A one day Conference organised by Greater Manchester HOUSING & DISABILITY GROUP

HOUSING & CARE SUPPORT

for people with physical disabilities

INFORMATION PACK

Sponsored by The Spastics Society

HOUSING & CARE SUPPORT
INFORMATION PACK

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HOW does it work?

Each Scheme, completely autonomous but linked to the national organisation, is administered by a co-ordinator, who is responsible for assessing the family need and supplying the practical help **at times required by the families.**

The Management Committee of each local Scheme is made up from representatives of health and social services departments and voluntary organisations. Disabled people are also encouraged, and welcomed, to serve on each Management Committee.

For details of literature available, advice on any aspect of the work of the Association or on Crossroads Schemes please write to:

Mrs. Pat Osborne, S.R.N., N.C.D.N.,
Chief Executive Officer,
Association of Crossroads Care Attendant Schemes Ltd.,
11, Whitehall Road,
Rugby,
Warwickshire CV21 3AQ.

who will be happy to help.

For details of your local Scheme please contact:

Crossroads
Care Attendant Schemes

Charity Registration No 282102

WHAT is it?

a registered charity which has as its objectives:

1 . . to recruit and provide Care Attendants:

a) to relieve stress in the family or carer of the disabled person.

b) to avoid admission to hospital or residential care of the disabled person should a breakdown or other failure occur in the household.

2 . . to supplement and complement, not to replace, existing statutory services and to work closely with them.

3 . . To strive to maintain a high standard of care.

WHY was it formed:

Many physically handicapped people are able to live at home only because of the constant support they get from another person - a friend, a housekeeper, or most often, a relative. Sometimes a large family of brothers and sisters will organise a shift system to look after their handicapped mother or father. But there is always a danger that the system will break down. The relative will fall ill, or the family providing help day in day out will begin to crack under the strain. How many physically handicapped people have had to leave their homes for long periods or forever, because the person or the people who looked after them, could no longer cope? One or two hours a week, at the time the disabled person needs them, can make all the difference.

It is perhaps surprising that with District Nurses, Health Visitors, Social Workers, Occupational Therapists, Home Helps, Meals on Wheels, and so on there should still be an unmet need. But there is. Without in any way duplicating the help provided by any of these services a properly trained, reliable care attendant can be the crucial factor in determining whether or not a disabled person is able to go on living at home. Everyone concerned with the care of the disabled believes that, wherever possible, they should be given a choice of living in their own homes rather than a hospital or an institution.

WHEN can a scheme begin in your area?

It is not the policy of the Association to initiate interest in a given area, but rather to help and encourage groups which have seen their own local need. The most effective way of establishing a Crossroads Scheme has been to form a Steering Committee to look at local need with a view to applying for finance from the respective statutory authorities.

The Association has the expertise and experience to assist each Steering Committee through the various stages and is pleased to offer help.

WHERE are Crossroads Schemes?

Basildon
Belfast
Braintree
Breckland
Brent
Broadland
Calderdale
Castle Point
Chelmsford
Cheltenham
Colchester
Coventry
Croydon
Daventry
Delyn
Dewsbury & District
Dudley
Dundee
Glasgow
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Hillingdon
Ipswich
Islington
Milton Keynes
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Rochester
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Rugby
Southend
Southwark
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Warrington
West Cumbria
Westminster
Wirral
Woking

(as at May 1982)

The Kingston Project

Ann Macfarlane

Residential Care

Residential care for severely physically disabled people is often in large adapted establishments which are situated some distance from a town. The maintenance of such buildings and the necessary level of care that they provide, is expensive.

The reasons for transferring people into such care are varied. It may be that the disability has progressed so that the able carer or carers can no longer manage to provide the sustained level of care required. The disabled person may live alone, and the existing community services be insufficient for the person to function adequately. Residential care for the disabled person may also be the only solution when the working hours of care attendants are not flexible enough to enable the family unit to remain together. Whatever the cause, the degree of disability may make it essential for a person to receive twenty-four hour care.

The Kingston Project is a plan to offer an alternative residential care facility in Kingston: an independent, integrated life-style in small, purpose-built units, near to relatives and friends, accessible to community facilities and with twenty-four hour care provided. The housing will not create an institution or a ghetto. On the contrary, the independent living units will be well integrated with the community.

The Kingston Project

The concept of care is that of the 'extended family' where a body of people can live together corporately, but take up individual activities within their own units and in the community. Twenty-four hour care will be provided to enable the disabled person to lead as flexible a life-style as desired. Care services can come from several sources — family, friends, volunteers, paid living-in and living-out staff.

Each member of the 'extended family' will need time to pursue an individual life-style and this must be respected by the disabled and able-bodied. Varied levels of care may also be drawn from the statutory community services.

It is important that the severely physically handicapped person has the opportunity to determine where and with whom to live; with whom to associate; what help is required and who shall give it; what to eat and what to wear. It should be possible for the disabled person to decide how to utilise each day and what risks to take. It is necessary that the handicapped person has as much responsibility for his own well being and environmental control as is practicable.

The accommodation will consist of not more than six self-contained units, each providing living and sleeping areas, a kitchen galley, bathroom and toilet facilities. An advanced call-system will provide maximum privacy.

Amenities will also be available for the provision of communal and separate meals, and for laundry requirements. The whole area will have level access to aid mobility and nearby carport facilities will ensure easy access to vehicles. The housing complex will contain small gardens with raised beds to allow those who wish to cultivate the area, the opportunity to do so. Mobility units with appropriate aids and equipment will enable the disabled person to achieve maximum independence and accomplish what might otherwise be impossible.

Integrated housing means easier communication and access for and with the disabled person. Many facilities must be within reach, such as place of work, shops, the library, pub, church and cinema, thus enabling the severely handicapped person to participate in community life and allowing the able-bodied person to call in frequently.

Relinquishing the responsibility of care for the disabled member of the family should, wherever possible, be a gradual process. The disabled person and able, but now less capable carer, need time to adjust to the changed situation. The involvement of the family and friends is still important: the able-bodied person has the ability and the need to go on caring for and helping the disabled person who has left the family unit or their own home. A scheme such as the one we plan in Kingston will encourage relatives to assist with the daily routine — shopping, laundry, cooking and performing tasks out of the range of the disabled person. This enables relatives to continue to help without having the exhausting responsibility of full-time care.

Ensuring Success

To put these principles into practice is a challenge which the Kingston Project is preparing to face. The level of care necessary to ensure the true independence of residents is clearly well above the requirements identified in government legislation. To ensure the success of this scheme, the Project therefore intends to raise about £50,000 by the end of next year. This will enable them first of all to persuade the statutory authorities that the units should be constructed and secondly it will go some way to ensuring that all the objectives of the project are achieved. It is of primary importance that the concept of independent living is not lost in the attempt to bring it to fruition.

The Kingston Project is under the aegis of the Kingston upon Thames Association for the Disabled. ●

For further information contact: Ann Macfarlane, Kingston upon Thames Association for the Disabled, c/o United Reformed Church, Eden Street, Kingston. Telephone: 01-549 8893 (Monday and Thursday 1.30 to 3.30, Wednesday 10.00 to 4.00)

BCODP standing committee HOUSING

The British Council of Organisations of Disabled People, founded last year during IYDP, brings together in one body many of the diverse national organisations that disabled people themselves control. It is a representative group of disabled people, democratically controlled.

The BCODP is disabled people working together to improve the conditions in which we live. If you are disabled, the BCODP is your national coordinating organisation.

