LIVING OPTIONS LOTTERY

HOUSING AND SUPPORT SERVICES FOR PEOPLE WITH SEVERE PHYSICAL DISABILITIES · 1986/88

BARRIE FIEDLER

THE PRINCE OF WALES'
ADVISORY GROUP
ON DISABILITY

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Report of the Living Options Project funded by the Department of Health and Social Security and The King Edward's Hospital Fund for London

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ADVISORY GROUP
ON DISABILITY

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THE LIVING OPTIONS WORKING PARTY

Chaired by Mrs Nancy Robertson, Director,
The Prince of Wales' Advisory Group on Disability

The following groups have been involved in the Living Options project and endorse the findings of the report:

Arthritis Care
Association to Combat Huntington's Chorea
Association of Crossroads Care Attendant Schemes
Association for Spina Bifida and Hydrocephalus
British Council of Organisations of Disabled People
The British Polio Fellowship
Centre on Environment for the Handicapped
The Chest, Heart and Stroke Association
CRYPT, Creative Young People Together
Disabled Living Foundation
Disablement Information Advice Line
Exeter Council for Independent Living
Greater London Association for Disabled People
Habinteg Housing Association
HEADWAY National Head Injuries Association
Informal Caring Support Unit, King's Fund Centre
Islington Disablement Association
John Grooms Association for the Disabled
The Lady Hoare Trust
The Leonard Cheshire Foundation
Long Term and Community Care Team, King's Fund Centre
Motor Neurone Disease Association
The Multiple Sclerosis Society of Great Britain and Northern Ireland
Muscular Dystrophy Group of Great Britain and Northern Ireland
National Council for Voluntary Organisations
National Federation of Housing Associations
National Information Forum
Parkinson's Disease Society
Queen Elizabeth's Foundation for the Disabled
The Royal Association for Disability and Rehabilitation
SENSE, The National Deaf-Blind and Rubella Association
The Shaftesbury Society
The Spastics Society
Spinal Injuries Association
Wales Council for the Disabled

KENSINGTON PALACE

Since my patronage of the International Year of Disabled People in 1981 and the subsequent formation of The Prince of Wales' Advisory Group on Disability, I have come to appreciate that a place to live and personal help with daily living tasks can mean that even the most severely disabled person can lead a full life and contribute to the community.

This Report on housing and personal support services for severely disabled people follows the Living Options Guidelines published by my Advisory Group on Disability in 1985. The enthusiasm and commitment of many of the major voluntary organisations working together led to the DHSS and The King Edward's Hospital Fund for London funding this action research.

Much of the evidence for the report comes directly from disabled people, as well as those working with statutory and voluntary bodies. Although there are obviously some exciting schemes which should be commended, services responsive to consumers' needs and preferences are apparently few and far between.

One of the aims I have had through my Advisory Group is to encourage opportunities for integration. Only by involving disabled people in planning the services that give them the necessary support in their lives can this be achieved. I am delighted that so many organisations are prepared to promote the findings of the report and intend to use it to work for change.

Charles

September 1988

Summary

The Living Options project was launched by The Prince of Wales' Advisory Group on Disability with a brief to document good practice in the way housing and care support services are provided for people with severe physical disabilities.

The reality of housing and care support options revealed by the project investigations, however, is alarming. Direct evidence from service users throughout England and Wales shows that few people obtain the flexible, dependable services essential for personal autonomy. The amount and kind of help a disabled person receives is determined less by need than by chance – a 'living options' lottery.

Disabled people are rarely involved in planning or managing the services they use. Most live restricted, isolated lives at home dependent on family or friends, or remain in institutions. Inappropriate residential facilities continue to be built. In many authorities the needs of this client group are not yet on the agenda.

Although consumer awareness and frustration are increasing, expectations for service provision are low. But the study shows that where housing and personal support are available, even the most severely physically dependent person can take responsibility for his or her own life and achieve independence and integration in the community.

Living Options Lottery offers guidelines for statutory and voluntary agencies on the preconditions to and ingredients of a quality housing and care support service for physically disabled people. It presents case histories from the project research, and documents some of the innovative schemes and services that are helping disabled adults to live in the way they choose. Starting points for change are suggested to encourage planners and providers of services to take responsibility for the development of genuine living options for people with severe physical disabilities.

CHAPTER 1

The Living Options Project

BACKGROUND

In 1984, more than 30 voluntary organisations of and for disabled people, sharing a concern that the needs of severely disabled people were not being met, came together under the auspices of the The Prince of Wales' Advisory Group on Disability. Following wide consultation, these organisations – the Living Options Working Party – produced *Living Options: Guidelines for those planning services for people with severe physical disabilities* in February 1985.

The *Guidelines* set out the 'key principles' of service provision for this client group:

- **Choice** as to where to live and how to maintain independence, including help in learning how to choose;
- **Consultation** with disabled people and their families on services as they are planned;
- **Information** clearly presented and readily available to the most severely disabled consumers;
- **Participation** of disabled people in the life of local and national communities in respect of both responsibilities and benefits;
- **Recognition** that long-term disability is not synonymous with illness and that the medical model of care is inappropriate in the majority of cases;
- **Autonomy** – that is, freedom to make decisions regarding the way of life best suited to an individual disabled person's circumstances.

A 'way forward' through 15 action points was also suggested. In conclusion, the publication expressed the hope that the *Guidelines* might be expanded, by elaborating the concepts expressed in the paper, and documenting some of the creative work currently being undertaken.

Living Options Lottery presents the findings of the Living Options project which was funded for a two and a half year period by grants from the Department of Health and Social Security (DHSS) and The King Edward's Hospital Fund for London.

Publication of this report occurs in a climate of ferment regarding community care issues, following the 1986 Disabled Persons Act, the 1988 Social Security Act, the Griffiths (1988) and Wagner (1988) reviews of community and residential care, and the recent reorganisation of the DHSS. The opportunity exists to achieve a significant expansion of housing and personal support options for people with severe physical disabilities.

Disabled people and their organisations, and the Living Options Working Party, intend to draw on the evidence of this report to influence the debate about these issues, to encourage a commitment to good practice at planning and policy level, and to foster innovative housing and care support initiatives at a local level.

THE RESEARCH PLAN

The Living Options project sought to identify housing and care support schemes and services which enable people with severe physical disabilities to live in the way they wish – independently, and integrated within the community. Information about existing good practice was sought from statutory and voluntary bodies, disabled people and their organisations throughout England and Wales. Letters to all directors of social services, directors of housing authorities and general managers of district health authorities invited suggestions of innovative, effective and collaborative services in their areas; nearly 200 statutory authorities responded (see Fiedler, 1988).

'Hundreds of service users gave evidence'

Acting on these responses to the initial trawl for information, a range of voluntary and statutory provision – home based services, supported housing schemes and residential settings – were visited. Loosely structured interviews with service planners and providers, disabled service users and their support staff were carried out. In all, more than two hundred severely disabled people in some 50 health and local authorities gave personal evidence to the project.

The Living Options project was concerned with those severely disabled people aged 16 to 64 whose physical limitations make them dependent on others on a long-term basis for normal daily living activities. Those with multiple disabilities and head injuries were included where the primary disability was a physical one.

'Improved services for younger severely disabled adults will benefit all disabled people'

While recognising that age limits are arbitrary and that continuity of provision is essential, services for 'younger disabled' adults with severe disabilities were felt to be particularly neglected. Expanding and improving services for this group will have a positive impact for people of all age groups and all levels of physical disability.

The method of collecting information meant that the project was only able to consider those schemes and services brought to its notice. However, all relevant statutory bodies, and those voluntary organisations known to be active in providing services to severely disabled people, had the opportunity to nominate to the project any facility or service currently in operation thought to represent good practice.

In choosing which services to examine further, good practice was considered in light of the principles stressing consumer involvement and control set out in the *Guidelines*, and assessed according to the direct evidence of disabled people receiving services. Instances where authorities were working together and with voluntary organisations to provide good services were particularly sought.

To make sure the assessment remained consistent, a checklist was devised covering physical design, support service design and delivery, funding arrangements and consumer involvement. These criteria are reflected in the descriptions of schemes in Chapter 4.

'Investigations revealed little inter-agency collaboration or consumer involvement'

'Housing and support needs are unacknowleged by decision makers'

Investigations, however, soon revealed that quality housing and care support services for severely disabled people were few and far between. Instead of choosing the best from among abundant good services, the project would be seeking out isolated examples of successful services from a wasteland of inadequate or non-existent provision. The ideals of inter-agency collaboration and consumer participation would rarely feature. Even those service planners and providers at the cutting edge of innovative service provision were keen to share their frustrations over obstacles to achieving service ideals. Elsewhere, the housing and support requirements of people with severe physical disabilities remain unacknowledged by those with the power and resources to bring about change.

In the light of this evidence it was decided to amend the brief of the Living Options project to consider why there has been so little progress, and what prevents good practice, as well as to document examples of effective service provision. This report therefore presents a discussion, illustrated by case histories, of:

- the ingredients of a quality housing and care support service for people with severe physical disabilities;
- some necessary preconditions if services are to be developed;
- innovative schemes and services that are helping disabled people to live in the way they choose;

and offers some recommendations to redress the situation.

THE NEED FOR HOUSING AND SUPPORT

Several recent publications give good accounts of the background to current provision for younger disabled adults (Beardshaw, 1988; Goodall, 1988; Harrison, 1986, 1988; Wagner, 1988); the following summary draws on these sources.

'More than 200 in every 200,000 people aged 16 to 64 have a severe physical disability'

The number of younger disabled people in England and Wales cannot be stated with any accuracy. National data, supported by local and regional studies, suggest that 418,000 people aged 16 to 64 will have a severe physical disability – more than 200 people in an area with a population of 200,000. The Office of Population Censuses and Surveys (OPCS) survey of disabled people due to be published in 1988 will update and refine this data.

Of the estimated 14,000 physically disabled people under 65 currently in institutional care, about 10% are in health service younger disabled units. 58 younger disabled units were built in England in the 1970s and 80s. Others continue to be developed despite growing evidence that the medical model of care is inappropriate.

The great majority of disabled people in institutional care are divided roughly equally between local authority and voluntary sector residential care homes. About half of the voluntary sector places are provided by two national organisations, the Leonard Cheshire Foundation and The Spastics Society. While many providers of residential care espouse the concepts of resident participation and choice, life in residential facilities continues in most cases to be determined by the requirements of staff rather than of individual residents.

'A strong church role did not emerge from the study'

Despite the growth in private (profit making) homes during the past decade, few have been targeted specifically for younger disabled people, probably because of the high cost of care for this client group. The project investigations did not indicate that facilities run by religious bodies contribute significantly to provision for severely disabled people.

'Most authorities know neither the numbers nor the needs of the severely disabled adults for whom they are responsible'

Probably three-quarters of younger severely disabled people, however, are living not in residential care facilities but in the community. The number receiving home based services from statutory, voluntary or private bodies is impossible to estimate but most depend on informal carers for most or all of their care needs. Few authorities contacted through the Living Options project claimed to know either the numbers or needs of the severely disabled adults for whom they are responsible.

Statutory domiciliary care services consist mainly of health authority community nursing (day and night services available to severely disabled people, but secondary to other acute/emergency duties), and social services home helps (mainly domestic tasks carried out during social hours) and meals on wheels. Services vary between authorities: a few are experimenting with care attendant services, to supplement or expand traditional roles.

'Few services target younger physically disabled people'

Home based services organised by voluntary bodies are dominated by two organisations: Crossroads Care Attendants Schemes, and the Leonard Cheshire Foundation's Family Support Services. Most statutory and voluntary home based care support services, however, mainly target other client groups, especially elderly and mentally handicapped people, not younger physically disabled people. Private attendant care services for this group are negligible; the church role is difficult to quantify and did not emerge from the Living Options study.

Some home based services aim to support the informal carer rather than the disabled person, whose requirements are not necessarily the same. The Living Options project focused on the needs of disabled consumers, but support for their informal carers is also increasingly demanded. Information about the needs of and services for informal carers is available from the Carers' National Association and the King's Fund Informal Caring Support Unit.

There are few alternatives for severely disabled people between the extremes of living in institutional care facilities and living with informal carers at home. Innovative services and schemes offering supported 'living options' are described in Chapter 4. Despite the emphasis on community care for the past decade, and considerable documentation of service needs, there has been little resulting benefit for younger people with severe physical disabilities.

CHAPTER 2

Quality Housing and Care Support

For a person who is not physically able to carry out the ordinary activities of daily living, quality care support, delivered in suitable accommodation, provides the foundation from which to lead a full and autonomous life. Sufficient, flexible and dependable services can offer people with severe disabilities the maximum opportunity to take responsibility for their lives and make a contribution to society, in the same way as able-bodied people.

There is certainly no agreement on what constitutes an appropriate standard and level of support, and perhaps no service can entirely compensate for the effects of disability. But there can be little argument against the improvement of the present inadequate systems.

People with severe physical disabilities require a range of support services which may include help with:

- personal tasks: activities of daily life such as getting in and out of bed, wheelchair transfers, washing, dressing, eating or going to the toilet;
- domestic tasks: food preparation, house-cleaning, washing up and laundry;
- social/quality of life tasks: escort to and enablement at work or in leisure activities (writing letters, shopping).

This chapter discusses the essential elements of effective care support and housing services. Case histories from the project fieldwork illustrate some of the difficulties encountered by disabled users when faced with inappropriate services. It must be stressed that these examples emerged from a study of best existing practice; many other severely disabled people are unknown to service providers and receive no support.

FLEXIBLE SUPPORT

Disabled people (as well as service providers) have different views about who should provide the support they need, and how it should be delivered. One user may prefer to have a care attendant for personal tasks, home helps for domestic tasks, and volunteers or friends for social activities. Another may wish one worker to help with all personal and social needs, but use home helps for household duties. A third client may prefer a single individual to provide all personal, domestic and social support.

'A jigsaw of support'

In reality care arrangements may be exceedingly complicated:

***Mr T**, who is tetraplegic, left a younger disabled unit to live independently in a housing association flat. Care attendants offer morning help with personal needs; home helps come twice daily to prepare meals and clean house; district nurses assist at bedtime (and twilight nurses at weekends); local people are paid casually to help out at weekends and as backup if other support arrangements fail; volunteers provide drivers/escort service. The housing association warden is on call for emergencies, and therapists and social workers make their occasional appearance.*

While some disabled people consciously select a large number of care workers to minimise dependence on any one person, in most cases such elaborate arrangements are the only way to piece together the total amount of assistance needed to support independence. Clients and informal carers are confused by the array of services which are often delivered in isolation or duplication, without overall co-ordination by or between agencies.

'Piecemeal organisation of support fails clients whose requirements are complex'

For those whose personal needs are very precise, or who are less able or eager to direct a profusion of workers, more continuity of support is essential.

