scheme failed. We do not believe arguments over provision for a remote and enormous catastrophe should inhibit the introduction of a general scheme.

The climate of opinion is changing. The inevitability of some such scheme is increasingly being accepted. We believe that discussions on financing a scheme should be opened between the principally interested parties with the aim of producing a scheme that is so obviously workable and in the public interest that the government will not wish to, indeed cannot, stand aside.

Conclusion

We believe that we have said enough to show that, failing a comprehensive compensation scheme for all the misfortunes of life, a no fault scheme for drug induced injury is desirable, workable,

and need not cost so much as to render serious discussion on implementation a waste of time.

Schemes already operate in other countries and much can be learnt from them. No doubt none of them is perfect, but they show that critics who spend their time on the easy art of proving that the difficulties are too great to contemplate action are wrong.

We consider that the principal interested parties should get together to propose a scheme which, after wide consultation, should formally be put forward. This should be done without waiting for the government to act, though ultimately government, and perhaps parliamentary, approval will be necessary.

This article is an abridged version of a chapter to be included in *Iatrogenic Diseases*, third edition, edited by J P Griffin and P F D'Arcy, and is published by permission of Oxford University Press.

Needs and Opportunities in Rehabilitation

Severe disability: 2—Residential care and living in the community

DAPHNE GLOAG

Disability has been defined as a restriction or lack of ability in normal activities resulting from an impairment, and handicap as the resulting social disadvantage.^{1,2} Some argue that disability is imposed by the material environment and the attitudes of society on those with physical impairments (see box), and is eliminated once people are reintegrated into society.³ Others have spoken of "the diminishing of personal authority [being] itself disabling."⁴

Clearly, however, disabled people are not a homogeneous group and there are very different needs and capabilities. There may be medical, social, or psychological problems, or all three. Some have no medical problems (notably many with spinal injuries) and these people on the whole should be living in the community. At the other extreme are patients severely affected by stroke and multiple sclerosis, for example, with difficult medical afflictions requiring 24 hour nursing care that is usually impracticable at home. In between are those with dementia or other mental impairment, who appear in many different settings (including at home with distracted and often unsupported families), and those with behaviour disturbances associated often with brain damage, for whom there is little adequate provision (see below). And, finally, there are people with moderate disabilities who need residential care largely for "social" reasons: if they are difficult and no one will fight to keep them in the community, or if they themselves want to give up the struggle for independence or need companionship.

Long term care and sometimes shorter term and intermittent care are provided by NHS units for the younger disabled, local authority homes, and voluntary homes, including the Royal Hospital and Home for Incurables and the Royal Star and Garter Home, which can cope with those needing a lot of nursing as well as rehabilitation. Living in the community may be possible with professional and voluntary support and sophisticated aids in a person's own home

and through various types of group living and sheltered accommodation schemes; some agencies provide a range of options from full residential care to independent housing.

Residential care

Writing in 1970, Miller and Gwynne say that the task of institutions in practice is "to cater for the socially dead during the interval between social death and physical death."⁵ Though this is still true for many residents, ideas and practices have changed a lot since then. Entering an institution is now much less the point of no return they saw it as, and flexibility is one of the most important features of the present scene. I have heard of people leaving even after years in a home. Commonly now a home or special unit is a medium term stopgap or transition house preparing some of its residents for the community and allowing a breathing space while a more permanent solution is being worked out. Short spells of residential care, especially to give relatives a break or to provide rehabilitation, are favoured, and crises such as family illness or marriage breakdown may also demand a refuge. A conference on this "dynamic approach" looked at the different patterns of care and of opportunities for independent living in a European context.⁶

"Ideally residential care," say Dartington *et al*,⁴ "is about providing a space in which disabled people are free to realise their potential," and it is helpful to look at different settings of care from this point of view. The "warehousing" or custodial and the "horticultural" or developmental models of care described by Miller and Gwynne are still valid, and so is their conclusion that everyone should have "the right to choose dependency, or to take advantage of developmental opportunities. It then becomes the task of the institution first to help the individual make this decision and second to provide him with the facilities to implement it." The right environment for privacy, independence, and autonomy was not easily provided in the 10 residential homes—NHS, local authority, and voluntary—studied in depth in 1979 in a DHSS survey (reported by H Canter to the Medical Disability Society, December 1984). But it appeared easier to hand responsibility over to residents in a voluntary home because of the simpler management

set up. Many residents were said not to want independence—going into the home had been the end of a long struggle living independently—and many attempts to provide for autonomy had failed; these might, however, it was thought, have been half hearted or the residents were perhaps not trained for them.