One of the standing committees of the BCODP is concerned with:

HOUSING AND COMMUNITY SUPPORT

* In the 1980's housing in Britain is in crisis.
* Last year around 75,000 households were officially "accepted" as homeless.
* New housebuilding is at its lowest peace time level for 60 years, and more houses are falling into disrepair than are being improved.
* More than 1.25 million people are on Council waiting lists.
* In this situation, people who have the least say in provision, and command the least resources are the worst affected, ie elderly people, immigrants, single people and "the disabled".
* 20,000 disabled people under 65 are living in residential institutions other than subnormality or psychiatric hospitals.
* Probably some 300,000 elderly disabled people are living in residential homes and long stay hospitals, many due to homelessness, bad housing, or lack of minimal personal support.
* Despite policies of increased "community care" , residential care still accounts for the predominant part of the resources used by Social Services Departments. Community services have been constantly diminished since the early '70s by savage cutbacks in public spending.
* Most physically impaired people, including elderly people, do not want to live in institutions.

DISABILITY = BAD HOUSING, LITTLE HELP, NO CHOICE

BCODP ACTION.....

Together with the national housing group, SHELTER, the BCODP is running a joint campaign to improve housing and living conditions for disabled people.

So far ten Housing Associations ar participating in the campaign, and specific projects are being planned in:

Leicester, Nottingham, S.London, N.London, Liverpool, Cardiff, Walsall, Newcastle, Salford and Leeds.

With modern resources and technology there can be no doubt that integration in the community is a realistic possibility for ALL disabled people. The BCODP supports local initiatives to set up real alternatives to segregated institutions, so that disabled people can choose how thay live.

To achieve this, the BCODP campaign rests on two main principles:

1. That suitably designed and equipped housing must be accompanied by appropriate arrangements for personal support.

2. That disabled people working together in their own locality must decide for themselves how their own housing and help needs should best be met.

* * * * * * *

If you are concerned about the housing needs of disabled people in your locality, the BCODP exists to support you. Our campaign is about your views.

Contact your local housing group. If there is no organisation working on housing and disability in your area, start one.

Contact us:

BCODP Housing Committee, c/o 5 Crowndale Road, London NW1 1TU.

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National Council for Voluntary Organisations 26 Bedford Square London WC1B 3HU Tel: 01-636 4066

Housing and Community Care

- What should be the proper aim of community care?
- Why are so many people in institutions, emergency or special accommodation, who are capable of living in ordinary housing?
- What changes are necessary in housing policy if community care is to work?
- How can we develop a more flexible and varied range of support services?

These issues are explored in Housing and Community Care, a report from NCVO's Policy Analysis Unit by Andrew Purkis and Paul Hodson.

The authors document the growing numbers of people with special needs to be met in the community: elderly, disabled or mentally ill people, addicts, ex-offenders and many groups of single homeless. They examine the major obstacles to a more normal and autonomous life for them and for caring families.

The report argues that the vast majority of people in special needs groups need decent, ordinary housing. It calls for a major shift in housing policy to take account of the needs of single people and other small households, including elderly owner-occupiers.

Housing and Community Care also proposes a radical diversification of social support services, with a major role for voluntary organisations as part of a strategic approach planned and funded by the statutory sector.

This is a major report bringing together ideas and experiences from many different agencies and client groups. There are recommendations addressed to both central and local government, and national and local voluntary organisations.

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3 chapters from
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by Andrew Purkis and Paul Hodson
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18. Care and Support

When work on this report began, our main interest focused on the potential of such provision as sheltered housing and housing association special projects, offering specially tailored environments for the delivery of advice, support or care outside traditional institutions. This assumption reflected a common tendency to discuss how much was being achieved for this or that group in terms of units of special provision – so many mental handicap hostel places, so many units of wheelchair or sheltered housing, so many million pounds for a 'hostels initiative', so many houses reserved for a particular client group. Surely, it might be thought, a review of housing and support for special needs groups would be mainly concerned with special housing?

The perspective that emerges from our overview of needs and services is different. The vast majority of people in special needs groups have ordinary housing needs, many of which cannot be met on current trends. That is why such emphasis has been placed on sound general housing policies. A considerably smaller but still substantial number need some sort of aids, support or care, beyond the services available to all citizens, to enable them to cope. Of these, only a much smaller minority require the kind of support or care which can only be delivered in special housing or institutions.

This is not to deny that special housing projects are one vital ingredient in developing community care. It has indeed been stressed that a far greater diversity is needed in available emergency services, in short-stay accommodation combined with information, advice or more specialised counselling or care, in staffed and unstaffed hostels for rehabilitation, or in group homes with different levels of support. The scale and variety of need, though relating very much to a minority, is nevertheless far greater than is catered for today.

But what many more people require urgently are schemes offering more diverse, flexible and sensitive support to individuals and caring families in ordinary, long-term housing. It is services linked to ordinary housing which could prevent so much unnecessary recourse to acute services and special environments. It is support at home that offers most people the best chance of autonomy and as normal a life as possible; and its absence that, as we have seen, forces so many to depend unnecessarily on unsupported carers, institutions or special treatment.

How, then, to set about multiplying care and support services not only in specially tailored environments but also for the far greater numbers in ordinary housing? There are no pat answers. The way forward lies in encouraging a radical diversification of services and initiatives, building on good practices and testing out new ones. The problems are not amenable to any master plan.

We begin with the issue discussed in Chapter 13: one precondition for improving care and support in the community is evidently to sort out the relative responsibilities of central and local government.

Between Two Stools: the Central/Local Government Split

We found two important problems. First, a number of services for people who need bridges back to the community are instead run quite separately by central government agencies. The main examples relate to long-stay NHS patients and people in DHSS resettlement units. Many thousands could take their place in the community. But the existence of separate, central government services maintains such people in isolation and constitutes an extra disincentive to local authorities to take on the task of their resettlement and support. This is, for example, one of the reasons that the sponsors of voluntary projects to house and support ex-NHS patients or homeless people have such extreme difficulty in obtaining topping-up money (funds to cover the support services) from local authorities. The objective, in a nutshell, is to get local authorities to take on more responsibility for support and care in the community for these people; but how?

Part of the long-term answer lies in changing formal responsibilities. We have already proposed, as an ultimate goal, that responsibility for resettling and housing all homeless people should pass to local authorities. And it will be suggested shortly that there may well be a strong case for establishing a national Mental Handicap Service to take the lead in transferring patients from mental handicap hospitals to a community setting. But whether or not these legislative changes are made, the question remains as to where the funds are to come from to build up community provision.

That brings us to the second major issue in relation to central and local government responsibilities for care and support services. Much experience shows that many local authorities are fundamentally reluctant to develop services from their own unhypothecated funds for marginal groups, especially outsiders who have no settled place to live within the community. Incentives and longer-term assistance are needed direct from central government budgets. But these have come only patchily and tardily because of the DHSS doctrine that social services provision must be a local authority responsibility.

DHSS is the central government department most extensively concerned with promoting care in the community, but its thinking about the proper role of central funding for locally managed projects and services is a cause of confusion. The doctrine that social services provision must be a local authority responsibility is linked to a pragmatic concern that once the Department allows a breach in its defences by contributing central finance directly to social services, there will follow a flood of further demands as local authorities try to load spending onto central government (particularly, perhaps, in relation to unpopular groups) by exploiting the precedent. But what does this mean in practice?