***Ms R**, in her late 50s, has rheumatoid arthritis. She has worked out with her home help – who has been with her for several years – the exact positioning of her hoist each night so that she can get up unaided in the morning. The placement of her fork on her tray, and her kettle by the sink, for example, are also crucial. Teaching new or relief care workers can be exhausting but imprecision is dangerous.*

The current piecemeal organisation of care support militates against good service provision for clients whose requirements are complex and/or exacting.

The examples in Chapter 4 demonstrate some ways in which personal, domestic and social support can be organised and delivered for maximum user autonomy. Peripatetic care attendant services are run by Crossroads, Family Support Services and a few local authorities. Staff working from a core-and-cluster base (for example the Oldbrook and Neath Hill schemes in Milton Keynes) is another approach to providing flexible support in clients' own homes. In some cases (Hampshire, Camden) funds are made available directly to disabled people to enable them to employ their own support staff. Paid volunteers or able-bodied neighbours can also offer severely disabled people the assistance they need.

Experience has persuaded some schemes to change from resident to non-resident staff, who work from neighbouring office bases. Very severely disabled young people requiring a high level of support are able to live in their own bungalow in Tiptree, Essex, because The Spastics Society can link their care support service to other local Society facilities.

'Mobile services help users distant from resources'

Flexible and individualised services to clients will need to be determined in the context of a sensible service system, with attention to the distance of disabled users from the service point and length of wait for service delivery. In rural areas, mobile services can help. Oldham Social Services' mobile, radio-controlled 'putting to bed' and bowel care services provide help at home outside 'social' hours.

'Independence can depend on just a small amount of help'

Sometimes severely disabled people are unable to live independently because they lack a very small amount of help, delivered frequently, or occasionally, or at unsocial times – especially night-time.

***Ms S**, 19, left a residential hostel to live in a shared house with three friends. She needs occasional rather than constant help – especially for toileting – and has hired a 'good neighbour' from her attendance allowance. However, such support is not always available when she needs it and she relies on her fellow tenants, which strains friendships within the house. Unless some form of peripatetic attendant care can be arranged, Ms S will be forced to return to residential care or a nursing home.*

***Ms M**, aged 62 with rheumatoid arthritis, lives alone with home helps offering care support for a few hours each weekday. She needs help getting into and out of her wheelchair and is dependent on her home help in order to leave the house. But Ms M doesn't want to go shopping, or for a walk, at the same scheduled times each week. She would like to be relatively spontaneous about going out when she likes, and staying as long as she wishes.*

Arbitrary rules and idiosyncracies often unnecessarily limit flexible service delivery: the requirement that staff work in pairs or that two are always on duty; that home helps are not allowed to cook so clients must take meals-on-wheels; that care attendants can't do domestic work; that home helps can't be provided for clients who work or are not at home. Such restrictions can be and are circumvented by sympathetic service providers.

'Inflexible services create dependence'

Sometimes independence is thwarted by inflexibility of service providers, especially in residential settings, who encourage overprovision of support and institutionalisation of clients.

***Mr and Mrs D**, in their 30s, both have cerebral palsy. They moved to their present registered bed-sitting flat because Mr D found work in the area, but are frustrated by the loss of independence. Although kitchens are provided, Mr and Mrs D do not self-cater because the scheme requires that they pay for the three meals provided daily (ironically, residents' kitchens are not being put in a new scheme because they are not used by residents). Domestic cleaning is provided. There are washing machines available but Mrs D can't reach them and laundry is done for her. The bed hoist provided is not the appropriate one and so Mrs D cannot get in and out of bed unaided. Although there is a private outside door to their flat, she must use the common entrance in order to get staff help to transfer from her electric to indoor wheelchair. On the basis of their current arrangements, Mr and Mrs D have been refused an independent bungalow in the grounds of the scheme because they require too much attendant care.*

Provision of night-time and weekend cover is problematic and often results in otherwise unnecessary residential solutions to personal assistance requirements for severely disabled people. Expensive overtime rates, and union restrictions, thwart local authority attempts to provide attendant care during unsocial hours. A few have found solutions (see examples Chapter 4).

Disabled people with individual funding packages often choose live-in staff who can provide night-time emergency cover. Others who have free daytime help from statutory or voluntary agencies, use their personal benefits to hire additional night-time and weekend care support. Those who are less generously supported rely on family or friends for backup support at night and weekends.

'Use of normal emergency services furthers integration'

The need for awake night staff is frequently cited but many schemes are successfully operating with on-call support only, including registered facilities with sleeping night staff. Where clients are encouraged to take personal responsibility for using normal community emergency services – GPs, police, emergency plumber, etc – service providers have found that there is little need for – or misuse of – emergency backup systems.

SUFFICIENT SUPPORT

There is considerable variation (and no minimum standard) in what service providers deem an appropriate level of care support. Even within the same authority, the circumstances of people with similar levels of impairment can differ enormously. Some may be receiving institutional care while others may be supported at a subsistence level of personal assistance at home, with no 'cushion' to allow for occasional extra help, crises, or increased need due to progression of disability or ageing.

'The all or nothing support syndrome'

Among disabled people living in the community, differences in the level of care support can be extreme. The 'all or nothing' syndrome of support characterises statutory service provision everywhere, with some individuals being singled out for 'special' treatment.

Mrs A, *was disabled from birth and needs a high level of support. She is married with a family and has a full-time job. A rota of care attendants provided by social services ensure that she has 24-hour help, including two staff on duty during the day, one to support her at work and the second at home to babysit, do housework, and prepare meals.*

Ms B, *25, lives in another district within the same county. Disabled by polio, she is a wheelchair user with limited arm use, but lives independently in a council flat with five hours home care per week. However, she has had to give up her car because there is no one to help her transfer to and from her wheelchair, and is now virtually housebound. Without transport she was not able to accept a recent job offer; furthermore, if she were employed, her home help would be withdrawn.*

'The lottery of support services'

The level of support can depend on geography, persistence, or chance; it can, as in the following example, result from inadequate determination of needs:

Mr V *left residential care to live on his own with just a few hours district nursing and home help each week but finds this level of help inadequate for any real independence or quality of life. Although he has limited strength and reach, Mr V does not require a wheelchair and looks 'normal'. He is, in his own words, stuck between being too disabled to manage without residential care, but not disabled enough to get sufficient care support in the community.*

Most severely disabled people need some social enablement as well as physical support in order to lead ordinary lives (though the level of such social support may always be difficult to demarcate).

***Ms W** left residential care in her 60s to live in a council flat, with essential personal help provided 'on demand' by a team of attendants who support a number of clients on the estate. Service restrictions, however, mean that attendants are not available for shopping, visiting, and 'just doing things around the house'. Ms W's potentially independent lifestyle is, therefore, severely restricted.*

'Married clients find assistance is limited'

A high level of assistance is rarely offered to disabled clients who have a spouse or other informal carer.

***Mr X**, 60, and incapacitated by multiple sclerosis, is housebound and requires help with all daily activities and considerable night-time attention. All his care needs are met by his wife except for one visit weekly by the home help and district nurse, and a few hours a week help from a voluntary organisation.*

***Mrs P**, in her late 50s, has a deteriorating spinal condition. The care demands on her husband caused the breakup of their marriage, following which the home care service was brought in to support her at home. Several years later Mrs P was reunited with her husband, but as a result her home care hours have been substantially reduced – although he has suffered a stroke in the meantime. Mr P provides the majority of his wife's personal support and she is now in her words, 'more fixed to bed'.*

'Lack of support causes marriage breakdown'

Lack of sufficient support to informal carers is often cited as the cause of marriage breakup. Ironically, many severely disabled clients – usually men – living independently with a high level of attendant care are those whose partners have left because they could not manage the amount of assistance needed without help.

***Mr J** has been tetraplegic since a teenage accident. He is married and has three children. His personal care needs were met by his wife, with minimal help from district nurses. Mr J believes that the nurses took advantage of the situation, leaving him until last in their morning calls knowing that his wife would fill the gap. The marriage disintegrated, and Mr J spent a brief period in residential care before moving back alone to the family home with nearly full-time help provided by social services. Mr J feels that if the local authority had offered even a portion of the support now provided, it would have prevented the breakup of his family.*

DEPENDABLE SUPPORT

Reductions in, or ceilings on, the amount of support offered also limit clients' independence. For some disabled people, the level of care support has decreased during the past 10 years, as a result of funding cuts and diversion of funds to other priority areas (eg children at risk). For others, the need for even small amounts of additional support cannot be met.

***Mr N,** in his mid-40s, has multiple sclerosis. He continues to live on his own at home with the help of care attendants provided by a voluntary scheme. As his condition deteriorates, however, the attendants' time is taken up increasingly with physical care support tasks allowing little time to accompany him out socially, etc. But the scheme organisers are unable to provide additional attendant care hours unless, as they say, another client should die. Mr N anticipates a future of increasing isolation, with an ever-present threat of residential care.*

'Uncertainty of support increases anxiety'

The fear of losing essential care support (or of its not being available if needed, for example due to loss of informal carer), is endemic among disabled people.

Withdrawal of social support, even where minimal, can also make dramatic differences to the lives of severely disabled people.

***Ms L** lives independently in a self-contained flat with a high level of day and night-time assistance provided from a registered scheme. She is very happy with this service. Recently, however, the additional help provided by volunteers was removed from the scheme. Now Ms L is unable to visit her parents as there is no one able to travel with her.*

APPROPRIATE SUPPORT STAFF

The availability and quality of staff to carry out personal, domestic and social tasks for severely disabled people emerged from the project research as central to any discussion of support services. While this report cannot offer a comprehensive discussion of care support staffing, some issues were frequently noted by project participants as affecting good service delivery, and demand mention.

Low pay. Poor pay and social security benefit disincentives limit the availability of care support staff; many have casual and undeclared pay arrangements. The community charge, due to replace domestic rates, is likely to further discourage potential live-in workers.

Anomalies in conditions of employment. Workers in different sectors and with different job titles and salaries may be doing similar jobs. Efforts to merge local authority job descriptions and service conditions have not materialised.

Boundary disputes. Job overlaps and rivalries between care support staff in different professions – particularly between nurses and unqualified staff – can limit co-ordinated and flexible delivery of support.

Attitudes. Care support workers may be as institutionalised in their attitudes as disabled clients; they may feel threatened by changes in service philosophy; and they may unintentionally undermine service goals of client independence.

Stress. The physical and emotional demands on staff, the intensity of one-to-one relationships, and the possible clash of interests between clients and workers, must be recognised.

Training. Disabled people are rarely involved in the training of the staff who provide their care support. Workers without formal qualifications are often preferred by users, to avoid confronting traditional attitudes about providing care.

Profile of support staff. The nature and status of care support work means that staff are likely to be housewives or young (unemployed) people. Few male, black or ethnic minority care workers were identified by the project. Care support needs to be enhanced and legitimised as a career.

Volunteers. The benefits of using unpaid volunteers to supplement paid attendant care must be balanced against concern about devaluing social care work. Traditional volunteer help can be thought patronising and unreliable.

Special skills. The basic requirement of severely disabled people is for staff to carry out personal, domestic and social tasks, but clients also need access to other professions including occupational, physio and speech therapists, clinical psychologists, social workers, sexual counsellors and continence advisers.

ORDINARY HOUSING

Lack of appropriate accommodation is often the first stumbling block encountered by severely disabled people on the road to independence. Whether they require or prefer more personal support or less, and whether they live in their own homes, shared housing, or residential settings, the principles of housing supply, design and adaptation remain the same.

HOUSING SUPPLY

More than three-quarters of a million physically disabled people in Britain are inadequately housed. With little suitable and financially accessible private sector housing, most disabled people look to the public sector for help, but there is a shortage of at least 150,000 purpose-built or adapted rented public sector dwellings (NFHA, 1987).

Some housing authorities are adopting policies of building all new housing to mobility standard plus a proportion to wheelchair standard. Housing Corporation regulations require that new housing association dwellings are built to mobility standard where possible.

'Shortage of suitable public sector housing'

But there is little new public sector housebuilding in the present financial climate and housing authorities are selling off bungalows and other 'desirable' (and adaptable) dwellings. The Housing Bill 1988 reinforces Government policy to increase owner occupation and private rental, effectively excluding people with severe physical disabilities (who are mainly on low incomes).

'Few incentives to the private house building sector'

The Bill makes no special reference to housing for people with disabilities except in relation to improvement grants. No incentives are proposed for the private sector to build according to disabled peoples' needs. Specially designed or adapted homes continue to be excluded from the 'right to buy' and from the right to transfer with discounts. And the Bill's requirement that housing associations raise larger proportions of their funds from private investors will mean fewer 'special project' schemes, which are not viable through private financing but require 100% Government funding to work.

The limited specialised housing resources available are not used to advantage. Housing authorities rarely keep records of adapted or adaptable homes in their districts; severely disabled people often do not register on housing waiting lists (because it seldom yields results).

Several voluntary organisations have developed accommodation registers: the Centre on Environment for the Handicapped and the King's Fund Centre have compiled a Housing and Care Register as an information source for planners (also available to users); the Residential Care Consortium's Carematch matches disabled people with appropriate residential facilities; HALO's Disabled Register offers information on adapted/supported housing association property for people with disabilities. These ventures require greater visibility and co-ordination to be most effective.

HOUSING DESIGN

Quality as well as quantity of wheelchair accessible housing is vital. Severely disabled people seek ordinary homes to suit their (and their family's/carers') needs. A flexibly designed basic dwelling, followed by meticulous attention to detail in consultation with the occupant, is a good starting point. Generous space standards to allow for wheelchair manoeuvering, and extra room to accommodate carers (80% of disabled people live with someone else), are perhaps the main 'special' requirements (NFHA, 1987).

Specialist design guides for wheelchair/mobility housing do exist. Habinteg Housing Association offers a particularly successful model for general family homes, all built to mobility standard, with 25% wheelchair standard units dispersed throughout schemes without special visual identification (Habinteg, 1988). Walbrook Housing Associations's Disabled Persons Housing Service offers multi-disciplinary advice on housing design, finance and adaptations (Walbrook, 1988).

'Adaptations require individual planning'

Many disabled people have been frustrated, however, by being presented with fully adapted homes which do not overcome the limitation of their particular disabling condition. Inflexible regulations by, and lack of co-ordination between, housing bodies can make a nonsense of good planning.

It is common practice, for example, for housing associations to provide standard fittings, then re-apply for Housing Corporation funding for individualised adaptations. Tenants can wait months and years – with restricted mobility and independence – for new baths and kitchen fittings to be removed and replaced by appropriate ones.

'Tenant involvement ensures greater satisfaction'

In one instance, a housing department refused to consult with prospective tenants or their occupational therapist about a supported housing scheme under development on the grounds that it was 'mobility' standard; subsequently £15,000 was needed to carry out adaptations before the tenants could move in. Satisfaction is invariably highest when clients are involved early in the planning process. (See for example the scheme in Gillingham, Kent in Chapter 4.)