The ways in which the vision of how things might be impeded by lack of resources is illustrated by what a social worker said to me. "We have gone as far as we can with present resources," he said, speaking of the small local authority unit for younger disabled people of which he was in charge. They need, he believes, someone to do in depth counselling with no restriction on time; an occupational therapist, especially to help those who are capable towards more independent living in the community; a business adviser to produce work contacts and contracts; and a member of staff who is a "mad artist or actor" to bring creativity into the home.

YOUNGER DISABLED UNITS AND THE MEDICAL MODEL

The creation of special units for younger disabled people, in response to the Chronically Sick and Disabled Persons Act 1970, was a great step forward for no longer should such people live out their days in geriatric units (though occasionally they are not in practice separated even today). "The aim should be to provide as relaxed and permissive an atmosphere as possible within a hospital setting," says a Ministry of Health memorandum,⁸ which lays down various standards of excellence that are still not generally met. There are, of course, many good units and good practices (see, for example, the Leeds symposium⁷); but there has been plenty of criticism.^{5,9} A small questionnaire survey by Scott in 1981 suggested that a minority provide for rehabilitation, day care, and short term admissions as well as long term care; have adequate levels of remedial, social work, or even nursing staff; provide a good range of activities including educational opportunities; or in short provide the setting for a good quality of life.^{7,19} He considers that many such units have become "long term custodial care units." NHS younger disabled units as permanent homes are also rejected on principle by many people, including doctors—because they provide an inherently institutional setting for "patients" in association usually with a hospital. Institutionalisation is not inescapable, but the "patient" aspect perhaps is and it may be demoralising. In Scott's questionnaire replies, some consultants said that they aimed at a homely, domestic, secure, or fulfilling environment for long term care, but others doubted the feasibility of anything like this: "Hospitals are to look after people, not help people look after themselves," said one.⁷

Depressingly, even new younger disabled units may misfire in one way or another. One I visited, with half long term and half "relief" beds, is in a former cottage hospital building that was specially adapted. Despite all the planning advice that had been taken it is utterly a hospital and moreover it was designed for bedbound residents rather than wheelchair users; wash bowls and other fittings do not "fit" wheelchairs, windows are too high, and the tiny wardrobes are derisory for people's total possessions. The enlightened consultant in charge (who had not been appointed at the planning stage) regretted that there were not more activities specifically for the unit. Inadequate planning, lack of resources, and staff shortages made it virtually impossible to run the unit as a "home." The physiotherapist and occupational therapist had little chance to use their skills; volunteers for activities and outings were scarce. Thus the process of institutionalisation was reinforced.

Hospital units might be expected to provide good remedial facilities as their main *raison d'être* and those that do not should surely make this a priority. For far from needing to be scrapped or taken over by social service departments, as some workers appear to wish, they have an important active role, though rather different from that actually performed by some units—namely, a medium term home for those who can profit from remedial therapies with or without medical care, while being prepared for life in a different setting. In addition, they must provide a permanent home for some who need a lot of nursing and short term care as needed. In the absence of a good local rehabilitation department or centre they may

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Union of the Physically Impaired Against Segregation, quoted in *Attitudes and Disabled People* by V Finkelstein, p 33³

This reality, that disabled people have choices in their lives and with help can have autonomous personalities, separate from the personalities of those on whom they are physically dependent, has not yet been fully realised. But the two levels, practical freedom of choice and the emotional quality of life, are linked at every stage.

From *A Life Together* by T Dartington *et al*, p 65⁴

also provide assessment, act as day units, and serve as a local resource centre. Those who run them emphasise that plenty of space and staff should be allowed for in planning. I have come across the suggestion that units might be run jointly by health and local authorities in an attempt to prevent a hospital orientation for those who have them as a long term home.