It was found in Chapter 13 that the absence of a reliable financial commitment from central government budgets, going beyond temporary assistance, had gravely inhibited the development of community services for long-stay hospital patients, alcoholics, drug addicts and single homeless people. This was all the more frustrating because, it was argued, there were a number of indications of what central funding could contribute: Home Office funding for ex-offenders; Housing Corporation finance to encourage pluralism in public housing; categorical programmes like Urban Aid and MSC Special Programmes, unleashing a great diversity of local initiatives, very much of the kind so badly needed in the field of community care. And, not least, joint finance, promising but limited by tapering arrangements, and the DHSS's own effective but short-lived backing for residential and support services to alcoholics.

What, then, *is* the DHSS policy on where its financial responsibilities in relation to local community care projects begin and end? What is the justification for insisting, save in exceptional cases, that social services should be funded in the long term exclusively by local authorities? What criteria define the exceptions? Do recent signs of flexibility, in relation to provision for homeless people in London and also to ideas for expanding joint finance, denote a change of heart? The public is left to guess. There is no statement of policy as to what kind of local project is or is not regarded as warranting DHSS financial support, on what basis, and why. There are said to be administrative guidelines covering these points, but they and their justifications remain a secret. It would be helpful if DHSS would publish a detailed policy statement, both to dispel confusion and open their working assumptions to questioning and debate. The circumstances in which central government funds should be deployed in support of community services is a question of great importance to the future of community care policies and might perhaps deserve attention from the House of Commons Select Committee on the Social Services.

Meanwhile, it is hard to discern why funds from central budgets should not in principle be made available to help in the development of more diverse care and support services on the ground. Outsiders need bridges back to the community: because their destination is within the community, the management responsibility of those bridging services should be local, offering direct links to other local people and services; but because their starting-point is outside, it is unrealistic and even unfair to expect local authorities to pay by themselves. The financial responsibility must be shared. If the permanent purpose of particular services is to receive and resettle people who have become detached from any local community, it seems on the face of it that a permanent contribution from central government budgets is also in order. Hence the problems posed by current restrictions on joint finance and other examples of purely temporary aid.

Our conclusion is that if resources are to be found *at all* to develop community care and support services for outsiders, that will have to involve a relaxation of current restrictions on the use of central funds. A removal, in particular, of the present limitations placed on joint finance and other NHS monies, as outlined in DHSS consultative document *Care in the Community*, together with a somewhat bolder deployment of DHSS funds in support of local community care projects for single homeless people, drug addicts and alcoholics as well as former NHS patients.

And what of responsibility for preventive services? It would, after all, be paradoxical if efforts were stepped up to enable people to move *out* of traditional institutions and social isolation if others, for want of timely support in their homes, were moving *in*. Of course, the lion's share of responsibility for preventive services must continue to fall on local authorities, but the need for diversification is so urgent and wide-ranging that it would be a pity if purist doctrine about local and central government responsibilities were allowed to rule out a modest leavening of central funds. Moreover, it is to the financial advantage of central government departments and the NHS - not local authorities - to reduce the long-term pressure on hospitals, prisons and hostels for homeless people. This interest should be recognised in considering whether a central funding contribution may sometimes be appropriate when it comes to the crucial, preventive aspects of developing community care.

Overcoming the Central/Local Divide

From these conclusions about the appropriate roles of local authority and central government we derive the following specific proposals.

(1) DHSS should clarify in a public policy document the rationale of its policy on funding for local community care projects.

(2) Joint finance should be amended and extended, along the lines outlined in the DHSS document *Care in the Community*, to allow more and longer-lasting support from central budgets to community services. There should be no maximum period stipulated as a universal rule for joint finance of revenue costs of schemes.

(3) The sums earmarked within NHS allocations for joint finance should be increased. Otherwise, many health authorities would probably not make use of any relaxation of the rules, preferring instead to spend money exclusively on NHS services. Earmarking is the incentive to give some priority to community care.

(4) The amended joint finance mechanism could also be used to make extra funds available earmarked in more detail for specific purposes, e.g. provision for drug addicts or alcoholics.

(5) Health authorities should be enabled to make lump sum or annual payments to local authorities and voluntary organisations, another of the options outlined in *Care in the Community*. Particular advantages are that ex-NHS patients, individually financed in this way, could be

catered for by a local authority even though they have no connections with any particular local authority area; and that direct arrangements can be made also between health authorities and voluntary organisations to transfer a patient to community provision.

(6) The division of responsibilities for the homeless and rootless should be removed as soon as practicable; in the long run responsibility for receiving, resettling and housing the homeless properly belongs with local authorities. Meanwhile, the staff of DHSS resettlement units should make what efforts they can to ensure that people in the units are put in contact with the community services they may need, and that those who may be eligible for housing under the 1977 Act are brought to the attention of local housing departments.

(7) There is also a case worth considering – without holding up action on other fronts – for a new National Mental Handicap Service. This would be asked to assume the responsibilities of regional health authorities in the field of mental handicap and to take a more vigorous lead than might otherwise be expected in applying NHS resources to developing a social model of care for those currently in hospital.

(8) There should be a central fund specifically designed to promote innovation and diversity in the field of community care, to complement other sources of funding. This fund would be applicable to preventive projects as well as those enabling transfers from institutions to the community; available to help capital or revenue costs of local projects; be administered by an independent body with charitable status, able to attract private as well as public funding; and receive grants from both DHSS and other government budgets. We return to this suggestion in more detail later.

(9) This community care fund would be one mechanism through which to make central funds available to projects for single homeless people as well as other outsiders, but there would be a complementary requirement to make additional funds directly available to local authority housing departments specifically for the purpose of receiving, resettling and housing all homeless people.

It is clear that most of these proposals involve making more resources from central budgets available for community care. Of course that will not be easy, but it is not impossible. The sums involved are not so daunting when compared with the massive flows of funds into the acute services of the NHS, to take but one example. If it is decided to accord higher priority to developing community care, these are the kind of steps which must be taken to tackle the obstacles posed by the central/local divide.

Co-ordination – a Mixed Blessing?

It was shown in Chapter 14 that a further series of difficulties in developing care and social support in the community was caused by vertical barriers, separating different departments and agencies from each other. It was noted that housing needs are a matter of social and emotional, as well as physical requirements; and that too often this interaction is ignored. Rigid distinctions between 'housing', 'social services', 'education' or 'work' must be melted if special needs are to be met in a community setting. The transition from an institution or social isolation, where needs are all met within one building or not at all, to a community setting where they are divided up between different bureaucratic departments and agencies, certainly calls for hard work to improve effective co-ordination, if needs are to be met in the round.

We also noted, however, that co-ordination is not an end in itself and no substitute for action. Generalised exhortations in favour of co-ordination tend to be ineffective. Interpreted bureaucratically, co-ordination without specific action in prospect and money to spend can mean policy-making machinery which is remote from practice on the ground and which runs out of steam. Joint finance, for example, did more than years of exhortation to promote purposeful collaboration between health and local authorities.

A further pitfall is to construe co-ordination as primarily a matter between government departments. This perpetuates the mirage of statutory bodies working out the answers to social problems, rather than supporting the much wider process of social caring of which families bear the main brunt, to which voluntary action makes a major contribution, and of which the autonomy of users themselves is a key objective.

Purposeful Collaboration

One encouraging practice which could be extended more widely is that of cross-departmental postings within local government. These bring new skills within the bosom of the host department and give the worker independence and scope to develop a consultancy role based on familiarity with user wishes and inter-departmental contacts. Thus, the London Borough of Lambeth have greatly improved the design and allocation of their houses for disabled people by employing in the housing department an occupational therapist from the social services department. Lewisham and Hammersmith have similarly improved their services to old people through Housing Advisers for the Elderly with social services experience who are concerned with old people's social as well as physical housing needs.