Service providers tend to group wheelchair dwellings together for convenience and economy, and to compromise standards of accommodation by accepting unsuitable sites for building new homes. But 'ghettos' isolate disabled occupants and strain local community services. Restricted mobility makes accessibility to jobs, transport and friends (including able-bodied people in their ordinary homes) that much more essential.

AIDS AND ADAPTATIONS

Lack of aids, adaptations, and equipment makes even a well designed home a prison. Many disabled people have little idea of what is now available that might help them live more independently.

Long delays in obtaining aids, or even advice, can prevent people moving home, and negate a lengthy period of rehabilitation. In some authorities, delays of up to two years were cited, and allocations for equipment and adaptations were frequently spent less than half way through the financial year.

The overlap of occupational therapy services between social services, housing, and health authorities creates additional confusion and delay for clients. In Rotherham, one occupational therapy service provides adaptations, equipment, and therapy; the service is run by the health authority, refunded by social services.

'It may take years to obtain adaptations and equipment'

Quick provision and frequent adjustment of aids and adaptations is essential, particularly for people whose disabilities are deteriorating and whose quality of life for a possibly brief time span is at stake. One client, for example, moved from long-term institutional care to a supported housing association flat where he has waited 16 months for occupational therapists to lower the kitchen units and provide a bed bar and bath rail. He currently needs help for almost all his personal needs, but if these adaptations were carried out would be almost entirely self-sufficient.

Some authorities are taking measures to minimise such expensive and destructive delays. In Oldham a reorganised service turns round requests within six to eight weeks. Hampshire Social Services has organised joint equipment stores with health authorities, with help from Community Programme trainees; hired home economists to deal with some aspects of overstretched occupational therapists' work (budgeting, meal planning); and agreed to top up by 25% any adaptations work towards which the district council provides 75% of funding. To help authorities provide an efficient service, the Disabled Living Foundation is computerising its database on equipment.

CHAPTER 3

Preconditions to Good Practice

The investigations of the Living Options project suggest a number of elements that are essential to the development of quality housing and care support services. This chapter proposes some preconditions to good practice and discusses some of the barriers to its achievement.

RESPONSIBILITY FOR EFFECTIVE SERVICE PROVISION

The Living Options study provides widespread evidence that housing and care support services for people with severe physical disabilities do not fall clearly within the remit of any authority, department or profession. It is difficult for disabled people and their advocates to ascertain who is responsible for, or capable of, providing them with the help they require in order to live independently.

Effective disability services depend on a commitment to good practice but this commitment must be backed by authority and resources. Achievements in community care for mentally handicapped people in, for example, Wales and Exeter attest to the importance of setting out principles of service provision and of guaranteeing the physical and financial resources to realize them.

Officers in an advisory capacity, without decision-making power, without staff, and particularly without a budget, have limited effectiveness. A number of authorities are now producing planning documents for physical disability services. But plans need to be translated into action and few 'model' services have resulted from 'model' plans. Commitment must extend to the development of workable service structures and funding mechanisms. Systems for monitoring and evaluating services are essential. A co-ordinated approach to staff training on disability issues and professional roles is also vital. The King's Fund Centre's exploratory workshops on the multi-disciplinary training needs of long-term care staff are a good example.

'Statutory authorities seldom collaborate to produce better services'

Where responsibility for service provision is shared by a number of agencies close collaboration is required. But there was scant evidence from the project investigations that statutory authorities are working together to produce better services. Usually health and local authorities proceed in isolation (if at all). Authorities occasionally referred to joint planning by Joint Care Planning Teams when asked by the project to suggest good practice services. But they did not make joint submissions and seldom nominated the same services or schemes.

Non-coterminous authority boundaries add to the nearly insurmountable problems of co-ordination. Partnerships between statutory and voluntary agencies are more productive, but lack of effective collaboration generally contributes to gaps and overlaps in service provision.

CONSUMER CONSULTATION AND CONSUMER CONTROL

The planning and delivery of services for disabled people generally proceeds with little reference to the preferences and experiences of disabled people themselves. The lack of an effective lobby for physically disabled people is also a factor in the low priority of physical disability services nationally. Differences between groups 'of' and 'for' disabled people, and disability-specific organisations which represent particular client groups, inhibit agreement on priority for action and weaken pressure for improvements. Support and encouragement are needed for disabled people who have little confidence or experience of consultation procedures and committees.

'Little consumer consultation, less consumer control'

Not only are disabled people not consulted about services planned for them, but they have little control over the services they use. In this report, 'consumer control' refers to the ability of disabled people to take responsibility for their own lives in the same way that able-bodied people do. It is used advisedly, in place of consumer 'participation' or 'involvement' which imply tokenism and are too often used where there is no intent to devolve power.

Disabled people, like their able-bodied peers, may not choose to exercise control in some aspects of their lives but the option should be theirs. Clients may prefer that an agent deals with the employment and day to day management of care workers while clients retain control over the direction of personal care support routines. Current options, however, usually mean either taking total responsibility for all aspects of supported independence (client directed care support), or relinquishing all control to the service provider (institutional care). Chapter 4 describes some successful alternatives.

'Low expectations, dissatisfaction and anger'

Disabled people's experience and expectations of housing and care services will colour their reactions to those services: gratitude for even inadequate support by those with low quality-of-life expectations; resistance to change and reluctance to accept responsibility by those from institutional and over-protected backgrounds; passive dissatisfaction by those who fear that complaint will lead to loss of support and independence; anger and defiance by those who have been unable to access sufficient support to achieve lifestyle goals.

Some disabled people will need help and encouragement to learn to make choices, decisions and demands. Housing and care services will only represent 'good practice' when they meet the needs of disabled people who are genuinely in control of their own lives.

SINGLE ENTRY POINT TO SERVICES

'Information about services is haphazard'

Common to all the Living Options project investigations was confusion amongst disabled people, their families and carers, and professionals about the availability of services and how to obtain them. Co-ordination of housing and care support, education, employment, transportation, day care and medical services is essential, especially for severely disabled people. Consumers shunted from one authority to another learn of services more by informal networking than organised information dispersal. A single entry point to all disability services would ensure that physically disabled people could find their way through the maze of information, services and procedures, and get help as needed.

Case management can provide that entry point, ensuring that each client's total needs are recognised and that support is given and services delivered in an individualised and co-ordinated way.

'Case management embraces a range of functions'

The concept of case management embraces a range of functions: giving information and advice, determining needs, providing advocacy and brokerage, and managing resources. The term is broadly used to include both service co-ordination (impartial support, crossing boundaries to guide clients to and through the appropriate service point) and service management (the control and organisation of resources).

CHOICE, the Case Management Service (formerly the Case Management Project, a pilot study funded by The King Edward's Hospital Fund for London) offers an independent, direct service for physically disabled people in Camden and Islington, assessing needs, co-ordinating and monitoring services, and advocating on behalf of those who need help.

Another King's Fund pilot project – the Head Injury Case Management Study – is evaluating the effect of a case manager on long-term outcome for severely head-injured people and their families. The case manager is responsible for assessing individual need, identifying appropriate services and ensuring that each service is informed and supported.

In Cornwall, five Community Rehabilitation Teams enable professionals from a range of statutory services to provide individually tailored, integrated programmes of support to help clients return to and/or remain in the community.

Neither case management nor case co-ordination should be confused with the 'key worker' concept, where a staff member is identified as the chief point of contact for a particular client within a service system.

Centres for Integrated (Independent) Living offer another approach to co-ordinated advisory services, operated by disabled people for disabled people. Centres for Integrated Living offer advice and information, as well as provide resources to which case managers might refer clients. The Derbyshire Centre for Integrated Living, for example, works with statutory services and provides a 'Link Worker' in each social services area. Centres for Integrated Living fulfil other functions involving attendant care, housing, transportation, access and peer counselling, and stress the need for disabled people to make their own life decisions.

Disabled consumers should be able to approach service providers directly, or to choose an impartial advocate or a service run by disabled people to act on their behalf. The importance of a 'care management' function is stressed in the Griffiths report *Agenda for Action* (Griffiths, 1988).

The individual service plan is one mechanism through which case management and co-ordination are effected. It refers to a contract, based on client choice and need, agreed between service provider(s), client and family/carers. This sets out service goals to be achieved over a given period of time, with provision for evaluation and change.

'Service contracts are essential'

Terms such as individual programme/service/client plan are liberally dispensed in service literature but can refer to a wide range of practice. Ideally, a service plan should begin with the identification of client need at the point of entry to disability services, and include the total package of ingredients required for living with disability. In reality client plans often deal only with the services offered within a particular establishment. If not based on client choice, discussed and agreed, however, service plans become just a set of rules with which the client must comply in order to get the package on offer.

In Hereford and Worcester, 'Personal Lifestyle Packages' are being developed with physically disabled clients, co-ordinating a programme of activities including (as alternatives to day care) education and employment for people leaving institutional care or living in the community. Key workers act as facilitators where appropriate, but lifestyle packages are based on informed client choice and are client-controlled.

CLEAR SERVICE OBJECTIVES

The evidence from the Living Options project research shows that actual services for severely physically disabled people often do not match the expressed aims of service providers. Most of the facilities put forward for consideration in the project consisted of residential homes, or schemes with integral care support services, and claimed to offer all or most of the following functions, despite apparent contradictions:

- Permanent or long-term accommodation with support;
- Transitional supported living (implying an element of 'life skills' training or experience as a stage on the way towards independence);
- Rehabilitation (encompassing both therapeutic and independence training models);
- Independence training (physical or social skills training);
- Independent living (ranging from exercising choice in one's lifestyle to total control over care support services);
- Respite care/programmed short stay/crisis relief;
- Day activity (including educational, rehabilitative and leisure activities as well as traditional craftwork).

'Support can be provided effectively at home'

Given the scarcity of resources of any kind, and particularly of home based services, the pressure on service providers to create special facilities encompassing a variety of service aims is understandable. Many of these providers, however – and a great many disabled consumers – expressed doubt about the necessity for purpose-built, 'special' solutions for any of these functions. They believe that all support services, including any (re)training element required, can be delivered most effectively when the client remains living in his/her own home.

Innovative schemes increasingly enable and encourage clients to live 'normally', using mainstream community services. These look beyond structured day care and sheltered employment to participation in ordinary education, employment and leisure activities.

'There can be little justification for building additional residential facilities'

Some professionals maintain that there are certain groups of disabled people, particularly those with progressive conditions, who will always need the supervision and care of residential settings. But the reality cannot possibly be known until ordinary living options are readily available and people have the opportunity, expectations and skills to choose their own lifestyle. Attention can then be given to the need to fill gaps with specialised, tailor-made services for clients whose needs are still unmet. In the meantime, there can be little justification for building additional residential facilities, until the need for community care support is explored and met.

'Even people with the most severe physical disabilities can and do live independently'

The Living Options study confirms that even people with the most severe physical disabilities can live independently, in the community, with appropriate support. (See also Wagner, 1988; Griffiths, 1988; Audit Commission, 1984; Shearer, 1982.) Consumers and professionals agree that compensating for physical impairments is the 'easy' part of independence. Overcoming the effects of long-term institutionalisation, overprotection or neglect may require a period of life-skills training and confidence building, and there may be some long-term residents of institutions who may never wish to embark on a traumatic change of lifestyle.

'The demand for residential accommodation reflects a lack of alternatives'

For new generations of young physically disabled people, however, independence training – both in physical and social skills – should be part of the same process of growing up as for their able-bodied peers. (See also Bennion, 1988; Thomas, Bax and Smyth, 1987.) The current pressure by disabled people – or, usually, their families/carers – for special residential accommodation may have more to do with there being few other options. The young physically disabled adults whose evidence to the Wagner review praised residential care, valued it as a 'means to greater independence from family or institution' (Sinclair, 1988, p.159).

No matter how finely tuned support services for severely disabled people may be, occasions will arise when almost every client requires backup provision. Service providers interpret this as a requirement for facilities to provide programmed and crisis respite care, for the benefit both of client and informal carer. Residential homes and younger disabled units are devoting a growing proportion of beds to short-stay use. Current demand for backup services, however, is probably a reflection on the paucity and inadequacy both of regular home based support, and of assessment and review procedures for people living in the community.

'Crisis relief services are scarce'

Crisis relief services delivered in the clients's home are not readily available. Many disabled people rely on a network of friends and family to fill gaps and breakdowns in care support arrangements. Voluntary care attendant schemes such as Crossroads and Family Support Services supplement and complement statutory services, often adding the last piece of the jigsaw that keeps a complex support arrangement functioning. The Spinal Injuries Association's Care Attendant Agency provides a much praised service for members' respite, emergency and holiday use. Ironically the DHSS has not renewed SIA's grant for this service in 1988.

FAIR ACCESS TO SERVICES

'People with socially acceptable disabilities receive most help'

The project findings indicate that people with physical disabilities who also have an additional disadvantage, such as a sensory handicap, difficult behaviour or a mental health problem, frequently do not obtain a fair share of housing and support services. Disabled people who are most able to articulate their needs and demand help, and who present the 'socially acceptable face of disability' (without disfigurement or speech problems) are receiving the bulk of the limited provision available to severely disabled people.

Some service providers noted that women were less assertive of their aspirations, more accepting of unsatisfactory living situations, and less likely than men to be receiving good services. Only a handful of black and ethnic minority people with disabilities were identified by the Living Options project.

The following groups have emerged from this study – either conspicuous by their absence or identified by service providers – as being particularly poorly served.

People with multiple handicaps. Independent living options for people who are multiply and severely disabled are particularly scarce. Physically disabled people who also have an intellectual or sensory handicap fall between services for each of these groups (although some profoundly physically and mentally handicapped people have benefited from funds earmarked for mental handicap hospital closure). The needs of those with communication problems, whose abilities and ambitions are difficult to discover, are often ignored.

'Support for people with head injuries is a pressing issue for the future'

People with head injuries and difficult behaviour. Almost without exception, service providers noted people with challenging behaviour – especially those with head injuries or Huntington's Chorea – as the most difficult to help, and many facilities specifically reject people with unpredictable or aggressive behaviour. There is evidence, however, that with intensive individualised work, enormous progress can be made even with those who seem most socially unmanageable. Spurred by Headway (the National Head Injuries Association), provision for head injured people is increasingly on the discussion agenda of service providers, but few services have yet resulted. With more people surviving road accidents with long-term brain damage, support for this group will be one of the most pressing issues for the future.

People with degenerative conditions. People with deteriorating disabilities often find it hard to obtain non-institutional support. Particularly for disabilities such as multiple sclerosis, where there may be intellectual as well as physical degeneration, the implications for nursing and terminal care mean service providers are often reluctant to offer support. Many health professionals claim that progressive disabilities – particularly multiple sclerosis – require a medical (hospital based) service, but this apparent need may only reflect the lack of other options for people with deteriorating conditions. A few authorities are offering programmed respite care to supplement community services for these clients.