These units should be aiming, much more than most do at present, at giving the widest possible range of stimulating experiences and opportunities—including educational and other classes and sporting and other outdoor activities; only a third of Scott's units provided regular swimming, and few offered any other sports.⁷ More generally, there is plenty of scope for innovation and enterprise^{7,9}: a five day unit in Chichester, for example, combats the danger of institutionalisation and helps family ties⁷; at one of the first units, in the grounds of Pinderfields General Hospital in Yorkshire, which aims at "structured informality," fund raising has provided among other things a minibus, a static caravan for holidays, funds for foreign holidays, and a potter's kiln and wheel, and contributed to a predischARGE flatlet.⁷ Associated with Hunters Moor Hospital young disabled unit in Northampton are three bungalows in the grounds for independent living with the security of an intercom link with the unit. But despite innovations the difficulties are enormous with a high proportion of residents having severe neurological problems in all homes.

A survey in Lothian of the younger chronic sick in hospital showed a need for a small specialist unit for those with serious behaviour problems.¹⁰ This is in fact widely felt to be a gap in the services and physically disabled people with mental impairment and especially behaviour disturbance are extremely difficult to place in residential care.^{11,12} Those who run younger disabled units, or indeed small residential homes, tend to be reluctant to take people who would not fit in with the home like milieu they are trying to achieve, and only large, well staffed institutions usually can cope with disturbed behaviour (I touch on the head injuries unit at St Andrew's Hospital, Northampton, in a later article). Though too young, these people with both physical and mental handicaps are sometimes taken by geriatric units; but more commonly they take up psychiatric or mental handicap beds, where they are out of touch with rehabilitation facilities,¹¹ or end up in private institutions—often, it is said, with minimum care. Or they may remain unhelped at home. Specialist units should serve populations of about 1 million, with facilities for both short and long term and intermittent patients and day patients, and act as a base for community work.¹¹

The officially recommended number of long term beds for younger disabled people is six per 100 000 for England and Wales.⁸ Many people both in the medical profession and elsewhere believe that this is a distraction from the real needs of the greater proportion of disabled people who are not or should not be occupying them. In

Lothian about half the people in long term beds could with help have moved into the community—though many of them could not realistically be expected to do so now.¹⁰ Once people with unmet needs, however, notably those with severe brain damage, are taken into account, six beds per 100 000 are not likely to be too many.

The Royal College of Physicians is supporting a study of residential care for younger disabled people.

AN EXPERIMENT IN AUTONOMY

"I'll have one of the residents with me when you come—after all, it's their home," said the social worker head of a local authority home I visited. Known simply as 48 Boundary Road, this home set up in North London by Camden Council as an experiment in autonomy has been the subject of much study and controversy, described in detail by Dartington *et al.*⁴

The residents are on practically equal terms with staff in managing the home, and there is not much communal living or group activity in the usual sense; the residents live in groups of four in six self contained flats to which their own social worker care staff are attached. The staff have been described as "extensions" of the residents, though this is a slight exaggeration; they provide arms and legs to do things or help with things the residents cannot do for themselves—the decisions and the organising being entirely the residents' responsibility; thus if residents do not arrange for shopping and cooking to be done they will go hungry. Similarly, they are responsible for seeing to their own medical needs. They could make use of local physiotherapy or other services if they needed them, said the head of the home; but in practice they seldom did need them. Only applicants showing potential for development and independence are selected; many of them in fact move on to even more independent living. A criticism I have heard—the opinion of a former resident—is that this kind of set up can be a great bore, with endless meetings and group discussions to thrash things out democratically. But for young people of the right temperament and capabilities it seems to offer a great release and a new start. Few other such places exist; a sprinkling of such homes is needed, I believe, throughout Britain but they are too expensive in staff to become widespread.

Living in the community

A man who broke his neck water skiing became stifled by his parents' care, longing for possession of his own life. Now he lives independently in his own adapted house with Cheshire Foundation care attendants and has a full time job as a personnel officer. Shearer describes some remarkable successes in independent living, but the going is often tough.¹³ Crucial needs are money and advice. More often, of course, a relative does the caring; but this too is often a struggle, physically, emotionally, and financially.