It is at the relatively mundane, day-to-day level that purposeful co-operation between workers in different agencies in consultation with users can be most effective. For example, the DHSS/DOE/Welsh Office Joint Circular (DOE 59/78) improved the definition of the borderline between aids for disabled people to be provided by social services departments and the major adaptations which became the responsibility of housing departments. But the procedure by which (say) an occupational therapist gets the housing department to adapt the house of a client may sometimes be too dependent

on high-level approvals to be speedy. Frequent and informal inter-agency meetings to discuss individual cases and schemes seem to be more promising. An encouraging example is the operational procedure worked out between the environmental health department of Basingstoke and Deane Borough Council and the social services department of Hampshire County Council which enables environmental health officers and occupational therapists to work together with disabled owner-occupiers to provide a package of aids, adaptations and repairs.[86]

Two specific areas of work where this review has found a need for better inter-agency operational arrangements warrant special mention. One is the application of the 1977 Homeless Persons Act in housing vulnerable single people. It is a complex task to assess vulnerability, requiring the help in many cases of health, social and probation services. Yet that help is sometimes either not called on, or not forthcoming. The other concerns local authority nominations to individual units of housing association accommodation for old or disabled people. Housing or sometimes valuation departments usually have the right to nominate to 50 per cent of units, but often these nominations are taken up slowly if at all. As a result houses stand empty or are hastily allocated to people known to the housing association. Housing associations, housing departments and social services departments in many areas would benefit from better machinery for working together, so that people whose pressing need is known to social services could more often be offered housing association accommodation.

Some encouraging initiatives of another kind involve the establishment of cross-departmental and inter-agency task forces focused on specific problems. For example, Lambeth council has set up a unit to tackle the needs of young, single homeless people bridging social services and housing departments and reporting directly to both committees. On a more ambitious scale, Oxfordshire Joint Care Planning Team developed an inter-disciplinary project to test out alternatives to residential care for elderly people living in the county. The project team comprises two social workers, a district nurse, a community psychiatric nurse and flexibly deployed domiciliary care assistants. But the team works by first identifying existing carers, including informal networks, and considering how their support might be modified.[87] It is worth noting that this project had the motivation not only of specific and urgent objectives but of joint finance.

This is not to deny also the importance of standing inter-agency machinery, working at the strategic level – where there is continuing money and action in prospect to galvanise it. We shall see that this is the case, for example, with bodies bringing together statutory and voluntary agencies to co-ordinate the approach to local housing problems for particular groups: an important incentive has been such crocks of gold as Housing Corporation funding, Home Office grant for ex-offenders and Urban Aid. If the aim is effectively co-ordinated action, it is incentives rather than exhortations which need to be multiplied; and incentives embracing non-statutory as well as statutory initiatives. Indeed, voluntary organisations have a particular responsibility to promote active inter-agency collaboration themselves, because they are client-based and are not prevented by departmental boundaries from seeing individual needs in the round. We return later to this issue of collaboration between voluntary and statutory sectors.

It might be argued that all these good practices and wider strategies are not enough; that central government should require different agencies to set up co-ordinating machinery to pull together policies towards a particular group or groups. We note the recent recommendation along these lines by the NACRO study group on Young Homeless Offenders, which deserves careful consideration. There are some difficulties. Central directives do not necessarily lead to effective action on the ground – witness, as one example, the much-neglected part of the 1977 Housing (Homeless Persons) Act which says that social services departments should where necessary co-operate with housing departments in dealing with cases of homelessness. Moreover, one cannot compel people to be motivated to collaborate: formal machinery may be set up, but whether it is put to vigorous use or runs out of steam is another matter. There may be problems about selecting one kind of need for this treatment rather than another.

All in all, it seems that the best approach in the long run lies through incentives rather than compulsion; incentives, for example, in the form of conditions attached to eligibility for specific funds. Thus, it could be a condition of disbursements from the proposed community care fund that support for a project proposal was demonstrated from other relevant agencies. Funding opportunities – something worth collaborating over – can give the motivation to co-operate in a purposeful way and yet allow room for local variations in the means that are chosen. And a leavening of funding from inter-agency, categorical programmes, may be particularly valuable in providing incentives to inter-agency action.

Beyond Standard Solutions

The problems just discussed were about how to meet individual needs in the round, rather than in fragments. But an analysis of existing care and support services in the community showed that an equal problem is how to address individual needs rather than stereotypes; how to match the tremendous diversity of individual requirements rather than settle for a limited range of standard services.

Thus, the home help service and meals on wheels are in most places offered as a standard package. This can nowhere near meet the variety of needs of caring families, or of clients whose requirements for assistance do not fall neatly in the days and hours that home helps are available. We identified a desperate shortage of flexible schemes for helping individuals and their carers in their own homes; schemes capable of adapting to the particular

circumstances of each case, working to sustain informal care where possible, of providing company, advice, practical assistance, tending or nursing, over shorter or longer periods.

It is the general sparsity of such schemes which not only imposes heavy burdens on unsupported carers, but erodes the capacity of the community at large to enable people to live as autonomously as possible. Many people, it was argued, are forced to depend exclusively on relatives, or to resort to acute services, institutions and other special provision, for want of diversity and flexibility in the support available to people at home.

Equally, it was shown that a good deal of community residential services aimed at particular client groups were also in danger of being applied as standard packages. For example, sheltered housing has been a widespread response to the housing needs of old people, but it is far from clear that many of its occupants need or want all that the sheltered housing package involves. Very sheltered housing for the frail elderly could become another blueprint solution. Local authorities have developed large numbers of hostels and Adult Training Centres (ATCs) for the mentally handicapped over the last decade, but this has been by no means an unqualified success, because they have been based on a small number of blueprints and cannot match the complexity of what is required by so many different people. For example, ATCs have generally failed to find ways of moving many trainees into open employment and other settings beyond ATCs.[88] And the standard local authority hostel for the mentally handicapped is a sad contrast to the individually tailored services, delivered to people in ordinary housing, which are now beginning to be developed in a few areas.

We also underlined the importance of diversifying away from any particular model of staffed hostel for the single homeless into a range of services to cater for people's requirements for very different kinds of support and care and of shared or self-contained housing. A further requirement is to reduce the current dependence on residential services classified by client group.

Indeed, community care should be about responding to individual needs, in contrast to the inherently standardised model of care in traditional institutions. But there is a long way to go to achieve this. What is the best route forward to a much more diverse pattern of community services? The answer certainly does not lie in seizing on a narrow range of blueprints and mass-producing them, but in a constant process of innovation, experiment and diversification. This in turn involves investing in a plurality of agencies and individuals to develop services offering variety and choice.[89] This is the approach on which the next chapter expands in more detail.

19. How to Develop Community Care

The Role of Voluntary Action

Many of the small-scale and diverse services developed for special needs groups by voluntary organisations are among society's most valuable assets in the effort to diversify and improve community care. In this field as in many others, voluntary organisations have responded (though in a patchy way) to emerging needs with which legislation and statutory bodies have yet to come to terms. Flexible support schemes to people in their homes; community services for alcoholics; projects to help the young single homeless; schemes that combine housing and support with employment opportunities, are just a few examples. A strategy for developing community care needs to invest in a multiplication of such initiatives – not as random and isolated projects but as an integral part of a concerted, collaborative effort between statutory and voluntary sectors.