Older 'young disabled' people. Increasing numbers of people with spinal injuries are living full lifespans. A generation of people who survived childhood polio are growing older. Those with 'modern' disabling conditions, such as victims of the drug thalidomide, are reaching adulthood. Many disabled people who have lived without help may begin to require it. Flexible support, increasing with need, will be essential to enable them to remain independent. Community living options – shared housing, young volunteer carers, etc – are often geared towards younger clients rather than those in their 50s and 60s. Many people in this older age group are living in residential settings because they did not receive the necessary support at the time of their accident, illness, marriage breakdown or bereavement.

SECURE SERVICE FUNDING

Revenue funding for housing and care support is crucial to the provision of services for severely disabled people. Government action on community care policies in light of the Griffiths and Wagner reports may lead to a fundamental overhaul of the organisation and funding of disability services. The new Social Security Act 1988 is already affecting the financial support available to disabled people.

'Funding regulations handicap service providers and consumers'

Funding structures in place at the time of the Living Options research may well be changed. In the meantime, however, the issues, obstacles and ambiguities described in this chapter will continue to confront providers and consumers of services.

Lack of money to fund care support services was almost universally cited by service providers as the main barrier to good service provision. Retrenchment means that innovation for one client group can cause restrictions for another, and authorities are having to make hard choices, for example between offering a service widely in small amounts, or limiting input to cases of exceptional need. There is frustration at the need for creative interpretation of funding regulations in order to achieve good practice.

Yet massive amounts of money continue to support institutional provision. The evidence of the Living Options project suggests, however, that even within the severely restricted resources available to statutory authorities, effective co-ordination and redeployment can substantially increase the level and quality of care support for severely disabled people.

SOURCES OF REVENUE FUNDING

At the time of the Living Options research, funds for care support were available from the following sources:

Statutory authorities. Mainstream provision by health and local authorities is discussed in Chapter 1. A very few social services departments have home care schemes targeted for severely disabled clients, or designated budgets to allow clients requiring a high level of care to live independently. Others may seek agreement at committee or director level to fund a special package of assistance for an individual.

Direct payments can also be made from health authorities to local authorities and to a more limited extent to voluntary agencies. They can also be made for individual disabled people leaving health authority long-stay facilities – the so-called 'dowry' system.

'Only one of the 28 pilot projects evaluated for the DHSS is for people with physical disabilities'

Under current financial restraints, health and local authorities are more able to provide capital resources for special schemes, or to fund disability posts, than to provide revenue funds for services which imply a cumulative budget commitment. Joint Finance was introduced in 1974 to encourage joint planning between health and local authorities, and was extended to housing provision through the 1983 Health and Social Services and Social Security Adjudication Act. Schemes for physically disabled people have not proliferated as a result: of the 28 pilot community care projects evaluated by Kent University on behalf of the DHSS, only one is for people with physical disabilities.

Where it has been used (see examples Chapter 4), Joint Finance generally supplements existing local authority programmes, with social service departments usually picking up the tab for programmes when Joint Financing ends. But programmes also can be financed by joint funding between a health authority and social service department.

'Community care initiatives are on hold pending Government reaction to the Griffiths report'

Community care initiatives have been further jeopardised by the reluctance to embark on new activities pending the Government's decision on whether to implement the recommendations of the Griffiths report (Griffiths, 1988).

DHSS benefits. By far the largest amount of money funding care support for severely disabled people comes from social security payments, which support clients in voluntary and private residential projects as well as in their own homes.

Most younger severely physically disabled individuals rely on state benefits in order to live independently. From April 1988, under the new Social Security Act, supplementary benefit is replaced by income support, supplemented by disability premiums; lump sum supplementary benefit payments are replaced by a discretionary social fund (grants and loans); domestic care allowance will no longer be available. Disabled people can apply to a new trust fund, which is intended to help the most severely disabled clients live independently in the community. This fund has been established separately from social security legislation, is administered by the Disablement Income Group, and is limited to £5m for 1988/89.

'Implications of the 1988 Social Security Act'

It is too early to evaluate the implications of the new Act. However, the changes in entitlement are such that many disability groups anticipate a loss of up to £80 weekly income for some severely disabled people. While those now receiving benefits will be protected from loss of income, new claimants – including disabled people attempting to leave institutions to live independently in the community – will not have access to the same level of support as of right as those now receiving benefit. There is considerable concern about the discretionary and limited nature of future funding. Even more than in the past, it seems, a special case will need to be made in order to achieve independence, and disabled people will be competing with each other for limited resources.

Client contribution. Disabled people's income depends substantially on how they become disabled: those disabled through accident are entited to more than those disabled at birth (who will not have paid national insurance contributions), and those injured at work are entitled to considerably more through industrial injuries benefits.

'Levels of income and of personal support are arbitrary'

Few severely disabled people have independent income or savings sufficient to significantly alter their access to housing and care support services. For those who do, however, largely from compensation settlements or personal wealth, the situation can be quite different: such individuals are likely to buy or adapt their own home, and buy in personal support to suit, bypassing or supplementing statutory and voluntary services. The fact that many disabled people with private income are disdainful of statutory and voluntary services for which others compete speaks for itself.

The contribution that the disabled person makes toward meeting the cost of his/her care support varies enormously according to the location and source of the service. The examples of housing and support services in Chapter 4 show almost as many variations in charges to clients as there are service providers.

NHS services are free to the client. Residential homes allow only a small personal allowance to be retained. Services in the community may be free, charge a fixed fee regardless of the number of hours of care support, ask for part or all of certain allowances to be paid over, or means test so that all clients remain at DHSS supplementary benefit level. There are additional anomolies for disabled people who choose or are able to work.

The following examples show the arbitrary differences in personal circumstances of individuals, all requiring a high level of support, according to where they happen to live and who happens to provide their care support. (All pay their housing costs separately.)

Mr W *was rehoused from a residential home into a housing association flat, where he receives 24-hour support from a rota of six workers. The cost of this package – nearly £50,000 – is paid for entirely by the local authority. Mr W receives invalidity benefit, attendant care allowance and mobility allowance amounting to more than £100 per week. No charge is made to Mr W for this service.*

Mr and Mrs B, *who live in a council flat after leaving residential care, manage on about 30 hours care support (personal and domestic only) weekly. This essential assistance consumes virtually all their joint income from DHSS allowances. They receive no help from the statutory services, and rely on friends and family for 'social' enablement. (Without domestic assistance allowance, which is no longer available to new claimants under the new Social Security Act, they could not manage at all.)*

Ms M, *a single parent, receives about 30 hours personal care support weekly to enable her to live in her council bungalow. Her income is from supplementary benefit, attendance allowance and mobility allowance, and she pays two-thirds of her attendance allowance to the voluntary body which provides the care workers, who come in three times daily, five days per week (family and friends help out at weekends). In addition, home helps offer another 17 hours per week domestic support at no charge.*

Views differ on what would be a 'fair' contribution from the disabled client, but there is some consensus that, while attendance allowance should pay for care support (as mobility allowance should pay for transport), personal income should not be tapped for basic personal assistance costs. Whatever arrangements are arrived at, it is important that they are consistent without regard to geographical location, or to cause or type of disability.

Charitable funds. Voluntary sector residential housing and care support schemes often depend on charitable funding to subsidise assistance costs not covered by DHSS board and lodging allowances or 'top up' from sponsoring authorities.

'Disabled people may be forced to seek charity'

Many disabled people have been forced to approach charitable bodies or undertake personal fund-raising for items such as new wheelchairs, cars or household items, because benefits and allowances are consumed by personal care support costs. There is concern that this situation will escalate under the new legislation.

INNOVATIVE FINANCING

Disability services often consist of considerable residential provision, token 'community care' gestures with one or two individuals maintained at home, and few other support services. Money for capital projects is far easier to obtain than for revenue services that enable people to stay in the community.

Some imaginative use of institutional care budgets is releasing funds for support services at home. The Milton Keynes health authority has, for example, agreed to divert money earmarked for a younger disabled unit to community services. In Hertfordshire, a number of people have moved through a short-stay independence training hostel to group homes or their own homes. Wiltshire Social Services uses some funds previously spent on out of county residential placements to top up the Cheshire Foundation Family Support Service, providing individualised packages to clients in their own homes.

'Imaginative use of budgets for home based services is rare'

Such cases are the exception rather than the rule, however. For example, one tenant of a housing association sheltered flat now needs help with toileting and bedtimes, but will be forced to go into registered residential care accommodation because this minimal help is not available. The authority where she lives quotes cases like hers to argue the need for more residential care facilities in the area.

Even where home care budgets do exist at local level, they are often fixed at a level that precludes more than token financial top up. In one authority, for example, applications for flexicare in excess of £2,000 per client must go to committee for approval. In another area, the home care budget consists of the equivalent of six full-time care attendants, so they are only used for short term or low cost support, and approval must be sought on a one-off basis at director level for clients requiring more than a few hours help per week. No upper cost limit is set by the Special Home Care Scheme in the London Borough of Camden, so disabled people requiring high levels of assistance can be supported within the £170,000 annual scheme budget.

THE COST OF CARE

'The cost of community care is unlikely to exceed the cost of institutional care'

'Quality home based services should not need to be shown as cheap options'

The findings of the Living Options research confirm the wide variation in costs, and the difficulty of attempting definite comparative costings, of different care support services. Home based packages helping clients who require constant support may be more costly than hospital or residential care. Chapter 4, however, gives ample examples of home based services offering a high level of support which compare favourably with the average cost of residential care, and cost far less than current out of county residential care charges.

With so many younger disabled people inappropriately maintained in institutional care, at such high cost to the public purse, it seems churlish to argue about whether residential or community care is ultimately more expensive. By any reckoning, a great many severely disabled people could lead better quality lives, and be enabled to make a greater contribution to their community, supported at home. It is likely that the overall cost of home based support for people with severe physical disabilities is not more expensive than institutional provision, and individual cases should not need to be shown as cheap options.

CHAPTER 4

Examples of Good Practice

There is an infinite variety of housing and personal support arrangements that could be created to enable people with a severe physical disability to live independently, in the way they wish. This chapter describes some examples that, within present limitations, achieve the highest level of consumer satisfaction. ('Satisfaction' will inevitably depend on the personal experience and circumstance of the client: one disabled person may praise as offering independence a service that another person finds restrictive.)

'Services must grow from local needs and local strengths'

These examples are not intended as models for replication, since new services need to develop from local needs and local strengths. They do suggest some ways in which the needs of some severely disabled people can be met across a range of home based, special project and residential services.

The services included in this chapter reflect the good practice elements outlined earlier in this report. They have been selected because they approach most nearly the ideals of user choice and control, and of service flexibility to adjust to normal lifestyles and adapt to changing needs.

The examples are weighted toward care support services delivered in clients' ordinary homes, encouraging ordinary lifestyles. They may be organised by the statutory or voluntary sectors or in partnership. Some examples are included of schemes registered under the Registered Homes Act 1984 that aim toward maximum consumer control without sacrificing maximum funds (under current funding mechanisms there is unavoidable compromise to be made). Traditional residential facilities are not included although they may be considered 'good practice' according to *Home Life* principles.

Many severely disabled people, of course – even those currently in receipt of substantial personal assistance – could live on their own without or with less care support (if they choose to do so) if appropriately and sensitively designed, adapted and equipped homes were available.

Mr B left his family home to live in a substantially adapted council bungalow. Although severely disabled by muscular dystrophy, he is able to live without personal care support, with individually designed kitchen fittings and equipment, a special shower and toilet, and bed and bathroom hoists. A warden alarm link gives extra security but Mr B prefers to use his cordless telephone. The location of his home gives him electric wheelchair access to local accessible transport.

The planning and design of wheelchair housing is extensively researched elsewhere. Living Options is about services for people who do require care support in addition to adaptations and equipment – including those like Mr B, who may with time and the progression of his condition also require assistance in order to continue to live independently.

'A range of living options is needed in every community'

The services described in this chapter are only a few of a wide range of options that ideally should be available in every locality, from which severely disabled people might choose according to their life stage and needs.

In fact, any one of these services is likely to be the only supported housing service for severely physically disabled people in a given district. It may be run on an experimental basis and so be insecure, and it will probably be helping a very small number of clients. Only a handful of districts have more than one type of service, and many offer nothing at all.

CLIENT DIRECTED CARE SUPPORT

***At age 21**, Ms J left the (over) protection of her family home and, after living in a succession of residential homes during the next few years, succeeded in moving into her own housing association flat. Ms J has 24-hour live-in assistance, shared between two care workers who live locally, whom she employs herself. The care assistants work alternate three and four day weeks, carrying out all the personal and housekeeping tasks necessary. Ms J's DHSS benefits – including domestic assistance allowance – are topped up by her local authority, which pays Ms J via the voluntary agency home from which she moved.*

'Client directed services afford optimum control and satisfaction'

Client directed services offer severely disabled people the greatest degree of control over the personal, domestic and social care support that they receive. Disabled people take responsibility for (and accept the risks of) the employment and direction of their support staff. Support services go to the client in his/her own home, and can (in theory) be altered within that home or relocated to another dwelling according to the user's choice.

The current difficulties and risks of client directed independent living are well known. 'Packages' of care support are slow to arrange, as each is apt to be a unique venture with approval required at senior management or committee level. Determination is required on the part of the disabled person. Co-ordinating the provision of housing and support is difficult, and obtaining accommodation at all is far from assured.

Staffing arrangements are prone to be precarious, backup facilities unreliable, and considerable client time can be spent on care support management. Live-in help (with the worker informally on call) is usually the only alternative for those who need night-time cover, as funding agencies are unable to pay hourly night assistance charges.

The greatest obstacle at present is the inability of statutory authorities to make payments for care support directly to consumers, requiring that funds be 'laundered' through a third party.

The experience of residents leaving Le Court residential home in Hampshire to live independently with self-operated support packages are best known. The books *Project 81 - One Step On* and *Source Book for Independent Living* (HCIL, 1986), written and produced by members of the Hampshire Centre for Independent Living, continue to be of invaluable assistance to others contemplating independence, and to service providers seeking to help.

At present, very few people with severe physical disabilities are able to negotiate adequately funded self-directed care support. For those who do, however, the level of satisfaction is high, and many more severely disabled people are aspiring to live independently in their own homes with full control over their support services.

CAMDEN SPECIAL HOME CARE SCHEME

Summary: Social services top up care support funds, paying care staff on behalf of clients.

Revenue funding: Client pays according to means from income and benefits (including attendance allowance), topped up by social services within limit of £170,000 annual scheme budget. Care workers paid hourly rate (less than home helps) plus 'sessional' payments for a 24-hour (sleep-in), seven day period (£150 for a single worker, £300 for shared care). Currently facing obstacles to paying carers as casual employees, on behalf of client: DHSS and Inland Revenue querying whether carers are actually self-employed. May shift to system of client paying through third party or to council direct labour.