Clearly graduating to home life or continuing with it is often a desired goal of rehabilitation and bars to its viability have to be tackled. The help given to one tetraplegic girl living at home is summarised in the legend to the figure. The chief problems are the organisation of services and information, accommodation (see p 220, 19 January), help and support for the disabled person or caring relative or both, and money. At another level, counselling, especially important but often neglected in the community, needs to be built more explicitly into the services; apart from practical problems, depression is common—40% of clients in a Southampton survey suffered from it.¹⁴ A report from Edinburgh emphasises counselling in social work with the chronically disabled and suggests the need for more specialisation¹⁵; a plea has also been made for better identification of the many potential sources of counselling.⁹ Peer counselling, which is likely to become more widespread with the growth of the centres for independent living movement, may and should be encouraged by the statutory services. A particular need, often neglected, is help with sexual problems.¹⁶

The multiplicity of agencies and services means that "in effect disabled people do not get the care and help they need, even though

This girl, tetraplegic as a result of a car accident three years ago when she was 14, lives at home and attends a comprehensive school, accompanied by a welfare attendant provided by the local authority. School nurses see to her catheter. At home she is cared for by her mother and by district nurses, one of whose visits is at 1 a.m. She goes to the Royal National Orthopaedic Hospital, Stanmore, once a week for physiotherapy. Once she has her compensation money she will employ a full time care assistant with the advice of community service volunteers. She is a guide ranger and has been given the highest award for bravery.

it is available somewhere."¹⁴ The sheer complexity is well illustrated by Brechin and Liddiard.¹⁷ The two priorities, in the view of one rehabilitation specialist I met, are improvement of administrative links and, for each disabled person, a coordinator or "fixer"¹⁸—for example, a social worker or general practitioner. The multitude of problems on many fronts found in a majority of 255 wheelchair users in an Edinburgh survey show the force of this (L MacKenzie, unpublished findings). Southampton has a district disability team to make assessments and coordinate all aspects of home care,²⁰ together with a register and monitoring scheme for the younger disabled in the community.¹⁴

In a different way, the kind of resource centre or "supermarket" for the disabled proposed by M Agerholm would bring everything together and act as a non-hospital information and educational centre; while centres for independent living give information and advice as well as offering services and a new ethos. Several publications give essential information on many aspects of living.²¹⁻²³

In a critique of current rehabilitation practice Brechin and Liddiard argue that disabled people are given a piecemeal system of professionals and services for helping them to cope with unacceptable social, financial, housing, and environmental circumstances—and that they feel themselves to be the passive subjects of rehabilitation services.²⁴ They press for directing more attention to the whole social context—which is indeed happening in the best services—but also for redefining the traditional roles to improve the quality of the needed problem solving, so that both helper and helped "work together in an atmosphere of open-mindedness."

CARE AND SUPPORT

How to get adequate personal care is the biggest problem for many severely disabled people, especially those wanting to strike out on their own, and there are great gaps in the provision of services. Those concerned with rehabilitation need to know just what does exist—the possibilities are not always much publicised.

Special housing schemes with support facilities incorporated (including the Swedish Fokus scheme) were critically discussed by Shearer in 1982¹⁵; since then the Centre on Environment for the Handicapped and Long Term and Community Care Team at the King's Fund Centre have developed an information bank on housing and care for the physically handicapped, to show professional workers and planners of services the range of possibilities.

A guidance document on living options is being prepared by a working party of the Prince of Wales's Advisory Group on Disability and the Long Term and Community Care Team of the King's Fund. One idea is special housing integrated into ordinary estates with built in 24 hour care services. An important advance, or the beginning of one, is provided by care attendants (usually untrained) giving help in a flexible way to supplement statutory services such as the district nursing service, normally with a small payment by the clients. A care attendant scheme is now organised by some statutory as well as voluntary services; occasionally, but not often enough, it covers disabled people living alone as well as with relatives (see below). Community service volunteers are also important. Scraping together enough help for surviving independently, whether alone or with a family, tends to be a great struggle, however.

