Needs and Opportunities in Rehabilitation

Severe disability: 1—Tasks of rehabilitation

DAPHNE GLOAG

"Restoration from patient to person" is how a relative of a severely disabled "patient" defined rehabilitation; and an important element is choice.¹ "Many people we see in the patient role do not believe enough in themselves to act," says Cochrane, and he mentions two essential qualities for those working in rehabilitation—the ability to restore confidence "when it has been weakened by reproach and disadvantage" and the diligence to "uncover talents that are obscure and to burnish them."² As someone said to me, "Maximise every conceivable ability—rehabilitation is thinking wide and thinking sensitively." Beyond this, "autonomy"—the kind of choice and control over one's life that adults normally have—and "opportunity" describe what many severely disabled people are striving for.

Of course, many people severely disabled with neurological conditions are in no position to exercise autonomy; some others do not really want to, and many feel threatened by all the talk about independent living. Staff used to traditional concepts of care may also have a sense of confusion and conflict about their roles. A further conflict may arise as workers in rehabilitation become more aware of how much improvement is possible even in apparently irrecoverable conditions, while social workers and sociologists on the other hand eschew the "medical model" and any paternalistic approach. At the same time many people live in residential homes, and for that matter in their own homes, quite untouched by ideas of either rehabilitation or autonomy.

My impression from the visits I have made, the people I have met, and the conferences I have attended is that with this kind of vision the different philosophies and approaches all have their place in catering for the multitude of different needs and personalities; the problem is that so often the right resources do not get to the right people or that efforts go off at half cock for want of adequate resources or adequate thought. In this article and the next I discuss rehabilitation in the context of care of younger disabled people (defined as those aged 16-64 years), looking at the extent of the medical role and at ways of helping people to achieve the best possible quality of life.

Medical rehabilitation

"The centre saved me," said one man 20 years after he was first seen with multiple sclerosis at a medical rehabilitation day centre I visited. "It kept me working while the children were young." He knew that he could keep in touch; they never said, "There's no more we can do," and he had refresher courses from time to time. This illustrates a vital point—the psychological as well as the physical importance of a rehabilitation facility that is "always there," to which the patient can turn for support as well as practical help of one kind or another in time of need. It may be achievable in all sorts of ways, with quite modest resources, provided that there is one

supportive person, whether specialist, general practitioner, social worker, or other professional—the "key worker" who is being increasingly advocated. But the existence of a special centre makes things easier: it might be a day or residential (or mixed) rehabilitation centre, a hospital department or day hospital, or a facility attached to a special unit or residential home. Where it is run jointly by the health and social services patients' total needs are most likely to be met. The common practice of isolated planning by the two services is thought to create one of the greatest barriers to adequate provision for people with disabilities.

It is not only the scarcity of resources that ensures that many badly disabled people, both at home and in residential homes and units, linger on year after year without this kind of help. There is much activity and innovation, but often too little communication between agencies. Moreover, irrecoverable disease and injury are too often thought to give no scope for improvement as time goes on. But, as the rehabilitation philosophy of one large residential home was described to me, while there may be an optimum period for recovery there is not necessarily an absolute cut off point. And where there is a relentless downhill course, as in motor neurone disease, there is still a lot of point in working for the best possible quality of life. As a general rule, attempts at movement are always worthwhile, it was said to me, and small advances may be possible—even, for example, long after contractures have set in; the ability, say, to stand and to walk a few steps may free someone from total dependence, and sitting better in a wheelchair may stave off complications. Where physiotherapists and occupational therapists work together activities of daily living may become possible, so preventing extreme helplessness; the fact that it so often does not work out like this gives an example of what has been called cost disaster—"the extra money which you have to spend because you didn't spend a much smaller sum in the first place."³

Rehabilitation clearly should start early so far as possible. With spinal injuries, for example, immediate admission to a special unit makes possible early treatment and early mobilisation in a wheelchair, but sadly logistic problems and shortage of beds may prevent this—I have heard of delays of three months. At the spinal injuries unit of the Royal National Orthopaedic Hospital I saw how the emphasis on independence aided by the physical features and facilities of the place (fig) capitalise on the early "mobility" that is now possible. There are close links with the catchment area, with a continuum from hospital to community rehabilitation.