Clients: After three years in operation, 20 people mainly under 60 years, employed and unemployed, with and without spouse/relative. Clients must require substantial daily assistance, and be able to direct their own care.

Care support: Aims to support individual's private care arrangements. Covers personal, domestic, social support. Allows for 24-hour cover if client wishes. Includes some who, for example, have deteriorating conditions and look to the scheme for support.

Staff/Management: Currently 35 care helpers, including five male, aged 18 to 60, from variety of backgrounds (mainly not trained or experienced). Plus two Community Service Volunteers from arrangements pre-dating the scheme. Care helpers are self-employed, hired by client. Scheme development worker (social services) acts as agent, paying worker on user's behalf; may help advertise and interview workers; and deals with problems arising from care support arrangements.

Consumer control: Client selects and directs own care support arrangement, with 'enabling' help from scheme development worker.

HAMPSHIRE SELF-OPERATED CARE SCHEME

Summary: Social services and health authority top up of care support funds, paid via third party agents.

Revenue funding: Client expected to claim maximum DHSS benefits and allowances, including domestic care allowance. The difference between client's personal assistance needs (social and domestic needs are expected to be met by allowances) and amount of support fundable through client's financial resources, is paid for by scheme (based on social services care attendant rate plus 15%). Money transferred to client in monthly instalments via a third party, usually the Council of Community Service and the Leonard Cheshire Foundation. Currently decisions about funding self-operated care are made on a one-off basis at senior management level; an annual budget for self-operated care services is being sought. If a self-operated care package fails, the money reverts to the local care attendant scheme, which can then provide care attendants for that client.

Clients: Usually under 65 years of age, with the motivation and ability to organise their own lives, and to manage both money and personnel. Currently twelve people use self-operated care scheme.

Care support: Under complete control of client. Care worker provides all personal, domestic, social needs. Needs assessed by client via a care plan, including chart of daily requirements. Each package is flexible and unique to meet client needs. Nursing and home help service also available.

Staff/Management: Care staff recruited by client; resident or non-resident. Pay rates agreed between client and care staff. Annual pay increase based on inflation; 15% on costs allowed to cover employment, insurance, travel, sickness and holidays. Advice (including advice about emergency cover) available from local care attendant agencies. Care arrangements monitored quarterly by care attendant organiser. Third party agency 'contract' with client sets out arrangements and responsibilities.

Consumer control: Clients employ and manage own care staff with backup from scheme and third party agency.

INDIVIDUAL CLIENT-DIRECTED CARE SUPPORT PACKAGES

A few severely disabled people have managed to achieve a self-directed care support arrangement on an individual basis, rather than as part of a scheme as in the preceding examples. This has largely been achieved in co-operation with authorities inclined toward generous interpretation of the rules. As they are individual arrangements, clients and/or providers prefer to remain anonymous. As innovative methods of achieving independence, however, they deserve mention.

'Client directed services offer optimum control and satisfaction'

- Mrs K, who lives with her husband and child in her own home, and works full-time, requires a high level of support. Her local authority agreed to fund four care attendants who share 24-hour cover at home and at her workplace. Initially paid through a housing association, the funds are now paid by social services to a trust set up by Mrs K and three colleagues, enabling Mrs K to have full control in employing and directing her care staff. There is no charge to the client.

- Mr L left a voluntary residential unit to live in his own council flat which is registered as an annex to the unit. After satisfying the DHSS and registration officer regarding supervision of the tenancy (through regular contact with the unit) and management of funds (agreement with unit staff, annually reviewed), Mr L receives the full residential care board and lodging rate of £190 per week, topped up by his health authority to the full cost of his former place in the residential home. The DHSS money is paid direct to Mr L (less an amount refunded to reflect agency support), while the top up is paid to him via the voluntary agency. Mr L, who requires a high level of care support, hires and manages his support staff, consisting of one live-in worker supplemented by a neighbour and local student.

- Mr M lives in a warden-assisted housing association bungalow. His mainsteam care support (home helps and district nurses) is supplemented by local staff paid casually for weekend and backup help. The health authority tops up his income and allowances, paid via the housing association, so Mr M can direct his own attendant care arrangements.

- Mr N, who needs 24-hour support, lives in a self-contained council flat. His local authority agreed to let the upstairs flat to a care worker, funded through the social services care attendant scheme, who provides personal, domestic and social support to Mr N.

- Ms O was considered 'difficult' by workers from her local care attendant scheme. The agency agreed to hire Ms O's friends as helpers, first as agency staff, and then as a client-operated package, with the agency taking on the third party role, passing funds to Ms O to employ her own staff.

CARE ATTENDANT SERVICES

Ms P, a single parent with multiple sclerosis, lives in a council bungalow. Care workers from a voluntary agency attendant care scheme come three times daily five days per week (total 125 hours per month) to help with personal tasks. Home helps come weekday mornings to prepare meals and clean. Family and friends assist on weekends by Ms P's choice, as she prefers a break from her support staff. The workers are paid from a portion of Ms P's attendance allowance topped up by social services.

In this context attendant care schemes refer to statutory and voluntary agency schemes which employ staff centrally to provide personal, sometimes domestic, and occasionally social support in disabled people's own homes. Few areas have extensive – if any – care attendant services. In Hampshire, care attendant schemes, run by social services, the health authority or a voluntary agency, cover the entire county.

Within local authorities, care attendant services (also called home care schemes, special home helps, etc.) enabling severely disabled adults to live independently may be separate from, or enhance, mainsteam home help services. They may top up help purchased from personal allowances or provide an exclusive service.

'Care attendant services are the starting point for independence'

The need for and benefits of attendant care services are obvious to disabled people living at home without help, or unable to leave institutions without help. At their best they offer consumers individually designed and flexibly delivered support under their personal direction. For those wishing to exercise full control, the main drawback is that service providers will ultimately be responsible for the employment and management of staff.

For severely disabled people who do not wish or are not able to assume total responsibility as employers, however, readily available home based attendant care services are the starting point for independence.

RESPONAUT CARE ATTENDANT SCHEME, PHIPPS UNIT, WEST LAMBETH

Summary: Personal, domestic and social care support for 15 'responauts', organised through health authority.

Capital funding: Life support machine running costs met by West Lambeth Health Authority.

Revenue funding: West Lambeth Health Authority. Five additional clients funded by armed forces, British Polio Fellowship, joint funding by local health and social service authorities.

Clients: 15 people with polio and/or other respiratory problems who depend on mechanical ventilators. Priority to severe responaut. Range from able and fit but needing respirator at night, to total paralysis requiring 24-hour care. Referrals nationally.

Care support: Care attendants provide flexible personal, domestic, and social care support, as required and directed by client. Programmes of support may include statutory and Crossroads services. Clients encouraged to choose and train attendants. Attendants usually live in when on duty and accompany clients while on respite/crisis stays at Phipps.

Staff/Management: 31 care attendants (mostly from Denmark), not trained nurses, recruited and employed by health authority. Co-ordinated by senior nurse at Phipps Respiratory Unit, which provides backup, assumes responsibility, and arranges 24-hour emergency/technical cover for ventilators.

Consumer control: Client selects and directs own care support.

OXFORD CROSSROADS

The Association of Crossroads Care Attendant Schemes is the oldest and largest national voluntary organisation providing care attendants to physically disabled people and their carers (and sometimes to disabled people living alone). Local schemes are autonomous but linked to the national organisation. Realistic funding (mainly from statutory sources) for at least two years is stressed as the basis for starting up new schemes.

Summary: Voluntary organisation, funded mainly by social services, provides personal and social help to 68 clients and their informal carers.

Revenue funding: Originally Joint Financed (ten years ago), now core funded by social services (£24,000 per annum provides 200 care hours per week), plus one-off additional packages for individual clients funded by social services and health authority (£8,000). Fund raise approximately £8,000 annually. Core funding cut considerably from previous years.

Clients: 68 physically disabled clients (some also mentally handicapped) to age 65. Cover Oxford City area. All disabilities including difficult behaviours and AIDS. Because of funding cuts, no new referrals without additional funding. Mainly clients with informal carers but some living alone. Support some students while at college. Huge unmet demand.

Care Support: Personal and social help, including meal preparation and counselling. Less social support than previously because of funding cuts. 24-hour, seven day per week cover, including overnight stays. Fill in gaps in statutory services. Up to 14 hours support per client weekly, but most receive just a few hours. Co-ordinator 'matches' clients and staff, agrees with client what staff will do, then arranges a regular schedule of help.

Staff/Management: 15 staff, plus co-ordinator and assistant. Voluntary management committee includes two clients. Staff often from nursing background. Local and national training. Intention to upgrade staff pay to level of local authority care assistants. Office base in younger disabled unit. Supplement with staff from local private care attendant agencies as needed to meet client commitments.

Consumer control: Sensitive to client wishes within limits of structured service.

NEWCASTLE FAMILY SUPPORT SERVICE

The Cheshire Foundation sponsors a number of Family Support Services around the country. In general, the Foundation provides a 'starter' grant to a local group which is ultimately answerable to the Foundation. However, local groups are run independently by local management committees who appoint paid organisers. Local groups can therefore vary considerably regarding funding, aims, and service.

Summary: Personal support to disabled people and their informal carers, provided by voluntary agency.

Revenue funding: Set up with Inner City Partnership money, then Joint Finance, now mainline social services funding (£40,000 annually), with grant from Cheshire Foundation, and fund-raising to reach annual £78,000 budget. 50p per hour client 'contribution'.

Clients: Remit to help people with disabilities (mainly multiple sclerosis) and their informal carers. Covers two-thirds of city. Huge waiting list, so only crisis referrals.

Care support: Personal help (agreed with client) between 7.30am and 11.00pm (hours gradually extending). No night assistance because statutory services provide. No social support because of pressures on service. Home helps give additional domestic help. No other attendant care options in Newcastle. 250 care hours weekly to 35 clients.

Staff/Management: Voluntary management committee includes social services, a client, a care worker. Care staff are women aged 25–60; recruitment is difficult. Weekly care attendant support group meetings, monthly in-service training.

Consumer control: Clients not involved in staff selection but direct care within schedules agreed with Family Support Service.

GATESHEAD HOME CARE SCHEME

Summary: Personal and social support provided by social services.

Revenue funding: Inner Area Partnership grant extends until 1990. Care helpers paid hourly to a maximum of 16 hours per week. No guaranteed minimum number of hours. Pay rate as for home helps. No charge to client (note clients pay £1 flat rate for home helps). Service provided within limits of Home Care Scheme budget, but will respond to crises despite budget commitment.

Clients: About one-third of Home Care Scheme clients are physically disabled (monthly average 28), the rest have learning difficulties or mental health problems (but may also have a physical disability). Scheme supports 'difficult' clients who require more than just physical help – eg. with family/psychological problems, or with a mental and physical handicap.

Care support: Personal and social support (including time for a chat and tea, and going out) but not housekeeping (clients may have a home help as well). Written contract between social services and care helper, always agreed with client, specifies care support tasks. Have provided support to enable client to die at home. Number of hours increased/decreased according to need (eg. coming out of hospital).

Staff/Management: Reorganised since project visit, scheme consists of two social workers, administrator, and 75 part-time care helpers, managed by mental handicap service. (Originally team of five staff headed by project leader). Social workers co-ordinate and support care helpers, but do not act as social workers to client. Care staff are casual employees, recruited locally, mostly married women but some younger men and women. Care helpers and clients matched by scheme.

Consumer control: Client directs care within limits of package agreed by social workers and care helpers.

INDIVIDUAL ATTENDANT CARE SERVICES:

A number of care attendant services organised by statutory and voluntary agencies help only one or several clients and cannot be considered 'schemes'. Some case histories are included below as examples of flexible and effective services.

- **Trafford**: Although increasingly disabled by multiple sclerosis, Mrs H has been able to remain in her council flat with a special package of support provided by the home help service. A 'nominee' home help – a neighbour hired by social services – helps with personal and domestic tasks up to 39 hours weekly, mainly early mornings and late evenings, seven days a week. Additional daytime support, approximately 12 hours weekly, is provided by other home helps. The client pays a £1.40 weekly stamp towards the cost of this service.

- **Oldham**: Following a brief period in residential care Mr W, who is tetraplegic and requires substantial personal help, returned to the community. The home care service has employed two male care workers who work three hour morning and two hour evening shifts, seven days per week, which are arranged flexibly between client and workers. Mr W's support package is enhanced by a mobile warden service which responds to his radio call later at night when he is ready to go to bed. Mr W is one of several physically disabled people who benefit from this 'peripatetic home help' service. No charge is made to Mr W.

- **Westminster**: Mrs E, who has been disabled from childhood by arthritis, recently married and moved from an out of county residential hostel to her own flat. In this pilot venture, three care attendants, managed by Crossroads and recruited and paid by Westminster Social Services, provide personal, domestic and social care support seven hours daily, five days per week. Mrs E's husband meets her support needs nights and weekends. It is intended to decrease the support input as Mrs E becomes more independent, but to maintain sufficient cover to minimise demands on her spouse. No charge is made to Mrs E.

- **Aylesbury Vale**: After many years in institutional care, Mr and Mrs D married and set up home in an adapted council bungalow. A care assistant from the health authority hostel provides personal and domestic help mornings and afternoons, assisted by home helps and Crossroads attendants. Sleep-in night-time attention is provided by health authority care assistants (three nights), night sitters (two nights) and Crossroads (two nights).

- **Glossop**: Mr F moved from a younger disabled unit to this special housing association scheme as part of the DHSS pilot community care study, which funds Mr F's support costs (long-term funding ensured by statutory authorities). Mr F was involved in the design and fitting of his flat. Personal, domestic and social support are provided by a rota of five home helps working a flexible day (approximately 8am-11pm). Night turning is provided by a warden who lives in her own flat and also assists the other two tenants of the scheme.

FLEXICARE SERVICES

***Although** increasingly disabled by multiple sclerosis over a period of 20 years, Mrs R has remained in her family home, following her husband's death and the departure of her children to start their own families. A local authority home help comes on weekdays to help with personal and domestic needs, and her sons and nurses from a local agency cover most weekends. Recently, additional support has been arranged for Mrs R through the health authority flexicare budget, which funds another worker to help with early morning personal routines and provides night-time and weekend relief cover.*

Flexicare services refer to budgets earmarked by local or health authorities to provide care support (and sometimes equipment) to supplement mainstream services, enabling severely disabled people to live in the community. Flexicare budgets can provide flexible help, tailored to meet individual client needs.

While undoubtedly a good service within current overall provision, flexicare budgets are inevitably inadequate because mainstream services leave so much unmet need. They can only plug the most glaring gaps in service provision for severely disabled people. For consumers they may appear as just another element of piecemeal care support.

DERBYSHIRE FLEXICARE

Summary: A central social services budget, to cater for domestic, personal and social care support needs not met by mainstream services.