A powerful force now is the wish of disabled people not to be segregated into a ghetto even within the community but to live like everyone else so far as possible²⁴; and a striking conclusion reached by Shearer was the need of the people she met not to have their lives dominated by the services and attendants they managed to get but to choose their own modes of care.¹³ Thus in the view of many disabled people and many professionals a new strategy is called for: the channelling of much more money directly to the disabled, for them to spend as they wish. But before looking further at this idea I must say something about family support from conventional services.

Nearly all the support given to disabled people in Harrow, according to a social worker, comes from family, friends, and neighbours; and this is believed to be widely true—which makes family support schemes so important. Stories abound of relatives driven to breaking point. A study in Southwark by the Association of Carers has shown both the needs and the value of support schemes.²⁵ Despite some excellent examples good family support is “not in the ‘bloodstream’ of basic provision.”²⁷ A North Tyneside survey found that a third of carers were regularly disturbed at night and nearly a quarter could not leave the handicapped person during the day.²⁹ In a Wessex survey 29% of carers had little or no support and only 19% regular support; over half were “moderately stressed” and 39% “under severe pressure,” while several marriages had broken down and others were on the verge of doing so.²⁰

Family support or care attendant schemes are intended to provide the kind of help a relative gives, like getting a paralysed person up and putting him to bed, and to supplement other services in a flexible way. Crossroads in 1972 started these schemes;³ other organisations, including the Spinal Injuries Association and the Cheshire Foundation,³⁰ now have care attendant schemes. Some schemes are financed jointly by the local authority and the health authority.²⁰ DHSS grants have been given recently to improve help to carers. In some cases such schemes stave off the need for residential care and even enable people to move out of residential care. I looked at one of the few London schemes run by statutory services; though appreciated it has three drawbacks—it can provide a care attendant for only a limited time, the scheme only relieves relatives and does not cover those living alone, and help is not given during the night.

CENTRES FOR INDEPENDENT LIVING: A RADICAL ALTERNATIVE

Two main themes characterise the independent (or integrated) living movement, which started in the United States in the 1970s: self direction and control over their own lives for disabled people and full participation in the life of the community.²⁴ It is described by the Hampshire Centre for Independent Living (CIL) as “a continuous process of identifying choices and creating personal solutions.” In Britain CILs have developed in Derbyshire, Exeter, London (Islington), Manchester, and Norwich as well as Hampshire. Public funds may help to set up such ventures.

A woman working for the American independent living movement argued that potentially everyone now in an institution could transfer to these sorts of services—“if the independent living movement continues to grow [in Britain] institutions will hopefully

become a thing of the past”—and even halfway houses should be unnecessary.³¹ Needless to say, the credulity of some at this London seminar was stretched. Nevertheless, many potentially capable people remain to be reached. Perhaps the most pervasive part of the “independence” philosophy will be the principle that the consumer directs the provision of his care, which could in time greatly influence the spirit of the most conventional services.

Conclusion: money, facilities, and choice

Keeping disabled people in the community struggling on with the minimum of help and facilities is cheap; no wonder it is so popular. With poverty and enforced isolation clearly it may be much worse than a good institution. Providing all the support and facilities they need is very expensive—but so is residential care. About £22 000 a year is spent on supporting one woman with multiple sclerosis in her own home; but she is thus enabled to provide a home for her young daughter.³² Respect for people's individuality and adulthood means giving them the choice of how to live, with a role or at least a say, if they wish, in the provision of facilities generally; and it means giving them the money to buy whatever form of community support and facilities or of residential care they want. This certainly would not imply a whittling away of public provision. But for choice to be meaningful there must be plenty to choose from: a range of statutory and voluntary facilities in all places, catering for a range of dependency, personality, and circumstances. This includes good support for families; according to one consultant running a younger disabled unit, the pressure to get someone into long term residential care comes not from the medical profession but from families and has to be resisted wherever possible. There is a need for more accurate information for all districts about numbers of severely disabled people, services available and needed, and the correct levels of benefits, and for better information services for everyone. Facilities must include access to fulfilling day centres³³ and, better still, to activities in the “normal” world, both for those in the community and for those in residential homes. This in turn calls for an extension of what volunteers are already doing as escorts, companions, transport helpers, and so on. Without all these things loneliness and poverty of life are the lot of so many. There is much frustration and bitterness, and many disabled people, it was said to me, come to terms with their disability but not with the lack of help. Yet such is the force of such things as choice, freedom, and privacy that they do, unfairly, go on struggling.