After making a patient move a limb, "we must go on to stimulate him to want to move that limb and to some purpose," says Mulroy, arguing that the important part of rehabilitation is "a matter of attitude amongst all doctors and all nurses and all patients" from the very beginning, and is not confined to the specific therapies.³ But the clinical psychologist may be invaluable, as Mulroy puts it, "in identifying possible motivating factors within the patient and in providing us with a strategy of personal reconstruction." The shortage of clinical psychologists means that many rehabilitation departments lack an important dimension.⁴ Demonstration of a good intelligence in a severely handicapped person is an important part of rehabilitation. Five brain damaged patients who could not speak or write and who could not be tested by conventional means were shown by means of tests using a microcomputer to have a far

higher intelligence than they or the staff expected. This led to more positive attitudes on the part of the staff and the patients.⁵

"Not the capacities they lacked but the difficulties of making the fullest use of those capacities that remained to them" were the preoccupation of the residents of a home studied by Miller and Gwynne⁶; and this is a central problem for people in the community as well as in residential care, especially as full employment is seldom possible. Rehabilitation both initially and over the years should clearly be concerned with this just as with physical functioning. Any rehabilitation programme should be based on thorough assessment of all needs, identifying both deficits and assets, by the different members of the team, including if possible a psychologist.

Thinking about needs obviously should include interests and hobbies, and new outlets in a perhaps intolerable predicament. The assessment form I saw in the rehabilitation unit of one residential home has an entry for interests so that remedial therapy can attend to the functions of most concern to the individual. A 14 year old girl in a hospital school wrote: "... I was walking through a golden meadow when / The sky collapsed, and all at once / The sky was upon my shoulders."⁷ Writing may be a form of rehabilitation and an outlet that could perhaps be encouraged more.

At Mary Marlborough Lodge (part of the Nuffield Orthopaedic Centre, Oxford) assessment and the programmes that follow have the benefit of the centre's own engineering department and the facilities for adapting aids very precisely to each person's needs. Patients can be realistically assessed to see whether they could live at home, alone or with families, and they get guidance and practice in living in the kind of conditions they would have at home. I saw among others a young woman with cerebral palsy defying many people's forebodings by looking after her baby with the help of complex gadgets, and a former opera singer with motor neurone disease learning to use a communicator, accompanied by her companion. One element here could be more widely adopted—namely, the assessment flat. Here people have a realistic trial run either alone or with whoever would normally be at home with them, and disabled couples wanting to set up house can live together for a spell. Such flats exist in other special centres, including Edinburgh and Stanmore, and in some geriatric units; but there is no reason why they could not be created in some general hospitals: in the long run it should be an economy since its occupants do without nurses and may be weaned from expensive long term care. Assessment flats should be available to both health and social services.

Thus facilities are needed for short and medium term rehabilitation in the early stages of disease or damage and for intermittent courses thereafter, backed up with a system of regular review. Residential centres may be combined with rooms for "respite" and emergency stays. Accommodation and care, ranging from residential homes coping with the most dependent to facilities for relatively independent living in the community, need to be open to varied opportunities and sources of stimulation. All these facilities exist and I have seen excellent examples, but many people have little or no contact with them.

Work and occupation

"It is not what a man has lost but what he has left that is important" is the slogan on the walls of all the homes for the disabled in the Philippines under the aegis of the Leonard Cheshire Foundation International.⁸ With "what he has left" a resident will usually be doing productive work of some kind—ranging from woodwork and other crafts to electrical and watch repairs and running small stores. This is true of most of these homes in developing countries—it has to be: residents are always encouraged to be as self sufficient as possible, learning skills and contributing as they can to the running and financing of the home. The homes are meant to be "... a place in which residents can acquire a sense of belonging and of ownership by contributing in any way within their own capabilities to its functioning and development."⁸ In the developed countries real work of any kind for severely disabled people usually has to be fought for. Despite the different economic conditions, could any positive elements of an ethos springing largely

Laundry room in the spinal injuries unit of the Royal National Orthopaedic Hospital, Stanmore, which includes a "minimum care unit," encouraging wheelchair mobility and self care (including care of catheters), often only two weeks after injury.

from poverty become a reality in the West? Employment rehabilitation is discussed in a later article and I make here just a few comments.

A disabled person's work potential should be fully analysed but seldom is.⁹ For the early stages of rehabilitation after injury or the onset of disability, expert counselling and the services of a disablement resettlement officer or someone similar are important, and the Manpower Services Commission has a Disablement Advisory Service. Not all rehabilitation centres, however, let alone all rehabilitation departments, can call on any such person. A few hospitals have their own resettlement officers rather than using those of the MSC, but this innovation has not spread. Often employment rehabilitation is not sufficiently integrated with medical rehabilitation, and for those with difficult problems specially trained vocational counsellors (whether employed by the health service or by the MSC) have been proposed.¹⁰

Finding work presents a daunting problem even for trained disabled people, and there is much sense of wasted potential. More facilities are needed both for modified work (the MSC will often provide grants) so that some disabled people can achieve a normal output and for sheltered workshops for those who cannot.

