living, with bioengineers on their staff and with the capacity for research and development.¹⁴ One problem for engineers clearly is maintenance, and insufficient maintenance services are one reason for the non-use of aids.

More generally, evaluation of aids tends to be inadequate and haphazard.² In addition, the ergonomic approach to design needs to be extended—in a clinical setting, some believe very strongly, rather than in departments having no contact with patients. The summer 1984 meeting of the Society for Research in Rehabilitation discussed the need for users, doctors, and therapists to talk to designers and manufacturers right from the start, and to spot requirements for new categories of aid. Conferences on stair lifts in Leeds for manufacturers and therapists did lead to changes in design (a booklet about selecting stairlifts has been produced¹⁵).

COMPUTERS AND HIGH TECHNOLOGY

The technological gadgets of the able bodied clearly can become vital aids for the disabled. Adaptations to ordinary equipment, or modifications to make particular aids more suitable for an individual, are sometimes taken on by students at polytechnics and elsewhere; this kind of thing could be done more widely, to everyone's benefit. The age of technology should be a good time for the disabled or infirm but effort and imagination will be needed to make it so; those who need technology to make up for failed physical functions are often in fact the least likely to have it. "New inventions," says Cochrane, "have not yet begun to reach the



William Merritt Aids and Information Centre, Leeds: woman with multiple sclerosis on a stair lift.

majority of potential users."²² Environmental control systems of the Possum type are a good example. Apart from money, there tends to be a lack of vigour in exploiting new ideas and new developments for the general run of frail and handicapped people other than the most helpless.

The use of microcomputers, however, in rehabilitation and as aids has really burgeoned in the past two or three years, holding out exciting possibilities. Computers have the great psychological advantages of novelty and fun, and above all of being coveted possessions in the ordinary world: they have status and a youthful image without being childish; even elderly people with no experience of technology can get hooked. They are of enormous value for neurological disabilities but by no means confined to these. Two residential homes I visited in the same street—a local authority and a voluntary home, neither of them rich—now have their own computers, and they are not unusual. The difficulty may lie in provision of adequate training and of suitable activities thereafter.

An important development is the use of computers by occupational therapy departments. A two year project has been supported by the Department of Trade and Industry. Thanks to a new "authoring system" for the BBC microcomputer—Microtext,¹⁶ developed at the National Physical Laboratory—people new to computers, with no programming experience, can produce their own training material for therapy and teaching on the basis of ordinary English. In all applications computers help motivation and concentration—the atmosphere of absorbed attention when a group of people are working at their computers is most impressive—and the immediate feedback is an asset. They are helpful for training or retraining thought processes and reasoning, perception and discrimination, and manual dexterity, and for communication, for psychological assessment (see next article) and work assessment, and for much else. Word processors are obviously useful for those who cannot write or manipulate. Ordinary educational programs and games can be used but more remedial programs are needed; it is hoped that students at polytechnics will help here.

For a few heavily disabled people the world of computers offers the possibility of a real career, perhaps pursued at home. The new MicroAid Centre at a day centre in Southwark (funded in part by the Department of Trade and Industry) acts as a training workshop for disabled people; it will be looking for real work that can be done within the training environment, and it should have the potential to

work on remedial programs as well. More commonly, a new world of recreation may be opened up for those who have little movement. I have seen, for example, computer chess and snooker being played by nearly helpless people in hospital units—the latter by a boy of very meagre intelligence and motivation whose one interest in life was snooker and who was absolutely riveted by the computer game.

Commercially available microcomputers (BBC and Apple II) have been adapted for use with a range of special switch devices by the most disabled, in a Medical Research Council project known as CARE at the National Institute for Medical Research, Mill Hill, which also includes development of programs for them. The emphasis is on providing communication for the speech impaired. Voice signals may be the best form of control for some people and a voice recognition system is being investigated for converting sounds into control signals. The interface control unit is available from Queenswood Scientific and CARE programs that have been fully tested can be supplied by this team (directed by W J Perkins). Some very disabled people use the eye controlled switch system developed at St George's Hospital, Lincoln (available from Specialised Switches). Two small discs stuck to the skin beside the eyes convert the electrical activity of the muscles into signals to control the microcomputer (both the BBC and the Apple IIe). The DHSS has a project for the development of communication devices. A Cheshire Home project, Compaid, is concerned with computer aids for speech impaired and disabled people; help is given to other homes and sometimes social services, and rehabilitation training—for word processor work and accountancy, for example—may be provided. The bulletin *Interface* is widely circulated.