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; Mr Paul Brearley, Leonard Cheshire Foundation; Dr M Anne Chamberlain, Rheumatism Research Unit, University of Leeds; Dr G Cochrane and Miss Diana Staples, Mary Marlborough Lodge, Oxford; Dr A O Frank, Northwick Park Hospital, Harrow; Dr K W Kennedy, Royal Star and Garter Home for Disabled Sailors, Soldiers and Airmen, Richmond; Dr C B Wynn Parry, Royal National Orthopaedic Hospital, Stanmore; Miss Diana Twitchin, Long Term Care Team, King's Fund, London; Mr Peter White, 48 Boundary Road (Camden Council home), London; Dr Kyra Williams, Younger Disabled Unit, Willesden Hospital, London.

Addresses

- Association to Aid the Sexual and Personal Relationships of the Disabled (SPOD) 286 Camden Road, London N7 0BJ
- Association of Carers Medway Homes, Balfour Road, Rochester, Kent ME4 6QU
- Association of Crossroads Care Attendant Schemes 94 Coton Road, Rugby CV21 4NL
- British Red Cross Society 9 Grosvenor Crescent, London SW1X 7EJ (provides escorts, transport, care in the home; runs clubs, day centres, residential homes)
- British Sports Association for the Disabled Hayward House, Harvey Road, Aylesbury, Bucks HP21 8PP
- Centre on Environment for the Handicapped 126 Albert Street, London NW1 7NF
- Centres for Independent Living Addresses from preceding centre
- Chest, Heart and Stroke Association Tavistock House North, Tavistock Square, London WC1H 9JE
- Community Service Volunteers Independent Hiring Scheme 237 Pentonville Road, London N1 9NJ

Disabled Living Foundation 380-4 Harrow Road, London W9 2HU
 Disabling Income Group Attlee House, 28 Commercial Street, London E1 6LR
 Joint Committee on Mobility for the Disabled 9 Moss Close, Pinner, HA5 3AY
 Leonard Cheshire Foundation 26-29 Maunsel Street, London SW1P 2QN
 Long Term Care Team, King's Fund 126 Albert Street, London NW1 7NF
 Multiple Sclerosis Society 286 Munster Road, London SW6 6AP
 PHAB (Physically Handicapped and Able-bodied) Clubs (450 throughout the UK)
 Tavistock House North, Tavistock Square, London WC1H 9HJ
 Queen Elizabeth's Foundation for the Disabled and Training College Leatherhead
 Court, Woodlands Road, Leatherhead, Surrey KT22 0DN
 Royal Association for Disability and Rehabilitation (RADAR) 25 Mortimer Street,
 London W1 8AB
 St John Ambulance 1 Grosvenor Crescent, London SW1X 7EF (provides escorts,
 transport, care in the home)
 Spinal Injuries Association 76 St James Lane, London N10 3DF

References

- 1 World Health Organisation. *International classification of impairments, disabilities and handicaps*. Geneva: WHO, 1980.
- 2 Tait F. Disabled or handicapped: what's the difference? *Health Trends* 1981;13:109-11.
- 3 Finkelstein V. *Attitudes and disabled people*. New York: World Rehabilitation Fund, 1980. (International Exchange of Information Monograph No 5.) Reprinted by RADAR.
- 4 Dartington T, Miller EJ, Gwynne GV. *A life together*. London: Tavistock Publications, 1981.
- 5 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.
- 6 *The dynamic approach to the residential care of disabled people in an integrating society*. Proceedings of seminar held under the auspices of the EEC. London: Royal Hospital and Home for Incurables and Development Trust for the Young Disabled, 1984. (See *Br Med J* 1984;288:1323-4.)
- 7 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.
- 8 Ministry of Health. *Care of younger chronic sick patients in hospitals*. London: Ministry of Health, 1968. (HM(68)41.)
- 9 Kent Area Health Authority and Kent County Council Working Party (Matthews G, chairman). *Physical disability—take a risk*. Canterbury: Kent Area Health Authority, 1981.
- 10 McAndrew L. *The survey of the younger chronic sick in hospital in the Lothian Health Board Area*. Edinburgh University: Rehabilitation Studies Unit, 1984.