Revenue funding: Approximately 25% of annual flexicare budget of nearly £1m. is for physically disabled people (most clients are people with mental handicaps, or children). No charge to client, but clients may use attendance allowance to hire weekend help. Packages of support requiring the appointment of new staff need committee approval.

Care support: Flexicare budget can be used to buy in staff hours of any service, but not for equipment. Provides for high care needs. Individual service plans agreed with client, reviewed with client and workers.

Staff/Management: Flexicare workers can be from any discipline normally employed by social services, but most likely to be home care aides (recruited by domiciliary service organiser separately from mainstream home care aides and home helps).

Consumer control: Client-directed support within service plan agreed between social services and client.

VARIATIONS ON FLEXICARE SCHEMES

- **Nottingham Project**: 'Community carers' pilot scheme run by social services to top up service provided by mainstream community care assistants. Specialist social worker controls budget providing 70 hours per week from three staff, currently helping seven severely disabled clients. Budget covers aids and appliances as well as care support.

- **Basingstoke and North Hampshire Health Authority**: A £100,000 budget delegated to patient care manager for flexible top up (care support, respite care, and equipment) for physically disabled people.

DHSS BENEFITS

Mr and Mrs S live in an adapted council bungalow following many years in residential care. While both are severely disabled, their complementary abilities enable them to manage on about 30 hours help weekly from casually paid local staff. Their care support funds come entirely from the DHSS, received as a lump sum made up from personal benefits and allowances. Their local DHSS office helps them maximise the number of hours which can be considered to be taken up with 'domestic' tasks, thus increasing the amount of discretionary domestic assistance allowance they receive.

Many disabled people are restricted to the care support they can fund from their personal social security benefits and allowances. Attendance allowance, available to all disabled people who need daily assistance, will only fund a few hours daily help even at the higher rate (when help at night is needed). Domestic care allowance (although poorly publicised, discretionary and not readily available in most areas) has been a source of increased funds for care support. It is intended to cover the cost of domestic help for those who require full-time support, do not receive home help, and do not have an able-bodied spouse.

In a few areas local DHSS officers have enabled clients to maximise their domestic care allowance to help resource an independent living package. This allowance is phased out under the new Social Security Act from April 1988, and while those currently receiving it will continue to do so, they will not receive increases to match inflation. Many severely disabled people have relied on domestic care allowance and fear its erosion or withdrawal in the future. Domestic care allowance will not be available to new applicants; the special independent living fund to be administered in association with the Disablement Income Group is not expected to compensate (see Chapter 3, Secure Service Funding.)

PAID VOLUNTEER SUPPORT

Although a wheelchair user since childhood, Mrs T lived a normal life as wife and mother until the death of her husband and her increasing disablement from osteoarthritis of the arms and neck. Mrs T has been able to continue to live independently in her family home, however, with assistance from a live-in paid volunteer who helps with personal, household and social tasks. Mrs T welcomes the variety of the six monthly changeover of volunteers.

COMMUNITY SERVICE VOLUNTEERS INDEPENDENT LIVING SCHEMES

The Independent Living Scheme (ILS) run by Community Service Volunteers (CSV) provides volunteer placements for young people nationally. The theory of ILS is that volunteers act as the 'arms and legs' of the physically disabled client, who is expected to 'manage' his/her volunteer.

ILS volunteers can be placed with any project or individual, but most are placed through local authority schemes. These can use partnership arrangements (with CSV taking a development role, aiming to turn the scheme over to the local authority within three years) or pay a monthly fee per volunteer. CSV requires that each project/volunteer has a supervisor/support worker. Nationally there are about 650 ILS volunteers each year.

All volunteers work full-time on placements of four months to one year. They live in, or live nearby but sleep in while on duty. They may provide occasional help to several clients, work one-to-one with a single client, or work in a rota with other volunteers providing 24-hour daily support. Volunteers provide personal, domestic, and social support and will do 'nursing' tasks (bowel care etc.) that home helps/home care aides may not do.

The ILS scheme was one of the poineering ways by which severely physically disabled people achieved independence. The scheme is valued by many disabled consumers, although the frequent turnover and relative youth of volunteers makes the arrangement generally more attractive to younger clients. Recruitment problems, especially in rural areas, can limit the development or expansion of ILS schemes.

Conflicts can develop between the needs of clients and volunteers, as CSV operates for the benefit of volunteers. The impersonal flavour of client/volunteer relationships due to the 'arms and legs' philosophy of care support is often cited; in practice, most disabled people and their volunteer helpers develop friendly working relationships based on mutual respect.

AVON INDEPENDENT LIVING SCHEME

Summary: Community Service Volunteers social service/health authority partnership.

Revenue funding: A pilot scheme originally joint funded, now re-negotiated. £80,000 annual budget, with approximately £20,000 provided from social services and additional amounts from the four health authorities in the county. Social services pays the scheme organiser's salary and administration costs, health authorities pay the CSV core costs (volunteer director and administration costs), and pay the volunteers' pocket money and fares. Client usually provides/pays the volunteer's board and lodging.

Clients: 13 physically disabled people, including people with multiple sclerosis, cerebral palsy, spinal injuries. Most clients require a high degree of support. There is considerable unmet demand.

Care support: Flexible support, delivered as and when client wishes. Clients may be getting additional help from district nurses and the home care service, which also provides sickness and holiday cover for volunteers. CSV volunteers mostly live in with clients.

Staff/Management: Organiser administers the scheme on behalf of the statutory authorities and supports the project supervisors, who are generally clients' social workers. The CSV director recruits and places volunteers. 20-30 volunteers; normally one or two full-time volunteers per client.

Consumer control: Clients direct CSV volunteers.

SHAD, WANDSWORTH

The paid volunteer schemes run by SHAD (Support and Housing Assistance for People with Disabilities) differ from the Community Service Volunteers approach primarily in that they operate as a series of small scale voluntary groups, run from a local base, and controlled by tenant management committees. SHAD aims at a 'mutuality of benefit' for disabled consumer and volunteer (whereas CSV's priority is to its volunteers). SHAD schemes also operate in Lambeth and Haringey.

Revenue funding: £130,000 annual running costs met by Wandsworth Social Services, less income from clients' domestic care allowance and rent payments where applicable. Volunteers receive £37 per week pocket money and food allowance.

Clients: Currently eight tenants, with ceiling of 10 units planned for 1991. All local, referrals mainly from social services or health authority, either returning from residential care or living with families.

Accommodation: Management agreement between SHAD and Threshold Housing Association. Tenants pay SHAD who pass on rent to Threshold (currently Wandsworth allocates money to the unit rather than to the disabled person: problem if client wants to keep flat but doesn't require SHAD carer). Volunteer carers are licensees if in separate dwelling from client.

Care support: Aim to enable client to take responsibility for own care system. Personal, domestic and social support from volunteers who may live in, live upstairs linked by intercom, or have separate accommodation but live in on duty. Backup from SHAD peripatetic volunteer, and occasionally from Spinal Injuries Association care attendant agency and local private agency 'Care Alternatives'.

Staff/Management: SHAD is a voluntary organisation, a charity and a 'support group', employing a co-ordinator and deputy, and clerical assistant. All tenants are members of SHAD's management committee, and urged to participate. Client draws up job description, SHAD support worker recruits, client involved if so wishes, client makes final selection. Volunteers mostly from England (recruited through advertisements) and from Europe (via Central Bureau for Educational Visits and Exchanges). Four to six month contracts. Untrained volunteers, so SHAD provides training and considerable support.

Consumer control: Clients select and direct own care staff with support from SHAD.

CORE-AND-CLUSTER SCHEMES

***When Ms A**, who has cerebral palsy, moved to her present council flat from residential college, she required substantial physical assistance. She was also totally unprepared for the responsibility and loneliness of 'independence'. Care staff, working on site, were able to offer intensive support in the early months to ease the adjustment. Now Ms A is self-sufficient except for help with preparing meals; she is planning to enter university and intends to live on her own with minimal personal support.*

Most of the following examples are variations on a core-and-cluster theme of service delivery. Common to all the schemes are non-resident support staff who assist more than one individual. Help can be delivered flexibly, by agreement with the client, if not always 'on demand'. Cover is available 24-hours per day, seven days per week, but night-time and weekend support may be at a reduced level or on an emergency basis only. Occupants are secure council or housing association tenants and the accommodation is self-contained.

All the accommodation in these examples is purpose-built, although the principle could be applied to adapted housing. Special projects can suffer from being identifiably 'special', but these examples are dispersed within ordinary family housing.

Client control of service delivery is limited by the structure of the service. The needs of clients sharing the same staff, particularly at 'peak' times, require that staff work to at least minimal routines. Preferences for late bedtimes and social support away from scheme premises cause particular problems. Other hazards of integral housing and care support are the 'silting up' of accommodation intended to provide for high care needs when tenants no longer require that support but are unable or unwilling to move on; and the inability to move the support input with the client if he/she wishes to move to another home or tenure. For many severely disabled people the security of built-in support arrangements outweighs any such disadvantages.

PELHAM WAY, LEICESTER

Summary: 24-hour voluntary agency support to self-contained housing association flats.

Capital funding: Housing corporation, through De Montfort Housing Association.

Revenue funding: Joint financed care support, now tapering to Leicestershire Social Services. Tenants make no contribution to the care costs.

Accommodation: 13 wheelchair standard ground floor flats (plus 14th training/assessment flat) part of a purpose-built low rise estate of 61 flats, which is in turn part of a 333-flat high and low rise estate in central Leicester. Mainly two bedroom flats, self-contained, let to single people and couples. Equipment (hoists, shower chairs etc.) on loan from the Red Cross, via assessment by social service occupational therapists.

Clients: Tenants between 20 and 60 years, all disabilities (including cerebral palsy, multiple sclerosis, spinal injury, polio) but not most profoundly disabled/demanding because of staffing levels; from residential homes, younger disabled units, hospitals, and the community. New tenants go through assessment flat.

Care support: Care assistants provide combination of personal and domestic help, and a great deal of general support re social skills, budgeting, etc. High level of personal assistance for a few tenants, assisted by district nurses.

Staff/Management: Care workers employed and managed by Leicestershire Association for the Disabled which has agency agreement with social services. Management committee includes the Leicestershire Association for the Disabled, De Montfort Housing Association, social services and health authority. Three assistants (none professionally qualified) cover 24 hours per day, seven days per week, working in shifts. Relief care staff cover sickness and holidays. Only one staff on duty at a time, with 'bleeper'. Staff work from first floor flat which serves as office base. (Originally had service tenancies on the estate, but changed by own choice).

Terms of occupation: Secure (housing association fair rent) tenancies. Tenants responsible for rent, rates and household expenses. Encourage tenants to move on to other accommodation when no longer need support.

Consumer control: Informal agreement with staff re care support delivery.

OLDBROOK, MILTON KEYNES

Summary: Home help 'extra care' to ten housing association bungalows in integrated scheme.

Capital funding: Housing Corporation through Habinteg Housing Association.

Revenue funding: Buckinghamshire County Council home help service funds £2,000 per client per year. Tenant pays £1.60 to £4.30 per week home help stamp contribution, and can supplement care from attendance allowance. Entitlement up to 28 visits per week.

Accommodation: Ten wheelchair standard one and two bed bungalows, dispersed in 86 dwelling development, designated as 'extra care' homes. All dwellings in Habinteg schemes are mobility standard to avoid segregation of disabled people, with 25% built to wheelchair standard.

Clients: No age/disability restrictions. Tenants from Habinteg waiting list, and nominations from Buckinghamshire County Council and Milton Keynes Development Corporation.

Care support: Personal and domestic support, plus laundry and meal preparation. Care packages agreed with tenants before taking up tenancy. 24-hour emergency alarm call backup from housing association community assistant. Service can be extended to other tenants, or reduced/withdrawn from current extra care tenants as needed.

Staff/Management: Two staff on duty, working from office base in one scheme house, carry 'pagers'. Staff work two shifts: 7.30am-3pm; 2.45-10.30pm.

Terms of occupation: Secure housing association fair rent tenancies. Tenants responsible for rent, rates, household expenses.

Consumer control: Support flexibly delivered to schedule agreed with tenant.

FARNBOROUGH CLOSE, BRENT

Summary: 24-hour social services support to self-contained council housing.

Revenue funding: Social services special family aides budget; no charge to clients.

Clients: Tenants chosen by joint panel including housing, social services and the Brent Association for Disabled People. Assessment of care needs is made by family aides and occupational therapist. Age range 25 to 45 years. Profoundly disabled people considered, including 'difficult' and emotionally disturbed people, but applicants need to be able to benefit from scheme. Aim to help clients become more independent through self-help and constructive support. Taking responsibility rather than functional skills is stressed.

Accommodation: 12 ground floor one and two bed flats built to wheelchair standard, in a purpose-built, low rise block, which is part of a large council estate. Emergency alarm call system, rarely used.

Care support: Personal and some domestic help. Individual care plans set out in contract, agreed with disabled person when offered tenancy, reviewed periodically or at tenant's request. A few tenants receive a great deal of support but this is limited by staff time. Emergency night-time cover. Tenants expected to use attendance and mobility allowances to provide additional help, eg. additional baths, weekend or evening assistance, or transport/escort, etc., and this may be written into care contracts. Times of family aide support by agreement rather than 'on demand'. Tenants also entitled to home helps for cleaning, shopping and laundry.

Staff/Management: Three social services family aides reporting to Home Care organiser. Service tenancies, but plan to change to non-residential system to include night shift, to enable support to more severely disabled tenants. Aides work from first floor flat office base, 8.45am-5pm five days per week plus another 35 hours per week on emergency cover basis, including night-times covered on a rota basis.

Terms of occupation: Secure council tenancies; encouraged to move on when ready. Pay rent, rates; telephone provided by social services.

Consumer control: Clients involved in drawing up care contracts; manage own affairs unless request help.

TENANT CARER SCHEMES

Ms C, who has muscular dystrophy, lived with her parents until, in her mid-40s, she moved to a housing association scheme where disabled tenants receive support from able-bodied tenants. Five tenant carers share a seven days per week rota (16 hours in total) helping Ms C with early morning personal tasks. A home help prepares breakfast, and helps her into her car (she works full-time). After work, a tenant carer helps Ms C from the car and prepares tea; and returns later for a bath and bed.

In these examples, able-bodied tenants provide personal, domestic and/or social support to their disabled neighbours. Terms of occupation, methods of payment, and mechanisms for putting the duties and responsibilities of clients and care workers on a contractual basis vary but can be problematic. The conflict between personal and professional relationships can be difficult.

The tenant carer model generally assumes that the homes of supporting tenants are on upstairs floors inaccessible to disabled neighbours, but in one example (Greenwich, below) all flats are accessible. Arrangements depend on the continuing commitment of both parties to succeed.

At their best, tenant carer arrangements bridge the gap between client directed care support and core-and-cluster models. Disabled clients receive flexible support, managed through committees of disabled and able-bodied tenants.