Two particular messages emerge from all this. Firstly, though the hardware is clearly expensive there is a lot of scope for providing intensive practice in repetitive or more complex tasks via a computer, with only modest supervision as time goes on. This may give great satisfaction to the patients and a training perhaps more precisely geared to their deficits and strengths. It could be a way of making a sparse complement of occupational therapists, or of staff in a residential home, go further. Occupational therapy aides, too, it is said, may be very much at home in this kind of work—they are often older women who have become familiar with computers through their children. Thus district general hospitals, residential homes, and many day centres need to be looking into the possibilities. A list of programs suitable for rehabilitation work is provided in the first issue of *OT MicroNews*.

Secondly, despite the growing awareness of handicapped people and their needs it is perhaps more than ever true that "the race is to the swift and the battle to the strong" in a society in which opportunity and material success are so much in evidence. We have all the more urgent an obligation to help the disabled to benefit from the fruits of technology in general.

A charity called SEQUEL assists severely disabled people with the purchase of electronic and electrical equipment.

The environment

Loss of mobility was the chief discontent found in two surveys—a study of arthritic patients in Leeds¹⁷ and a study of handicapped people, of whom over half had arthritis, in rural Wiltshire.¹⁸ In both series having a car, not surprisingly, made a great difference; but most did not have one. Public transport tended not to be near enough even if it could be used.

The country people often complained about having nowhere accessible to go to if they did go out. Declining rural transport and other services add to the number of housebound, and the authors urge more mobile services and more flexible arrangements for providing limited post office, chemist, food shop, and transport facilities.¹⁸ In Leeds, people in the poorer, older houses fared best for shops and bus stops, and this report recommends that the layout of towns should provide for accessible services.¹⁷ Its other recommendations concern kerbs, avoidance of steps, and so on; bus design; larger and more flexible mobility allowances; "dial a bus" services for the handicapped; and more suitable housing. Things are beginning to change; for example, the Tyne and Wear transport

system was designed with the disabled, including wheelchair users, in mind; and buses with split level steps or steps that can be lowered at the bus stop are a help.

In Leeds there were far more unsuitable houses than in Wiltshire, and the authors make a plea for more "mobility housing"—that is, ordinary council houses with small modifications to make them usable by people who cannot manage steps (as distinct from the purpose built "wheelchair housing"). Mobility housing was built by the local council in Crawley, for example, many years ago; and some newer housing estates include a proportion of such houses. There is plenty of guidance on design—for example, by Goldsmith¹⁹ and in the form of a British Standard (BS5810 (1979)). More probably the solution will be adaptations to an ordinary house,²⁰ with the help of the social services department. Grants are available for these, as described in a government circular.²¹ This emphasises the importance of discussion with an occupational therapist, and a few authorities have one who is specifically concerned with housing adaptations. Cheshire County Council has published a booklet giving examples of its own house adaptations.²² In San Diego there is a legal requirement to build all houses for the convenience of disabled people; in Britain, the Building Regulations are being rewritten and will incorporate some access requirements for the disabled, the extent of which is being debated. Meanwhile it is sad that, as Buchanan and Symons point out,²³ so many professionals as well as patients and their relatives are ignorant of how much can be done to existing houses. For some adaptations, Cochrane suggests the joint funding of a domiciliary rehabilitation engineer (possibly assisted by offenders doing community service) as an alternative to local authority maintenance staff or a private builder.²

Although access for the disabled to ordinary buildings and facilities is improving all the time there is still a long way to go—even GPs' surgeries still present problems. Many towns have their own booklets listing accessible buildings. Work opportunities may be limited in this way, though the Manpower Services Commission will provide grants for adaptations. Leisure activities also may become a battle or be sadly restricted. An article by Chamberlain lists sources of information²⁴; and various aspects of the environment in relation to leisure are dealt with by the Countryside Commission,²⁵ the Department of Transport,²⁶ the *Directory for the Disabled*,²⁷ and publications of the Disabled Living Foundation, including *Sports and Recreation Provision for Disabled People*,²⁸ and of the Royal Association for Disability and Rehabilitation, including a handbook on arts centres²⁹ and much besides on access and publications on mobility.