This report suggests four priority areas for expanded investment in voluntary action.

(1) *Flexible support schemes for people at home and for caring families*

These must come high on any list. Home is where most people need help and where most want to be. It is in schemes of this kind that the best hope lies of avoiding unnecessary recourse to institutions and special environments, while at the same time recognising and alleviating the tremendous burden borne by caring families; though such services need to be combined with a fairer system of financial allowances, particularly for married women who are caring for others or who are themselves disabled. The current campaign being waged on this issue by the Equal Opportunities Commission deserves widespread support.

Examples of flexible support organised by the voluntary sector include Crossroads and the Leonard Cheshire Family Support Services which address the needs of carers of physically handicapped people. There are other local schemes run by voluntary organisations to give periodic relief to parents of mentally handicapped children. These schemes all operate through support of informal care. On the other hand, the 'One to One' schemes of Community Service Volunteers involve direct work with individuals. Community Service Volunteers do anything from living in a hostel for homeless young people to working in teams of four doing whatever a severely disabled person asks of them. No social services department could easily give this time or flexible service except by investing in such schemes.

Another area where voluntary organisations

have advantages which must be used to the full is the *continuing social support needed by people who are trying to settle down in independent housing* after a period in institutions. Thus young people leaving childrens' homes often reject the authority represented by a social worker and yet are ill-prepared to cook, shop and organise for themselves; organisations such as Dr Barnardo's 'Sixteen Plus' project have been able to help. Similarly, the Lance project in Manchester found that NACRO's Onward Workshop was much more successful at preparing men for taking up regular employment than social services-run day centres which were felt to be stigmatising. Again, it is becoming clear from experience that, when single homeless people move on from hostels to more independent housing, many require continuing contact with a source of support and advice which at the same time encourages self-confidence and independence rather than a client role. This is not a task that comes easily to local authority departments and may fall more naturally to voluntary organisations, like the recently formed North Lambeth Day Centre Housing Support Team (funded by the GLC), or the Cyrenians, who put a lot of effort into helping previously rootless people to develop a stable network of social contacts.

The schemes mentioned so far are aimed at individuals with needs that only a minority of people ever have, or at their families. Very important also are mutual aid organisations through which the same kinds of people come together in groups. These groups are perhaps uniquely helpful when it comes to the need for understanding and friendship from people with common experience and problems – a crucial form of support in coping with life, if less immediately relevant in avoiding recourse to institutions than services delivered to individuals. Mutual aid organisations like the local MENCAPs are themselves heavily involved in direct services too.

Voluntary organisations which address themselves less to such acute or minority needs, and more to the sort of requirements which are familiar as part of a normal life-cycle, are also relevant to developing community care. Good Neighbour schemes seek to draw on the resources of informal care in a particular neighbourhood in order to keep an eye out for problems, provide company and practical help with transport, shopping, gardening or odd jobs. A central aim is to promote neighbourliness in the community. They are usually set up by voluntary organisations such as Age Concern groups, churches and tenants' associations. A recent study of over one thousand varied Good Neighbour schemes found a pattern of mixed success but great potential.[90]

As another example of voluntary action addressed to life-cycle needs, Task Force in London have challenged some of the usual ways of doing things for old people. As well as matching volunteers to people in need, some of their borough teams have worked with local people to set up systems by which pensioners and their neighbours exchange services. And action groups are formed in which old people can campaign on issues like heating costs or welfare advice services.

Efforts like these to assist with practical, social and emotional needs in the community are less obviously relevant to developing alternatives to institutions than schemes which meet individual minority needs. They are nevertheless of immense long-term significance in encouraging informal, neighbourly care and sustaining people's ability to maintain a place in the community.

(2) *Specially-tailored residential care and support*
Schemes of supported housing are a second major growth area for voluntary action. The numbers involved are far smaller but the scope for diversification none the less significant.

Some of the best designed, best managed sheltered housing for old people and housing for the disabled has flowed from the voluntary sector. Voluntary organisations run many of the hostels and group homes for ex-offenders, alcoholics, mentally handicapped people, mentally ill people and the single homeless. It is very important that voluntary organisations should continue to build relationships with local authority housing departments and seek access to their great stock of housing for these purposes, linked to allocations of permanent accommodation to which individuals can move on. But there is also scope for the continued expansion of housing association special projects undertaken in association with a voluntary organisation, and the Government's annual earmarked allocations of Housing Corporation funds to such projects is very much a step in the right direction. This is the right kind of incentive to rapid diversification of alternatives to institutions or social isolation, and of bridges back to the community.

However, the multiplication of housing association special projects carries some implications which are worth noting before we consider further growth points for voluntary action.

First, there is a continuing task to unravel the red tape in which special projects have in the past been tied. This process is what the NFHA's Special Projects Steering Committee is there to try to encourage, and it is through them and the NFHA's Special Projects Officer that the many detailed difficulties besetting such projects are best pursued with the authorities. There have already been very many improvements as teething troubles are gradually sorted out. One general observation may suffice here. Double scrutiny of projects (by both Housing Corporation and Department of the Environment) was recently abolished and procedures simplified; it is to be hoped this speeds up the approval of projects and makes their fate more predictable. There may, however, be scope for further progress towards an 'arms length' relationship between the Housing Corporation and the housing associations, in relation to special projects as well as other programmes. Like the industrial companies which Government subsidises, housing associations could be left to run their own business

but be called periodically to account. Close checks throughout the course of a scheme cause delay and tend to put a premium on standard models which involve less protracted bureaucratic negotiations.

Second, the expansion of special projects involves important development and training tasks. Training for staff in schemes of housing and support in the community is better for some client groups than others. NACRO, for example, ran training courses for nearly 2,000 people in 1980/81, including some working with alcoholics and mentally ill people as well as ex-offenders. Such training opportunities are not reaching staff in some projects for some kinds of need, particularly perhaps those which do not have a major national voluntary organisation like MIND or NACRO to take the lead. People working with single homeless groups may be particularly likely to find themselves without any obvious source of continuing advice and training.

The same points apply broadly to development work to assist local projects. Housing development officers in national voluntary organisations find that local projects often need help and advice on such matters as:

- ensuring that needs are accurately and systematically identified before a project is launched;
- considering whether improved access to ordinary accommodation, or support services linked to existing housing, might be a better response than a special project;
- developing the necessary liaison with other agencies;
- making complicated funding and planning systems work;
- how to keep a record of a project's activities, appoint staff, handle public protest, or raise funds.

Otherwise, there is a strong probability that unnecessary mistakes will be repeated again and again. Even NACRO's relatively well developed complement of four national housing officers, and the inter-agency co-ordinating committees covering about half the probation areas, are by no means able to deliver developmental and advice services which match up to the potential need over the whole country.

This is a matter of concern in relation to all sorts of client groups, but perhaps particularly single homeless people for whom no national organisation is systematically involved in developing services. How will projects for the single homeless tap accumulated wisdom and avoid falling again and again into the same traps? And who will come together to form alliances or new organisations to develop more non-specialist provision (as suggested in Chapter 15)? There are in many places relatively strong local organisations ready to take up the cudgels for, say, the mentally ill or mentally handicapped, but few indeed for less well-known groups of single homeless. Councils for Voluntary Service, Rural Community Councils, alliances of local groups involved in housing, are among those who will have to develop answers to these needs.

We conclude, therefore, that if the necessary diversification of special projects is to proceed, an expansion of developmental and training activity will have to be a complementary growth point for voluntary organisations. That will require fresh initiatives from existing and new voluntary organisations and alliances - and financial support from central and local government.