Miller and Gwynne in 1972 contrasted "real work" (of which they give some examples—pp 151-3) with the more common occupational therapy approach in institutions, which fails, they suggest, by "equating work with finding occupation for idle hands and, perhaps, providing some pocket money."⁶ With the work approach residents are concerned with such things as marketing the results of their labours, deciding how to use the money, and perhaps obtaining contracts. Miller and Gwynne concluded from their observations that activities in an institution are related less to the residents' capacities or to the amount of physical care they need than "to the prevailing ideology, which supports either dependency or achievement, but seldom both." What has changed most since then is the availability of work, but the difficulty of getting contracts in the ordinary sense need not rule out a professional seriousness in whatever activities those in residential care, attending a day centre, or living entirely at home can take up. The local community often has needs for printing, typing, or clerical work, for example, and outlets for crafts. I have seen excellent craft work on sale in a home—but done more as occupational therapy than as work (see also Carter,¹⁰ p 300). Cantrell points to the importance to morale in disability of finding talents that can be put to financial gain.¹¹

At a voluntary home I visited, however, my host was a resident with muscular dystrophy who was completely happy, he said, in what he felt was a full working life. He was the only resident to have a full time "job" in the home, and he worked all day at the word processor with a specially adapted microwriter attached, producing the home's magazine and doing the layout and typing for small

outside printing jobs. He had previously run a greengrocery business, which his family bought to save him from unemployment.

Computer technology provides the chief way ahead for severely disabled people both in residential care and in the community (see last article, p 220). Many homes and units of all kinds have acquired at least one microcomputer. Apart from aids and recreation, a whole new world of work can open up, offering some of the most severely disabled the possibility of a proper career and source of income while working at home or in a residential setting. Two paralysed men in a younger disabled unit I visited had started their own computer programming business, but this clearly needs a lot of drive. There is a need for more projects like the MicroAid Centre in Southwark (last article, p 220).

The restriction on earnings, however, for people receiving social security benefits is a disincentive to work or at least a dampener of morale. Would it be a great drain on the exchequer if partial earnings and allowances¹⁰ became possible? The earnings rule has also prevented severely disabled people from taking full time jobs when offered them, if they continued to need care.

For the many who cannot work, more day centres are required. They provide a regular outside activity for some in residential care (attendance at one is sometimes a condition of residence in a local authority home) and a lifeline for some who live at home—and perhaps for their relatives. But they need to aim higher than providing ways of passing the time, offering constructive activity that caters for individual interests and is not desultory.^{10a}

More generally, many disabled people need much more energetic help and counselling in developing talents and interests and in unearthing things that perhaps they can pursue with passion. The disabled are not properly cared for, says Cantrell, if they have useful but unused talents or interests—“Many remain depressed and defeated because they assume that their ‘real’ interests are impossible.”¹¹ His examples of possible interests range from toy making and electronics to the stock market. In a residential home people have the one asset of time—potentially time to think and learn and pursue all sorts of things if they are not brain damaged—but they probably need a lot of help in putting it to some use. And here is the slippery slope of a paternalism that most “normal” adults do not experience. The opposite danger is leaving people, in homes or at home, apathetic and out of touch with whatever opportunities they might have enjoyed; the ideal is to make possible an environment where control over their lives and surroundings is possible⁶ and where varied opportunities are within their reach, so that apathy is less likely. This is what many are working for today.

Education and other activities

The educational should replace the medical model in rehabilitation, many believe. There are three separate strands: using effective educational methods in the remedial therapies; retraining if necessary, or for young people new arrangements for education, after injury or the onset or worsening of disease; and counselling about the possibilities of educational pursuits with the provision of facilities or of access to them.

A few hospitals have their own schools. The school of the Royal National Orthopaedic Hospital, Stanmore, for example, funded by the local authority, offers an impressive range of subjects and makes individual arrangements for patients, both children and adults, using specialist teachers as needed. An advantage of this system is that people can easily try out subjects even when their commitment is uncertain; but more commonly local authority teachers have to be specially provided for the few patients in a hospital who need to pursue their studies. I saw bedbound children completely absorbed in their work, some with computers and electric typewriters; adults with spinal injuries were also using computers, and some go on to pursue computer studies outside hospital. Similar computer facilities exist in other such units, including Stoke Mandeville spinal unit

with its computer training programme in which success is not determined by previous attainments. Some severely disabled people make it to university or college. An approach to disability at the University of Illinois is worth looking at—for over 30 years 225-250 students with severe disabilities have been admitted each year, thanks to a rehabilitation programme enabling them to take a full part in university life.¹²