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- Disabled Living Foundation
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- Joint Committee on Mobility for the Disabled
9 Moss Close, Pinner, Middx HA5 3AY
- Microtext Transdata Ltd, Microelectronic Systems Division,
11 South Street, Havant, Hants PO9 1BU
- MicroAid Centre
Aylesbury Day Centre, London SE17 2BA
- OT MicroNews (edited by Janet Brown)
Education Department, College of Occupational Therapists, 20 Rede Place (off Chepstow Place), London W2 4TU
- Queenswood Scientific Ltd
The Paddock, Stubbington, Fareham, Hants PO14 3NS
- REMAP (Rehabilitation Engineering Movement Panels)
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- Royal Association for Disability and Rehabilitation
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- SEQUEL (charity concerned with electronic and electrical equipment)
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Personal Paper

Kilimanjaro expedition

A R GREEN

The aim of the expedition was to make a documentary film about the ecology of Mount Kilimanjaro. It would mean six weeks' trekking over the mountain including several days' camping in the volcanic crater just below the 19 340 foot summit. Was I interested in acting as the expedition doctor? Even as I reached for my atlas to clarify my rather hazy concepts of east African geography there was little doubt about the answer.

Thus began a series of events that ended with a jarring Land Rover ride as we skirted the south western margins of the

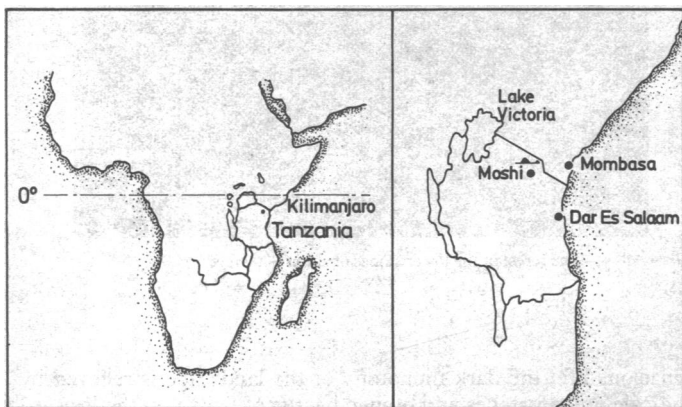


FIG 1—Map of Africa and Tanzania. (From *Kilimanjaro* by John Reader, published by Elm Tree Books.)

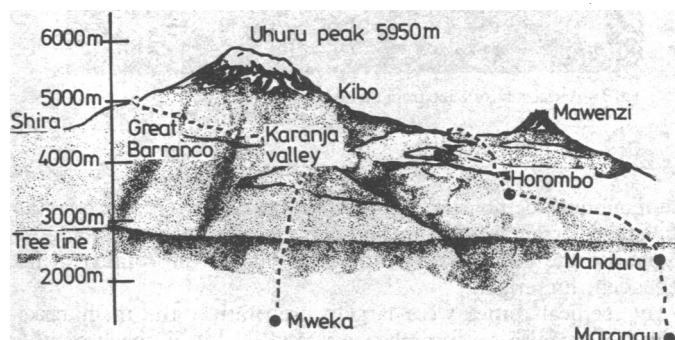


FIG 2—Diagram of the Kilimanjaro complex viewed from the south. (From *Kilimanjaro* by John Reader, published by Elm Tree books.)

mountain before we climbed up through the belt of forest that girdles the lower slopes, and finally emerged on to the savannah and moorland of the Shira plateau. There the canvas hamlet that was to be our base camp nestled in a shallow gully amid the heather.

The Shira plateau comprises the western shoulder of the Kilimanjaro complex, the ice capped central mass of Kibo separating it from the higher shoulder of the Saddle, which in turn rises to form the jagged secondary peak of Mawenzi at its eastern margin. As befits its status as the highest mountain in Africa, Kilimanjaro plays a dominant and vital part in the ecology of the whole region by virtue of the plentiful streams that radiate from it. These are largely supplied by the rain that falls on the lower slopes as a result of the upward diversion of the prevailing trade winds. Little rain falls on the upper reaches, the summit receiving only 12.5 cm a year, and melt water accounts for only a small proportion of the water produced by the mountain. Its height and