(3) *The combination of employment and work with care and support*

Another key area for voluntary action is the placing of work and employment opportunities alongside care and support. This applies as much to the minority of people who require special housing as to the majority of people who live at home. The statutory organisations responsible for care and support services are bound to be reluctant to get involved in employment matters, which are outside their remit. However, this segregation may be very damaging from the point of view of people who need to feel that they have a worthwhile contribution to make and are not simply dependent on support from others.

Voluntary organisations are in a better position to look for ways of providing work and housing opportunities simultaneously, so that each supports the other. NACRO's 134 Project in Clapham is centred on short-term accommodation as a base for ex-offenders. They are given assistance designed to help find work as well as accommodation for themselves. The maximum period they can stay there is three months, and of 110 men who used it during a sixteen-month period 56 left with jobs and 69 with a place to live.[91] The Peter Bedford Trust in London directly provides both independent housing and, through the contract cleaning company John Bellers Ltd, real jobs for people who have spent long periods in institutions. They are therefore given employment and accommodation, together with support of a style which requires them to take decisions for themselves.

There are many other ways in which voluntary organisations can help open up opportunities for employment and satisfying work - by developing more specialist agencies to place disabled people in open employment, like MENCAP's *Pathway* schemes; creating bridges to employment such as vocational training, or work experience programmes using MSC Special Programmes funding and developing more 'intentional communities' such as those pioneered by organisations like L'Arche.[92] These possibilities are crucial to the potential contribution of voluntary action to ensuring that community care is not simply about delivering services to dependent people but about enabling people to fulfil themselves and contribute to others.

From a different angle, voluntary organisations concerned primarily to develop employment schemes have also found that they can marry this task with meeting the housing needs of young single people. They have combined 'mini-HAG' money from the Housing Corporation, i.e. funds to undertake rudimentary improvements on short-life

property, with MSC Special Programmes funds to provide work for people on renovating dilapidated short-life houses, which people on the MSC schemes can then live in. Examples are Shape Housing in Birmingham and the Brixton Family Housing Association.

It is on short-life property that lower standards permit the use of MSC-funded trainees. Mini-HAG is an obvious source of money for the tools, equipment and so on, and the demand for and availability of short-life property would probably justify the Department of the Environment in restoring the mini-HAG budget to its 1979/80 level of £2 million. But there are alternative sources of funds, including local authority housing budgets and private trusts, which are worth trying in the meantime to complement the MSC's Community Enterprise Programme (CEP). We commend the work of the Housing Emergency Office in London in exploring and promoting the possibilities in this field: possibilities which deserve to be pursued with vigour as part of expanded voluntary action to tackle requirements for support, housing, employment and other individual needs as a whole.

(4) *The initiation and development of inter-agency approaches*

Here is another key role for voluntary action in community care. Voluntary organisations are well placed to look beyond the vertical barriers between different local agencies. It is vital for their own sakes that they do not get isolated from each other or let lack of contact with statutory services set artificial limits to their work. More positively, because their area of concern is not divided up by administrative boundaries, they can use their position to pull together action on neglected groups and to open up statutory bodies to new ideas.

The South East London Consortium has shown one way in which voluntary organisations can do this. As an umbrella organisation for fourteen projects for single homeless people in the boroughs of Lambeth, Lewisham and Southwark, it has been able to put homeless people's needs before the three local authorities more consistently than they could have done as individual projects; and it has co-operated with the authorities to argue for a co-ordinated London answer to homelessness.

Another example of voluntary action in support of inter-agency collaboration is the network of county co-ordinating committees for ex-offenders, in large measure inspired and serviced by NACRO working in close consultation with the probation service and other relevant agencies. These co-ordinating committees cover thirty of the fifty-six probation areas. They include representatives of the probation service, local authorities, local voluntary projects such as those of the Stonham Housing Association and NACRO. Drawing on probation service resources and advice from NACRO's housing development officers they identify what is needed, work to develop new and existing accommodation in a co-ordinated way, and support local projects with advice and training. This is a crucial objective, increasingly important both for ex-offenders and other groups as more needs are met in the community. The Home Office and NACRO set up the groups because in the early 1970s they were concerned about one-off projects becoming isolated or failing in their objectives. They have the advantage of a statutory agency - the probation service - with a relatively clear-cut interest in the client group and an efficient system of central topping-up funding by the Home Office to complement housing finance. It is partly because, with such incentives, the statutory and voluntary agencies involved with ex-offenders co-ordinate and plan strategically that services to clients are more systematic than for other groups.

In some areas of the country Councils for Voluntary Service (CVS) have catalysed committees of people concerned with housing in their districts. Croydon, Harlow, Reading and York are examples of places where CVS have organised the joint planning of housing for 'special needs'. *This suggests an important potential contribution from intermediary bodies like CVS and Rural Community Councils, as well as from client-based voluntary organisations, in pulling action together in developing community care.* For example, they can develop alliances of existing projects and agencies, or support new ones, to promote services for single homeless people or others not covered by specialist voluntary organisations in the area. Similarly, they could lay the groundwork for further development of non-specialist, supported accommodation. Both these requirements are unmet in most areas. There is also plenty of scope for more general brokerage and co-ordination between agencies in each area: are efforts of housing departments and housing associations complementary, or duplicating each other? Do local voluntary and statutory organisations know what can be done through housing associations to provide diverse alternatives to institutional care? Have they discussed their priorities with local housing associations to see what the latter could do? Could local voluntary organisations concert their efforts to put forward for discussion with the local authority proposals for flexible care and support to people in their houses? These are very much the sort of questions which need to be tackled if community care is to be diversified; and intermediary voluntary bodies locally may feel themselves well placed to take a lead.

We have identified four key areas in which expansion of voluntary action appears to be of central importance in the effort to diversify community care:

(1) flexible care and support for people in ordinary housing;
(2) development of accommodation where support or care is on tap, not least housing association special projects;
(3) linking housing and support services to better opportunities for employment and work;
(4) taking a lead in developing inter-agency initiatives.

Efforts across this broad front could benefit from a generalist development agency within the voluntary sector. Good practice is at present fragmented and scattered around the country in different areas and agencies. Funding opportunities and sources of practical advice and information are also diverse. A general development agency would operate across the usual departmental, agency or client boundaries. It could be a valuable resource for local authorities or other statutory bodies (as well as voluntary organisations) wanting information about the good practice, resources and contacts in the voluntary sector on which they could draw, in meeting the challenge of community care.

The Strategic Role of Statutory Authorities

In many of the examples of voluntary projects cited in the last few pages, voluntary organisations have relied in large measure if not entirely on statutory funds. And if voluntary action expands in the field of community care, as we believe it should, it will have to be done through increased investment by statutory authorities in voluntary effort.

It is, indeed, important not to confuse two separate issues. One is whether statutory authorities should invest in an expansion of voluntary action as part of their strategy to carry out the wishes of national and local electorates; we argue that they should. A quite different idea is that voluntary action should be a *substitute* for the commitment of statutory resources and strategic planning; this would be the opposite of what is required. Unfortunately, in some fields voluntary organisations have been used as a patchy and cheap substitute for elected authorities taking on effective responsibilities. This has traditionally been the case, for example, with services for alcoholics or homeless people. The dangers of serving as substitutes for a more systematic approach involving statutory bodies, or of effectively isolating people from the statutory services, are dangers of which most (though not all) voluntary organisations are as conscious as anyone else. It is also fundamental that elected authorities should determine minimum standards and ensure that they are applied by all those involved in service delivery.