- 11 Newson-Smith J. Who cares for the adult brain damaged? *Bull R Coll Psychiatrists* 1983;7:181-3.
- 12 Lishman WA. *Brain damage and psychiatric disability*. London: Royal Hospital and Home for Incurables and Development Trust for the Young Disabled, 1983. (Paper given at conference.)
- 13 Shearer A. *Living independently*. London: Centre on Environment for the Handicapped and King's Fund, 1982.
- 14 Cantrell T, Dawson J, Glastonbury G. *Prisoners of handicap*. Southampton: University Department of Rehabilitation, 1983.
- 15 Porter C. *Social work specialisation and people with physical disabilities*. Edinburgh University: Rehabilitation Studies Unit, 1984.
- 16 Greengross W. *Entitled to love: the sexual and emotional needs of the handicapped*. London: National Marriage Guidance Council/National Fund for Research into Crippling Diseases, 1976.
- 17 Brechin A, Liddiard P. *Look at it this way: new perspectives in rehabilitation*. Sevenoaks: Hodder and Stoughton, 1981. (For the Open University course "The Handicapped Person in the Community.")
- 18 Aitken C. Psychological aspects of disability. *Psychiatry in Practice* 1981;ii:22-34.
- 19 Scott CJ. Hospitals for the disabled. *Int Rehabil Med* 1984;6:166-9.
- 20 Lovelock R. *Friends in need: three care attendant schemes for the younger physically disabled in Hampshire*. Portsmouth: Social Services Research and Intelligence Unit, 1981.
- 21 Darnbrough A, Kinrade D, eds. *Directory for the disabled*. 4th ed. Cambridge: Woodhead Faulkner, 1984.
- 22 Disability Alliance. *Disability rights handbook. A guide to rights, benefits and services for all people with disabilities and their families*. London: Disability Alliance, 1984.
- 23 Jay P. *Coping with disability*. 2nd ed. London: Disabled Living Foundation, 1984.
- 24 Brechin A, Liddiard P, Swain J. *Handicap in a social world*. Sevenoaks: Hodder and Stoughton, 1981. (For Open University course "The Handicapped Person in the Community.")
- 25 Bonny S. *Who cares in Southwark?* Chatham: Association of Carers, 1984.
- 26 Association of Carers. *Help at hand*. Chatham: Association of Carers, 1984. (Sources of help.)
- 27 Social Work Service Development Group. *Supporting the informal carers. A project paper and report of a seminar at Oxford, June 1983*. London: Department of Health and Social Security, 1983.
- 28 Social Work Service Development Group. *Supporting the informal carers. Information (initiatives, literature and contacts)*. London: Department of Health and Social Security, 1983.
- 29 Buck K, Hibberd A. *The handicapped in the community (OUTSET survey)*. North Tyneside Social Services Department, 1982.
- 30 Inskip H. *Family support services for physically and mentally handicapped people in their own homes*. London: Leonard Cheshire Foundation, 1981.
- 31 Heuman J. In: *Centres for independent living in the US and UK—an American viewpoint. Report of a seminar held at King's Fund Centre*. London: King's Fund Centre, 1983.
- 32 Price T. Aspects of social work involvement in rehabilitation. *Demonstration Centres in Rehabilitation Newsletter* April 1982;28:91-8.
- 33 Kent A, Massie B, Newman B, Tuckey L. *Day centres for young disabled people*. London: Royal Association for Disability and Rehabilitation, 1984.

A middle aged patient has had successful surgery for bilateral cataract caused by trauma; the lenses were removed and he now has 90% normal vision using soft contact lenses. A surgeon has advised further surgery for intraocular lens insertion. Is this procedure justifiable in the circumstances?