GLEBE ROAD, GILLINGHAM

Summary: Housing association flats with care support provided by able-bodied tenants.

Capital funding: Housing Corporation through Habinteg Housing Association. Additional funds for garages, conservatories, and kitchen fittings from Medway branch of Muscular Dystrophy Group of Great Britain and Northern Ireland.

Revenue funding: Disabled tenants pay minimum £14 per week from attendance allowance (whether or not they use seven hours per week care).

Accommodation: Five one and two bedroom wheelchair standard flats on the ground floor of a two storey 10-flat purpose-built scheme. Intercom system linked to tenant carers. Near high street, shopping centre and park in residential area.

Clients: Disabled tenants all have muscular dystrophy, chosen by management committee with Habinteg's agreement.

Care support: Five able-bodied tenants share care support on rota basis, with two days off per week. Tenancy agreements specify care input of seven hours per week, and disabled tenants' obligation to pay. Provides personal and domestic support, supplemented by home helps.

Staff/Management: Voluntary management committee including disabled tenant. Carer tenants are couples, families, single parents; usually no previous training.

Terms of occupation: Secure housing association fair rent tenants. Tenants responsible for rent, rates, household expenses and payment to care attendants.

Consumer control: Consumers and tenant carers agree support service, managed through tenants' group and management committee.

VARIATIONS ON TENANT CARER AGREEMENT

- **Combedale Road, Greenwich**: A £20,000 Joint Finance grant enables three severely disabled tenants of a recently completed housing association scheme to employ full time personal assistants. Additional support is provided by Community Service Volunteers. Funds are administered through the Greenwich Association of Disabled People but disabled tenants recruit and pay their own assistants. The scheme consists of five flats for disabled tenants, four for able-bodied tenants, and one rent-free flat shared by the personal assistants. All ten flats are wheelchair accessible.

- **Grove Road, Sutton-in-Ashfield**: Tenant carers in three first floor flats provide personal support to three disabled neighbours in adapted ground floor flats. Care support is based on eight hours per week per tenant, funded from tenants' attendance allowances (about £20 per week). Tenant carers share seven day per week 'on call' cover. Commitments for tenant carers and clients written into tenancy agreements. Extra support can be contracted for separately, and home helps and district nurses are also available. Arrangements are managed by a tenants' group. The Grove Road scheme pioneered the tenant carer model and has been in existence eight years.

RESIDENTIAL SCHEMES

Ms G, aged 24, suffered onset of severe multiple sclerosis several years ago, which has left her also blind and epileptic. She now lives in a self-contained flat which forms part of a registered hostel managed by a voluntary agency. When in remission, Ms G needs only night-time checks and help for epileptic seizures, and is otherwise independent and active. During a multiple sclerosis attack, however, she is paralysed from the neck down and requires constant attention. Her needs are met by hostel staff – including some qualified nursing staff – in her own flat. The self-catering arrangements (food money is reserved from the hostel fees) allow Ms G to buy back a meal voucher when unable to prepare her own meals.

'The creation of new institutions cannot be sanctioned'

'Residential' schemes employ traditional institutional settings, with shared wards and care delivered according to the 'medical model'. Clearly the Living Options study does not endorse as good practice any such institutions provided by health, social services or voluntary agencies, nor does it sanction the creation of new institutions.

Present structures for care support funding, economies of scale, and the comparative ease of obtaining money for buildings rather than services, combine to make residential care a compelling option to service providers. Furthermore, the legacy of so much residential provision for this client group means the best use of existing facilities cannot be ignored.

The following examples therefore illustrate the use of residential registration under the 1984 Registered Homes Act, and the use of maximum DHSS board and lodging allowances, to provide a high level of care in a different way or to make innovative alterations to traditional provision. Several local authority facilities are also included.

Common to all the schemes in this section is the provision of accommodation and support elements as part of a package. At least one meal is provided and staff cover is available on site round the clock (though there is not always awake night staff). Clients do not have security of tenure, although neither registration nor receipt of the maximum level of allowances precludes this.

Other traditional residential homes may be working toward the best use of inappropriate facilities but are not included in this report. Large homes are dividing into smaller units to address the differing needs of residents – for example, for independence training or terminal care. Health authority younger disabled units are turning their attention to the demand for planned short stay. Such facilities, however, cannot be considered as best practice in long term housing and care support provision.

Within the limitations of residential provision, the following examples offer residents a considerable degree of independence and choice in their lives. It must be stressed again that these examples are not suggested for replication but as a source of ideas for change or the transitional use of available resources.

'Independent living is not synonymous with living alone'

Finally, a word of caution: 'independent living' has become such a buzz word among service providers and consumers that it is sometimes sought as an end in itself, not in relation to a holistic life plan. People functioning on their own tend to be viewed as 'successful' regardless of the quality of their lives. Independent living, however, is not synonymous with living alone. As a result of long term institutionalisation, low self-confidence, age, life stage or progression of disability, some severely disabled people may choose to live in shared residential settings, with the security of built-in care support.

Individually Registered Dwellings

Some agencies are obtaining agreement to register self-contained flats individually as annexes to residential units. These are usually bungalows in the scheme grounds but the principle can be applied equally to dwellings dispersed in the community. Individual registration means that the disabled person has his/her own home but the unit maintains ultimate control of both premises and care support funds.

Separate dwellings can also attract higher level board and lodging allowances without registration under the 1984 Act if they fulfil the criteria for registration, but DHSS officers have appeared reluctant to endorse this, preferring agencies to seek registration. Registration ensures inspection and monitoring but can mean complications such as the need to satisfy the fire officer. An example where a dwelling is both registered and a council tenancy is included under the section on Client Directed Care (page 43).

Individual registration of accommodation can mean greater independence for severely disabled people leaving residential care, but the principles and process are poorly understood, difficult to achieve, and generally demand that the disabled person compromises full financial control and security of tenure in order to gain sufficient care funding to live in the community.

NEATH HILL, MILTON KEYNES

Summary: 24-hour on demand support by The Spastics Society to 24 dispersed, self-contained registered flats.

Capital funding: Milton Keynes Development Corporation, transferred to borough housing department.

Revenue funding: Fees paid from DHSS board and lodging allowances, topped up by sponsoring authority. Clients keep £26 per week housekeeping from board and lodging allowances, plus 'rent', household bills, and care support costs. Clients receive in addition a £285 per annum lump sum holiday and clothing allowance.

Clients: 33 clients, many requiring total care; if couples are admitted both parties must be disabled. Originally residents selected by The Spastics Society from their residential homes; now a waiting list is operated with referrals from any source; no formal admissions criteria. Applicants expected to visit the scheme and exercise judgment as to whether it is suitable.

Accommodation: 24 wheelchair standard flats, dispersed through the Neath Hill estate. Comprises 18 one-bed flats, plus cluster of six single person flats. All ground floor with carports and small gardens.

Staff/Management: Scheme managed by The Spastics Society on behalf of housing department. Client representation on panel to select staff. Society policy to consult residents re management matters. Mainly women staff, but increasingly young people and men. Four staff teams, each with a team leader, work in four patches; report to scheme manager. Provide average 34 hours support weekly per person. Two awake night staff. Staff pay is higher than local authority pay for similar jobs in Milton Keynes.

Care support: 24-hour care support provided 'on demand', within limits of staff resources, which means some queuing for meals and bedtimes. All help delivered in client's own flat, via intercom system linked to two staff houses. Personal and domestic support includes preparing meals. Clients manage own lives with help of individual service plans. Neath Hill Professional Workshop, formerly linked to scheme, is now independent; some clients do attend its computer based activities.

Terms of occupation: Individually registered flats; The Spastics Society holds tenancies on behalf of housing department. Residents called 'tenants', but do not have tenancy agreements or contract with Society; verbal assurance of permanent home. About 10% move on to live more independently.

Consumer control: Clients request and direct care support in own homes.

KELVEDON PROJECT, TIPTREE

Summary: 24-hour support by The Spastics Society to young adults with physical and/or associated disabilities, living in registered bungalows.

Capital funding: The Spastics Society.

Revenue funding: Cost of high care provision – including day activity, transport, staff backup and administration – shared with two other large residential facilities within the Kelvedon Project. Fees funded from DHSS board and lodging allowances topped up by sponsoring authorities.

Clients: 14 young adults who have range of physical disabilities associated with cerebral palsy, severe learning difficulties, severely impaired communication and restricted emotional development. Selected from the Society and other residential schools to meet urgent needs of high-dependency school leavers.

Accommodation: Two four-bed converted bungalows and two three-bed purpose-built bungalows. Each has single bedrooms, two bathrooms (one with shower, one with Parker bath), lounge and kitchen/dining area. Ordinary residential location, domestic decoration, ordinary furnishings and equipment used where possible. Staff accommodated in attached coverted garages which serve as offices and 'sleeping-in' stations.

Care support: Aim to enable residents to develop skills, maturity, acceptable social behaviour, own style of living. Flexible care support routines. Common meals by resident choice. Stress personal, not physical achievements (which are hard to measure because of degree of impairment). Staff as enablers, not carers. Individual service plans. Provide total personal care including feeding. Residents (with staff) use Society day service resources.

Staff/Management: Staff recruited locally; high staff/resident ratio. No nursing staff; use local medical/therapy facilities. Managed by The Spastics Society; part of the Society's local Kelvedon Project.

Terms of occupation: Individually registered bungalows. Permanent homes.

Consumer control: Residents encouraged to exercise choice within limits of disabilities.

Hostels with Client Directed Care Support

The following examples share a substantially non-institutional approach to service delivery. Care support tasks are carried out at the direction of disabled people with staff facilitation. While sometimes offering permanent homes, the emphasis of these schemes is on encouraging personal responsibility and training for independence. Residents aspire to, and in some schemes are expected to, move on to more independent living options; two of the hostels have links with self-contained housing.

Issues regarding the philosophy of transitional and training schemes are discussed in Chapter 3. In the present service scene, and within restrictions implicit in residential provision, the facilities described below do enable severely disabled people to achieve a considerable degree of personal autonomy.

FREDA EDDY COURT, KIDDERMINSTER

Summary: Assistance on demand in 10-bed social services residential hostel, together with sheltered housing unit.

Capital funding: 60% county council and health authority, 40% district council.

Revenue funding: Social services.

Accommodation: Purpose-built hostel near town centre. Ten single rooms on four levels in two units sharing kitchen, dining area, bathrooms, and social facilities. One pair of rooms in each unit can be used as suite for a couple. Shared common room and laundry. Hostel joined by covered walkway to block of six self-contained wheelchair standard sheltered flats. Hostel rooms have own French door and terrace, letter box.

Clients: Potential for taking responsibility for running own lives and sharing joint decision-making. No limit to physical disability level, within staff capacity. 18 to 60 years: can stay past upper age limit. Long-stay or transitional, plus short-stay respite.

Care support: Facilitation ('arms and legs' principle) for residents to carry out personal, domestic, and social tasks. Clients direct staff who respond on demand to 'ensure that the normal status of the individual is safeguarded'. Clients responsible for running own life including shopping, cooking, cleaning, requesting help as required. Negotiate to distribute staff time. Also involved in staff and resident selection.

Staff/Management: Each unit has staff team of four resident social workers, plus volunteers. Also emergency assistance to sheltered housing. Community medical/health services.

Terms of occupation: Social services residential hostel; sheltered housing tenancies.

Consumer control: Clients request and direct own care support.

HOSTELS WITH SIMILAR PHILOSOPHY OF CARE SUPPORT:

- **King Henry's Walk, Islington**: 17 residents in three units share kitchen/dining area and bathroom. Clients self-cater and carry out other tasks with staff support on demand. Seven occupants in four satellite flats share a separate staff group working from hostel.
- **Boundary Road, Camden**: Purpose-built (10 year old) two storey block, 24 single bedrooms divided into six 'flats' with clients sharing kitchen and bathroom. Clients self-cater and carry out other tasks through staff facilitation.

SHAFTESBURY COURT, TROWBRIDGE

Summary: Enabling support by Shaftesbury Society to 18-bed registered special needs unit and bungalows.

Capital funding: Housing Corporation.

Revenue funding: Fees funded from DHSS board and lodging allowances, with top up from sponsoring authorities.

Clients: Wide range of physical disability, some with progressive conditions. Most residents undertake individual planned programme leading to independent living although some may stay long term. Referrals include the Society's own schools and extended education units and are vetted by a professional advisory panel including representatives from social services and health authority. Age range 18 to 45.

Accommodation: Cross-shaped core-and-cluster design, with central administration and lounge area and four wings, each with four single bedrooms, kitchen/dining area and bathroom (each bathroom equipped differently). Three bungalows adjacent to special needs unit, with linked alarm system.

Care support: Balance between sufficient care support and high level of independence. Residents ask for help needed; staff facilitate, encourage, supervise, motivate. Residents encouraged to handle own personal needs or have potential to do so. Residents expected to prepare own breakfast and lunch with staff assistance if necessary (main meal provided), do own shopping, laundry.

Staff/Management: Managed by warden, deputy, care officer, plus four and a half care staff, and cook. No awake night staff.

Terms of occupation: Residential needs unit and one bungalow registered; remaining bungalows Shaftesbury Housing Association tenancies.

Consumer control: Residents manage own lives with support, take active role in management of unit.

DOLPHIN COURT, SOUTHEND

Summary: Independence training for young people by John Grooms Association for the Disabled.

Capital funding: John Grooms Association charitable funds.

Revenue funding: DHSS allowances topped up by sponsoring authority. Cash allowances to users for self-catering.

Clients: Age range mainly 16 to 35, priority to Essex residents. Accept anyone who will benefit from planned short-stay independence (approximately two years) training. Any physical disability level including total care, but not people with unsocial/behavioural problems. Sponsoring authority requested to co-operate with rehousing. One assessment/holiday/respite flat.

Accommodation: Three storey purpose-built block comprising 15 self-contained flatlets each with bathroom and kitchen. Residents dining room/lounge, laundry, bathrooms and shower room. Central, sea front location. Individual front doors with mail and milk delivery; fully furnished. Technical aids provided as required.

Care support: Individual client plans agreed on entry with client and sponsoring authority; reviews. Residents hold room keys, staff input only with resident's agreement. Training for future independent living without attendant care, with maximum of technical aids. Waking care staff to midnight. House keys available. Other support per schedule agreed with resident. Care staff provide personal, social and domestic help to residents and informal training.

Staff/Management: House manager, plus three senior nursing staff, six care staff; sleeping night cover. Some volunteer helpers; catering/domestic staff. Day to day policy discussed with clients (eg. self-catering) but not management or selections because short-stay facility.

Terms of occupation: Registered home. Clients encouraged to move to more independent living arrangements.

Consumer control: Clients agree support arrangements, encouraged to take responsibility for own lives.

ST. MICHAEL'S HOUSE, WELWYN GARDEN CITY

Summary: Independence preparation by Hertfordshire Social Services in 24-bed short-stay hostel, with associated day centre and group homes.