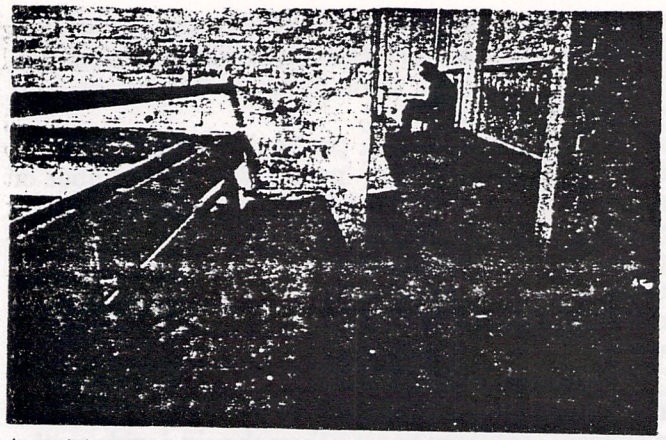
Moreover, many mutual aid organisations and neighbourhood care groups can often benefit out of all proportion from relatively small injections of funds or advice and encouragement from social or community workers, provided that their independence is carefully respected. There are also many circumstances in which social services departments can diversify community care by direct encouragement, support and use of informal caring networks: witness the Kent Community Care Scheme, based on devolving responsibility and resources to social workers who identify informal carers and organise volunteer effort to back them up. Consider, also, the potential importance of paid fostering schemes as an alternative to residential care. It is for statutory authorities with strategic responsibility to make the most of the potential contribution of voluntary organisations where they exist or can be evoked, but also in some cases to forge direct relationships with informal carers to help improve the range and quality of social caring.

It is heartening that, particularly through variations on the theme of 'patch' work, a number of social services departments are developing approaches explicitly based on the objective of identifying and strengthening local resources for voluntary action and informal care rather than concentrating too heavily on casework with individual clients.[93]

What seems important, therefore, is that strategic responsibilities should rest squarely on national and local statutory bodies; they should decide on the fair allocation of resources between different areas and services and the overall policy for applying resources most accurately. It is within such a framework that, it is to be hoped, they will invest in a diversification of community care, supporting informal care and encouraging an expanded contribution from voluntary organisations, particularly in the four key areas which we have identified.

With the exception of ex-offenders, it is clear that this strategic responsibility for local housing and social support services must rest with the local authorities. In the case of local housing departments, it has already been argued that strategies should include renewed investment in housing associations to help meet the need for different kinds of accommodation for single people. It was also suggested that housing departments could usefully support voluntary action in giving advice to elderly owner-occupiers or providing reception and resettlement services for homeless people. But when it comes to the bulk of social caring and support services, the key strategic responsibility should rest with social services departments.

Social services departments can only develop strategies to invest in a more diverse pattern of community care, if they either receive more resources or make them available by cutting back expenditure on existing commitments. We have already made proposals for amending and extending joint finance and other ways of making more resources from the NHS budget available for local authority and voluntary services; and we return in a moment to the question of incentives and support available from other central government programmes. But, though significant, these funds from outside will be relatively small-scale compared to mainstream social services department budgets. As for finding funds from within, the debate goes on about the extent to which it is realistic to expect social services departments to generate savings from greater efficiency or from closing more residential accommodation, with which to finance an expansion or diversification of priority services.[94] What does seem clear is that such savings are increasingly hard-won and fragmentary, that existing services are already inadequate and that the demands on social services departments are growing: the level of resources available to them will need to reflect a recognition of these facts if room is



A waiting room in Camberwell Resettlement Unit, now destined for closure. Credit: Mike Abrahams, Network

to be found for investment in developing community care. It is also very important in assessing priorities to bear in mind that resources for community care are not only potentially the most accurate way of meeting many individual needs, but also prevent demands on more acute services. These points apply also to the work of the probation service and other agencies involved in providing aftercare services for ex-offenders and alternatives to prison.

Incentives for Community Care

Yet it would not be an adequate response by central government to the urgent challenge of community care merely to keep mainstream local authority and probation programmes in funds. Specific incentives are required to encourage a diversification of care and support services. These incentives can be both positive and negative.

There is an important role for *negative incentives*, in the form of firmly planned closures of large, isolating institutions. Because there is a dearth of places in old people's homes, voluntary and statutory bodies have had to seek alternatives. The London Borough of Southwark has forced Camberwell Resettlement Unit to close, and this has concentrated minds wonderfully and given voluntary bodies and local authorities the chance to press for a strategic approach to homelessness in London, involving collaboration between statutory and voluntary bodies and even some topping-up money and capital expenditure by DHSS, to help develop the necessary range of temporary and permanent, supported and unsupported housing. More local authorities could insist that large hostels and other institutions close so that the need for new and better services can no longer be evaded. It has been argued that they should be kept open until alternatives are in operation; this has been said for years and the alternatives, without incentive, have clearly not developed adequately.

Similarly, as regards long-stay NHS patients it may be found that a programme of closures is a precondition for galvanising adequate efforts to develop alternative provision. For example, without leadership committed to abandoning a medical model of care for mentally handicapped people, it is not at all clear that either health or local authorities will find the motivation to find alternative ways of caring for those now in mental handicap hospitals.[95]

In considering the kind of *positive incentives* which would be most helpful, it is worth recalling some general conclusions which have already been suggested about the development of community care:

- more and longer-term funding needs to be available from central budgets, as opposed to unhypothecated local authority budgets, if community services for outsiders are to be properly developed at all;
- there is no apparent reason why a leavening of similar funding should not be made available to the preventive community care services which are so badly needed;
- encouragement to voluntary action, within a strategic framework, may offer the best hope of progressive diversification of community care where it matters most;
- there is a powerful case for approaches which cater for needs in the round - housing, social support, employment, and so on; and for developing more non-specialist residential provision and services for single homeless people as well as more specific client groups;
- inter-agency collaboration in planning is most effectively motivated by funding opportunities.

There are some existing financial incentives which are relevant to one or other of these five criteria; and the case has already been made for maintaining or in some cases expanding them. Important examples are healthy allocations of *Housing Association Grant* for general housing as well as special projects; expanded *joint finance* and other transfers of NHS funds to build up community services; *topping-up money and other resources from the Home Office, and from DHSS as well as social services departments*. Attention has also been drawn to the possible use of *MSC funding* for some aspects of community care. More use could probably also be made in this context of *Urban Aid*. Both the traditional Urban Programme and the Inner Cities Programme are appropriate for local projects which encourage voluntary action and self-help and many more proposals could be submitted. Projects to assist the single homeless might usefully be a priority area.

Another possible source of funds is the *EEC*. The European Commission's policy for disabled people strongly emphasises their 'social integration', and the coming review of its pilot action programme on housing and associated areas will give special attention to housing schemes which 'provide explicitly for greater day-to-day contact between individuals irrespective of their disabilities'.[96] The pilot programme has contributed to several projects in Britain, including the Crossroads Care Attendant Scheme, and is specifically intended to support new ways of doing things. Organisations who have

new ideas in this area will no doubt wish to explore the possibility of a contribution from the EEC.*

During 1982 another new EEC initiative will set up 'locally based development actions'. The EEC will finance co-ordinating teams (two in Great Britain) operating over districts of up to 300,000 people. The teams will include local statutory and voluntary agencies and disabled people. They will bring together policies on employment, training, housing, welfare and the environment so as to allow disabled people to take part in life in their areas. This may well prove a useful initiative; it will be necessary to make sure that the 'direct actions' draw on the experience and imagination of disabled people and the voluntary sector in practice to the extent the Commission intends.