The answer must be that further surgery is not advised if the patient is middle aged and is a successful contact lens wearer. If the contact lenses are causing problems then secondary implant surgery is worth considering. Certain mitigating circumstances, however, might cause a surgeon to advise against secondary implant surgery. Since the patient is middle aged with an expectation of life of possibly 20 or more years, the late complications of implant surgery must be considered. Thus the surgeon must be satisfied that the endothelium of the cornea can withstand the further damage likely to result from secondary implantation. Since trauma has been stated as a cause of the cataracts the health of the other eye tissues must be considered. The type of procedure used to remove the cataracts, and therefore the present anatomy of the anterior eye segment, will largely determine the suitability of an implant and the type of procedure. Indeed, some surgeons are correctly quite dogmatic about the use of anterior chamber as opposed to posterior chamber implants in certain cases. Lastly, the ability of the surgeon and the availability of facilities for diagnosis of the corneal endothelial state must be a deciding factor when considering any lens secondary implant operation procedure.—M RUBEN, honorary consulting ophthalmic surgeon, London.

For years users of beta stimulant inhalers for asthma have been told that "it is dangerous to exceed the stated dose." I always presumed that this followed the salutary experience of the 1960s, when deaths followed the introduction of the pressurised aerosol. What, then, is the rationale of the current volte face on nebulised ventolin with children being advised to inhale 10 or 20 times the former dosage as a matter of course?

The questioner correctly recognises that the cause of the increase in the number of deaths from asthma in the 1960s still remains controversial and that the evidence that it was due to excessive use of beta stimulant inhalers is not proved. Increasingly it has been recognised that the standard doses of beta sympathomimetic agents when given by tablet as a systemic medication are many times higher than the doses from conventional pressurised aerosols. In addition, the aerosol is deposited more specifically in the airways, although probably 80% or 90% is swallowed and passes through the

gut and liver. Even so, the original restrictions on the aerosol dosage were probably far too stringent, and it would seem reasonable to allow more liberal use of aerosols than before. A useful practice is to prescribe specifically for the individual patient, setting a dose range from aerosol that may be regarded as normal for that individual—for example, 10 to 20 puffs a day—indicating to the patient that, in the event of needing to use considerably more than that dose, medical advice should be sought as soon as possible. So for nebuliser treatment there are grounds for misgivings, as 90% of the dose is ingested through the gut, and the content of the conventional doses for nebuliser solutions amounts to considerable systemic doses of bronchodilators equal to or greater than those usually given by tablet, being 40-50 times greater than a standard single aerosol dose.—JOHN COLLINS, consultant physician, London.

What investigations are appropriate and what treatment is available for an otherwise fit patient without dermatographism who has a long history of intense generalised pruritus after exposure to water during the summer months?

Aquagenic urticaria is the name given to urticarial weals that occur after exposure to water, irrespective of its temperature.¹ It is rare. Aquagenic pruritus has a somewhat similar history, sometimes with intense itching, although, by definition, no weals.² It is probably not just a partial form of aquagenic urticaria as there are other clinical differences. It is probably not rare. The main differential diagnosis is the pruritus of polycythaemia rubra vera, which is often characteristically worse after bathing. Other physical urticarias such as cholinergic urticaria, dermatographism, and cold urticaria may at times cause itching after bathing, and mixtures of the physical urticarias are not uncommon. It sounds as if this patient has aquagenic pruritus. A full blood count is clearly indicated. The physical urticarias are usually best diagnosed by careful history taking, perhaps with some homely tests of the effect of water, exercise, and cold. Treatment of aquagenic itching is usually not very successful but reassurance may be all that is required. There is no very clear explanation for the summer exacerbations but, interestingly, cholinergic urticaria may be worse in the winter months.³—R H CHAMPION, consultant dermatologist, Cambridge.

- 1 Shelley WB, Rawnsley HM. Aquagenic urticaria. Contact sensitivity reaction to water. *JAMA* 1964;189:895-8.
- 2 Greaves MW, Back AK, Eady RAJ, Coutts A. Aquagenic pruritus. *Br Med J* 1981;282:2008-10.
- 3 Udassin R, Harari Z, Schoenfeld Y, Keren G. Cholinergic urticaria: a seasonal disease. *Arch Intern Med* 1981;141:1029-30.