Some people in residential care are capable of attending ordinary local authority adult education classes (a few residents of a younger disabled unit I saw go to an art class) but transport may be a problem. The Royal Hospital and Home for Incurables is hoping to arrange some classes jointly for residents and for anyone interested in the community, to be held in the building. The smaller voluntary home I have referred to has teachers on its staff and brings in others as needed—I saw, for example, a spastic man without comprehensible speech with a sociology tutor for his Open University course on the handicapped in the community. Everyone except the man who works with the word processor must attend classes of some kind; some are receiving basic education they missed as children. There is also much emphasis on swimming and special yoga,¹³ which are thought to have made a lot of difference to some of the residents. Sport and outdoor activities^{14 15} are important in all settings.

This and a large, well equipped home for ex-servicemen I visited have full programmes of varied outings. Many units and homes can do little in this way because they do not have adequate transport or perhaps enough volunteer helpers. Others believe that it is not their job—the residents are adults who can think for themselves what they want to do and be helped to do it as necessary. Again, for this to work the setting must not be conducive to apathy. The desirable balance between autonomy and opportunity will differ between different people and the problem is to get it right for each.

I am grateful for help from many people, especially Dr Margaret Agerholm, Heenan House Rehabilitation Centre, Hackney; Professor Cairns Aitken, Rehabilitation Studies Unit, University of Edinburgh; Dr M Anne Chamberlain, Rheumatism Research Unit, University of Leeds; Dr G M Cochrane and Miss Diana Staples, Mary Marlborough Lodge, Oxford; Dr A O Frank, Northwick Park Hospital, Harrow; Dr F R I Middleton, Royal National Orthopaedic Hospital, Stanmore, and Camden Road Medical Rehabilitation Centre; Miss Diana Twitchin, Centre on the Environment for the Handicapped, London; Dr J Wedgwood, Royal Hospital and Home for Incurables, Putney; and Dr Kyra Williams, Younger Disabled Unit, Willesden Hospital, London.

References

- 1 Agerholm M, ed. *Handicapped people in our inner city*. Report of a conference in London, July 1979. London: Heenan House Rehabilitation Centre, 1981.
- 2 Cochrane GM. Hidden resources for rehabilitation and care of the disabled. *J R Soc Med* 1982;75:89-95.
- 3 Mulroy R. Experience of an early younger disabled unit, Pinderfields Hospital, Wakefield. In: Chamberlain MA, Blomfield I, eds. *Young disabled units*. Report of the conference held in Leeds in October 1982. Leeds: University Rheumatology and Rehabilitation Unit, 1983:1-10.
- 4 Nichols PJR. Some psychosocial aspects of rehabilitation and their implications in research. *Proc R Soc Med* 1975;68:537-46.
- 5 Wilson SL, Thompson JA, Wylie G. Automated psychological testing for the severely physically handicapped. *International Journal of Man-Machine Studies* 1982;17:291-6.
- 6 Miller EJ, Gwynne GV. *A life apart: a pilot study of residential institutions for the physically handicapped and the young chronic sick*. London: Tavistock Publications, 1972.
- 7 Moore M. In: Russell M, ed. *Now this wont hurt!* An anthology of poetry by children of the Royal National Orthopaedic Hospital School, Stanmore: RNOH School, 1981:70.
- 8 Leonard Cheshire Foundation. *The Leonard Cheshire Foundation International*. (Obtainable from Leonard Cheshire House, 26-9 Maunsel Street, London SW1P 2QN.)
- 9 Chamberlain MA. Work for the disabled. *Br Med J* 1984;289:639-40.
- 10 Brewerton D, Nichols PJR. Return to work. *Br Med J* 1977;iii:1006-7.
- 10a Carter J. *Day services for adults: somewhere to go*. London: Allen and Unwin, 1981.
- 11 Cantrell T, Dawson J, Glastonbury G. *Prisoners of handicap*. Southampton: University Department of Rehabilitation, 1983.
- 12 Nugent T. System of care enabling educational and rehabilitation study by disabled people at universities. In: *International seminar on the long term care of disabled people, London 13th January 1981*. London: Royal Hospital and Home for Incurables, 1981:1-14.
- 13 Brosnan B. *Yoga for handicapped people*. London: Souvenir Press, 1982.
- 14 Croucher N. *Outdoor pursuits for disabled people*. Cambridge: Woodhead-Faulkner, for the Disabled Living Foundation, 1981.
- 15 Thomson N, Dendy E, de Deney D, eds. *Sports and recreation provision for disabled people*. London: Architectural Press, for the Disabled Living Foundation in cooperation with the Sports Council, 1984.