Capital funding: Social services department.

Revenue funding: Social services. Clients claim own benefit and pay about £15 'rent' and charges (retaining £24 per week for self-catering and other personal needs).

Accommodation: Purpose-built 24-bed hostel, four wings each with six single bedrooms plus bathroom (all differently equipped) and kitchen area; central dining room and lounges; own letter box, phone point. Centrally located in residential area; adjacent to day centre. Two social services group homes nearby, to which some St Michael's residents have moved.

Clients: No limits to physical disability level, including brain injured and difficult behaviours (however, people with Huntington's Chorea not accepted). 75% have learning difficulties. Age range up to 55 for long-stay, 65 for respite beds. Hertfordshire residents only (including out of county).

Care support: 24-hour personal and domestic support. 18 long-stay and six respite beds. Care plans agreed with clients but not formal contracts. Longer stay residents expected to live as near 'normally' as possible, taking responsibility for own lives/personal tasks. Care staff, through key workers and individual client plans, facilitate this aim. Residents expected to self-cater for a minimum of three days a week. Domestic staff, called 'home helps', visit residents' rooms by appointment only and help residents learn housekeeping/laundry tasks. (For respite/intermittent care residents, full support is provided.) No entertainment or outings provided; residents expected to plan own daytime activity (with staff facilitation). Many residents attend day centre adjacent to the hostel.

Staff/Management: Eight full and part-time care assistants. Hostel, day centre and group homes, managed by project co-ordinator.

Terms of occupation: Criterion for admission is the motivation to move on. Not a permanent home. Anticipate a two-year stay. Would like to reduce stay to six months (so residents don't lose local contacts and get too 'comfortable'), and provide similar training for independence in clients' own homes.

Consumer control: Responsibility for personal/domestic matters through client plans agreed with staff.

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Conclusions and Starting Points for Change

The Living Options project aimed to identify innovative housing and care support services enabling prople with severe physical disabilities to lead autonomous, integrated lives in their communities. Widespread evidence, however, of the discouraging circumstances experienced by disabled people has emerged from the project findings.

The response from statutory authorities to the project's initial request for information suggested that housing and support services for severely disabled people are scarce, patchily distributed, and a low priority amongst service providers (Fiedler, 1988).

An even starker picture is painted by the project fieldwork. 'Good practice' services often help only a few individuals, are *ad hoc* and arbitrary, and marginal to the lives of most people with severe physical disabilities. The project set out to investigate good practice, and the schemes visited represent the best of the services available. For the disabled people who contributed to the study, however, these services usually go only part way toward meeting their requirements for housing and support.

The effects of the 1986 Disabled Persons Act and of the 1988 Social Security Act are not yet fully felt. Nor is the Government's reaction to the Griffiths or Wagner reports on community and residential care yet known. Hopefully, positive changes in the circumstances of severely disabled people will result. The following points, however, summarise services for this client group in 1988.

CHAPTER 1

1. Set against estimates of need, the number of younger severely disabled people benefiting from effective housing and care support services is appallingly small. The national map of service provision shows whole areas where severely disabled people's needs remain unassessed and unmet.

2. The majority of younger severely disabled people are cared for at home by relatives with little or no input from the statutory authorities. Others are in hospitals or residential homes, frequently some distance from family and friends. For most disabled people there are no supported living options between those extremes.

CHAPTER 2

3. Even in pockets of creativity and action, only a few severely disabled people benefit from 'good practice' housing and care support services.

4. Those severely disabled people who are living independent lives in the way they wish, have achieved this through personal determination and years of hard work in the face of overwhelming obstacles, or because a committed advocate has fought on their behalf.

5. Support services are complicated, piecemeal, inflexible, insecure, and idiosyncratic, and often limit users' lives or result in unnecessary institutionalisation.

6. Appropriately designed and equipped housing is in short supply. Housing and care support systems are rarely planned in unison. Delays in assessment for and provision of adaptations and equipment militates against independence.

7. The economics of service provision for severely disabled people have more to do with the cause of disability, agency taking responsibility, and geographical location than with need.

CHAPTER 3

8. Service arrangements, the roles of professionals and workers, and funding mechanisms for accessing and delivering services are arbitary and inconsistent. Consumers, their families, care staff and advocates, and professionals find the system confusing. There is no clear structure whereby disabled people can achieve autonomy in their housing and personal support.

9. Disabled people as consumers of services rarely participate in the planning of services, or exercise choice in or control of their housing and care support.

10. Many of the supported housing and residential facilities that do exist are occupied by people who could live in their own homes if better community support services were available.

11. There is frequently no logical relationship between the level of physical disability of a client and the amount of support, or type of supportive environment, provided. The profile of disabled people living in local authority homes, in health service facilities, or at home with informal carers, is similar.

12. There is no degree of physical disability that cannot be supported in the community (non-institutional, non-medical setting). Even the most severely disabled people can and do live independently with appropriate help.

13. Service providers continue to produce special facilities despite evidence that support services are more effective when delivered to users' own homes. An apparent demand for residential care, and for short stay respite care, results from the lack of home based alternatives.

CHAPTER 4

14. There is no single housing and care support model that is appropriate to all people with severe physical disabilities. Different services may suit different individuals at different stages of their lives, but services are most effective when they result from consumer choice and respond to consumer demand.

15. Although innovative schemes are being planned and developed, the pace of change is so slow, and the numbers catered for so small, as to make little appreciable difference to the majority of younger severely disabled people.

Overall, the Living Options project study points to a dearth of effective housing and support provision for people with severe physical disabilities. The achievement of quality services demands urgent action by policy makers, funders and managers. Massive additional funding is not always necessary. All those involved in service provision, even at the most local or small scale level, can undertake practical measures with consumer involvement to expand and improve housing and care support services for those who cannot live independently without help.

STARTING POINTS FOR CHANGE

Quality housing and care support services demand that those who plan and provide services:

CLIENT NEEDS

1. Recognise that people with even the most severe physical disabilities can live in the community with appropriate support.

2. Be alert to the needs of people with multiple disabilities, and ensure that severely physically disabled people who are less able to articulate their needs, or who lack advocates, have equal access to appropriate accommodation and support services.

PROFESSIONAL RESPONSIBILITY

3. Produce policies and plans for housing and care support but ensure that these result in real services. Beware that the language of good practice does not replace good practice itself.

4. Acknowledge responsibility for good service provision, define responsibilities between professions, and ensure mechanisms for effective collaboration.

5. Set professional standards for service provision, and ensure that all staff acquire the necessary knowledge and skills. Maintain standards through staff training and service monitoring.

6. Examine the pay, conditions of employment, job image, professional standards and training of care support staff to ensure sufficient quality and quantity of support workers to achieve an effective support service. Rivalries, service overlaps and gaps also need exploring.

CONSUMER CONTROL

7. Begin all future planning and provision of services with consumer consultation. Offer practical help to disabled people to enable them to participate in consultation procedures and become genuinely involved in service planning and delivery. Support consumer-run organisations such as Centres for Independent/Integrated Living.

8. Ensure that future generations of severely disabled people gain the confidence and skills to take responsibility for their own lives. Provide assertion and skills training to young disabled people, including training by other disabled people.

9. Provide a single entry point for information about, access to and co-ordination of disability services, including provision for advocacy. Evaluate the different existing models of case management and set professional standards for this service.

SERVICE PROVISION

10. Undertake to offer sufficient, appropriate, and flexible support services to people with severe disabilities in their own homes. Ensure that services can be funded and delivered flexibly to meet user needs rather than create special facilities to which disabled clients must go for assistance.

11. Ensure that lack of appropriately designed, adapted and equipped housing does not prevent severely disabled people from taking up options for independent living in the community. Policies of building all housing to accessible standards, and maintaining records of adaptable/adapted property, will be important starting points.

12. Examine budgets for and the co-ordination of assessment and provision of adaptations and equipment, and aim to eliminate expensive and destructive delays.

13. Ensure that no additional residential facilities are built by local authorities or health authorities, and discourage residential provision by voluntary organisations, unless it is established that potential residents would prefer such facilities to community based housing and support services.

14. Explore the use of existing residential facilities for independence training, transitional accommodation, and respite care as interim measures. But ensure that these functions do not become substitutes for long-term, home based support services for severely disabled people.

15. Pursue local ideas, and consider innovative services used elsewhere (based on consultation with disabled people/potential users), to provide a range of flexible, dependable long-term housing and care support options in the community. Support voluntary agencies that are demonstrating quality service delivery (as evidenced by disabled service users).

NATIONAL POLICY POINTS

In order to create the framework in which good practice can flourish, central government must:

16. Establish minimum national standards for personal, domestic, and social care support for people with severe physical disabilities, whether they are living alone or with partners or families. Set consistent standards for the provision of accessible housing and for adaptations and equipment.

17. Guarantee fair, secure and consistent funding regardless of cause or type of disability. Commit sufficient resources to maintain quality service standards and to enable people with severe physical disabilities to embark on life plans without unnecessary disadvantage compared with their able-bodied peers.

DIRECTORY OF ORGANISATIONS

Arthritis Care
6 Grosvenor Crescent, London SW1X 7ER

Association to Combat Huntington's Chorea (COMBAT)
108 Battersea High Street, London SW11 3HP

Association of Crossroads Care Attendant Schemes
10 Regent Place, Rugby, Warwickshire CV21 2PN

Association for Spina Bifida and Hydrocephalus (ASBAH)
22 Upper Woburn Place, London WC1H OEP

British Council of Organisations of Disabled People (BCODP)
St Mary's Church, Greenlaw Street, London SE18 5AR

Brent Association for Disabled People
154 Harlesden Road, London NW10

The British Polio Fellowship
Bell Close, West End Road, Ruislip, Middlesex HA4 6LP

Carers' National Association
29 Chilworth Mews, London W2 3RG

Centre on Environment for the Handicapped
35 Great Smith Street, London SW1P 3BJ

The Chest, Heart and Stroke Association
Tavistock House North, Tavistock Square,
London WC1H 9JE

CHOICE, The Case Management Service
152 Camden Road, London NW1 9HL

CRYPT, Creative Young People Together
21 Plover Close, East Wittering, Chichester, West Sussex
PO20 8PW

Derbyshire Centre for Integrated Living (DCIL)
Long Close, Cemetery Lane, Ripley, Derbyshire DE5 3HY

Disablement Information Advice Line (DIAL)
117 High Street, Clay Cross, Derbyshire S45 9DZ

Disablement Income Group (DIG)
Attlee House, 28 Commercial Street, London E1 6LR

Disabled Living Foundation (DLF)
380-384 Harrow Road, London W9 2HU

Disabled Persons Housing Service (DPHS)
Walbrook Housing Association, 66-68 Curzon Street,
Derby DE1 1LP

Exeter Council for Independent Living
The Ashclyst Centre, Hospital Lane, Whipton,
Exeter EX1 3RB

Greater London Association for Disabled People (GLAD)
336 Brixton Road, London SW9 7AA

Greenwich Association of Disabled People (GAD)
Christchurch Forum, Trafalgar Road,
London SE10 9EQ

Habinteg Housing Association
10 Nottingham Place, London W1M 3FL

HALO Promoting Mobility in Housing
11a Apollo Place, London SW10 OET

Hampshire Centre for Independent Living
39 Queens Road, Petersfield, Hants GU32 3BB

Head Injury Case Management Study
Department of Neurological Sciences,
St Bartholomew's Hospital, London EC1A 7BE

HEADWAY National Head Injuries Association
200 Mansfield Road, Nottingham, Notts NG1 3HX

Informal Caring Support Unit,
King's Fund Centre
126 Albert Street, London NW1 7NF

Islington Disablement Association
90-92 Upper Street, London N1 ONP

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John Grooms Association for the Disabled
10 Gloucester Drive, London N4 2LP

King's Fund Centre for Health Services Development
126 Albert Street, London NW1 7NF

The Lady Hoare Trust
Alma Lodge, 75 Alma Road, Windsor, Bucks

Leicestershire Association for the Disabled
6 St Martin's, Leicester LE1 5DB

The Leonard Cheshire Foundation
Leonard Cheshire House, 26-29 Maunsel Street,
London SW1P 2HQ

The Living Options Project
Flat 6, 12 Dorset Square, London NW1 6QB

Long Term and Community Care Team, King's Fund Centre
126 Albert Street, London NW1 7NF

Motor Neurone Disease Association
61 Derngate, Northampton, Northamptonshire NN1 1UE

The Multiple Sclerosis Society of Great Britain and Northern Ireland
25 Effie Road, London SW6 1EE

Muscular Dystrophy Group of Great Britain and Northern Ireland
17 Selby Road, Plaistow, London E13 8NB

National Council for Voluntary Organisations
26 Bedford Square, London WC1B 3HU

National Federation of Housing Associations
175 Gray's Inn Road, London WC1X 8UP

National Information Forum
c/o DLF, 380-384 Harrow Road, London W9 2HU

Parkinson's Disease Society
36 Portland Place, London W1N 3DG

Personal Lifestyle Packages Project
Careers Centre, 11 St Owen Street, Hereford HR1 2JB

The Prince of Wales' Advisory Group on Disability
8 Bedford Row, London WC1R 4BA

Queen Elizabeth's Foundation for the Disabled
Leatherhead, Surrey KT22 0BN

The Royal Association for Disability and Rehabilitation (RADAR)
25 Mortimer Street, London W1N 8AB

Residential Care Consortium (Carematch)
286 Camden Road, London N7 0BJ

SENSE, The National Deaf-Blind and Rubella Association
311 Gray's Inn Road, London W1CX 8PT

SHAD Wandsworth
The Nightingale Centre, 8 Balham Hill,
London SW12 9EA

The Shaftesbury Society
2a Amity Grove, Raynes Park, London SW20 0LH

The Spastics Society
16 Fitzroy Square, London W1P 5HQ

Spinal Injuries Association Care Attendant Agency
Newpoint House, 76 St James's Lane, London N10 3DF

Walbrook Housing Association
66-68 Curzon Street, Derby DE1 1LP

Wales Council for the Disabled
Caerbragdy Industrial Estate, Bedwas Road,
Caerphilly CF8 3SL

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ACKNOWLEDGEMENTS

Above all I would like to thank the many people with severe physical disabilities who welcomed me into their homes during the course of the Living Options project, and who shared the often painful details of their experience of housing and care support services. Their evidence provides the basis for this report, and I hope that service options for them will increase as a result.

Thanks are also due to the statutory and voluntary organisations who invited me to learn about the problems as well as the successes of the services they provide, in the interest of promoting better practice. Many concerned individuals also shared their personal and professional knowledge.

I am grateful to the members of the Living Options Support Group for their enthusiasm, ideas and practical help during the course of the project; and to the participants of the Living Options Working Party, whose concern originally sparked the production of the Living Options *Guidelines* and led to the launch of this project.

Barrie Fiedler
September 1988

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ISBN 0 9513914 0 2