However, although these sources of finance are all potentially important, they do not measure up to the urgency of expanding community care or to our five criteria of what kind of incentives are needed. Housing finance cannot be used for social caring. The use of joint finance or other transfers from NHS at local level may be subject to objections within some health or local authorities, or to disagreements between them over relative financial contributions or priorities. They may be committed in particular areas to a few big capital projects. They may simply not stretch far enough to cover important projects. And they will seldom be available for single homeless people and others who are not current or potential NHS patients. Current sources of topping-up money outside the offender field are inadequate. There are many pressing claims on MSC Special Programmes and Urban Aid – projects to develop community care deserve better than to jostle in these queues and these programmes offer only temporary assistance.

Community Care Fund

We therefore commend the idea recently put forward by NCVO, on the advice of its Health and Handicaps Group, for *a central fund specifically designed to promote diversity in the field of community care, complementing other funding sources, and encouraging inter-agency collaboration including voluntary action.* The main features of such a fund might be as follows:

- it should apply to preventive projects as well as those enabling transfers from institutions to the community;
- projects would have to be designed to enhance the diversity of community provision;
- eligible projects would normally have a strong voluntary component and be submitted by local authorities or voluntary organisations;
- the fund could make capital and revenue grants;
- there would be safeguards against any attempt to use this fund as an easy substitute for joint finance, local authority funding, etc. One of several options would be to specify that applicants must demonstrate that they were ineligible for or unable to secure sufficient joint finance or other local funding.
- the fund would be administered by an independent body with charitable status, free to attract tax-deductible grants from private sources as well as the Government. This would mean getting more out of each pound of public funds.

The use of the fund must respect the key strategic planning role of local authorities: qualifying projects submitted by voluntary organisations would need to demonstrate explicit local authority support.

In so far as the fund was concerned with projects for current or potential NHS patients, Government funding could take the form of earmarked NHS funds, retained centrally. NCVO's suggestion is that it might be worth while to start from an earmarked NHS contribution of around £10 million per year and work upwards thereafter.

But the challenge of care in the community goes beyond NHS patients to include many kinds of single homeless people, alcoholics and other addicts and ex-offenders, and the fund could make a more significant impact if it operated across the whole range of relevant client groups and applied to non-specialist, as well as specialist, provision. It could then attract Home Office and DHSS funds in addition to NHS, and private funds from a wider range of sources. There might also be MSC funding if the fund could apply to work and employment as well as care and social support activities. The Department of the Environment could appropriately contribute in respect of services to homeless people.

The independent charity could become a focus of experience, action and innovation operating across the boundaries which separate different client groups and different aspects of individual need. Relatively modest sums of public money could bring disproportionately important returns in developing key elements of community care.

*Advice on this can be sought from NCVO's International Department.

20. Beyond Special Treatment

One of the basic purposes of community care is to avoid treating people unnecessarily as special cases, identified by what divides them from others. This review has sought to disentangle the real issues from the special needs ideology which has confused a good deal of discussion about the housing and support needs of this or that special group.

It was therefore emphasised that the vast majority of people categorised in special needs groups live in ordinary houses. Their housing needs do not relate primarily to particular disability or weakness but rather to common housing problems and common requirements. It was argued that the key to these needs lay in sound general housing policies, which were thus crucial to the objective of meeting individual needs in the community as an alternative to unnecessarily special treatment.

Another central theme has been that most of those who need some sort of support or care are people in ordinary housing; and that many others, who now find themselves in institutions, special housing or homelessness, could be living in their own private homes if the right support services and housing were available. Hence the emphasis on the priority task of widening the range of care and support services linked to ordinary housing; and of expanding preventive services, rather than waiting for people to become acute cases for special treatment. Hence, too, at the level of public debate, a challenge to the habit of discussing what has been achieved for special needs groups primarily in terms of special provision.

It also followed from taking individual needs as a starting-point, rather than a stereotype of special characteristics, that reproduction of a few blueprint solutions would not do. The suggested strategy for developing community care rested on expanded investment in a diversification of services and service providers, both for the majority in ordinary housing and the minority needing supported accommodation.

Nor was it seen as enough to recognise the variety of individual need when it comes to care and support services. The individuals concerned have much to contribute and do not benefit from being identified by others as, first and foremost, dependent on other people's help. The profound requirement of many for employment and satisfying work is a challenge to be met alongside other needs in the community.

In all these senses the strategy for developing community care should, it is argued, be based on individual rather than special needs. A corollary is to rely less on general assumptions about the requirements of this or that client group and to find out what individuals want.

User Influence

We have already discussed the evidence from general council housing that 'good management' is a concept which cannot be detached from 'user influence'. This is equally true of provision to meet particular needs.

Moves towards helping elderly owner-occupiers to maintain their homes would have been less piecemeal and tardy, had policy-makers paid more attention to consumer views; for 'what is shown more clearly than anything else by surveys is the desire of the elderly to be able to live in the way they want in their own home'.[97] The work of Alan Butler and his team at Leeds University on sheltered housing shows how consumer views can correct policy assumptions: thus, for example,

> 'the work conducted at Leeds would seem to suggest that sheltered housing is chiefly valued by those who currently occupy it because it offers good quality accommodation. The alarm system rarely figures in the consumers' assessment of the scheme. A balanced approach to the housing needs of the elderly would place emphasis not simply upon alarm systems but would include the wider issue of improving the quality of existing stock occupied by older people'[98]

Similarly, earlier progress might have been made away from large institutions for single homeless people, had more attention been paid to the repeated views of users in surveys. These surveys have indeed proved vital ammunition in the continuing and not unsuccessful campaign to shift official views as to what kind of provision should be encouraged.

Close consultation with individual users is equally important in developing community care. This is one of the most encouraging aspects of the work which occupational therapists are increasingly doing to advise on the housing needs of physically disabled people. In the context of group homes or shared accommodation, bitter experience shows what happens unless steps are taken to determine who is happy to share.

There is also no substitute for *independent and detailed* discussion with users as a means of checking whether particular forms of statutory or voluntary provision are achieving their objectives or are suited to the needs of the individuals concerned. This is not at all the same as a cursory 'Are you satisfied?' from the project management or staff. Perhaps this seems obvious, but the fact is that it is relatively rare for either statutory or voluntary bodies to create opportunities for users to express their views independently on the services being offered. This should be an important growth point if community care is really to apply resources accurately to individual need.

Putting Individuals First

A trite phrase, no doubt, but it sums up the purposes underlying the general strategy we have proposed for developing community care, and the specific proposals which follow for accelerating the trend

As normal a life as possible. Credit: Barry Lewis, Network

away from unnecessarily special treatment when it comes to particular items of provision.

It has been argued that, to facilitate as normal a life as possible, even specially tailored residential services should wherever possible be located in homely and family-size housing. This is the antithesis of traditional, large hostels for the homeless and a contrast with many local authority hostels for mentally handicapped people. The Housing Corporation already favours small and homelike buildings in allocating funds for special projects, taking thirty places as the normal maximum for any purpose; and it is to be hoped that this policy will if anything be strengthened rather than relaxed. It is for similar reasons important that wheelchair housing is not concentrated in segregated 'blocks for the disabled', but features instead with mobility housing as part and parcel of ordinary housing development. It is encouraging that, so far as housing associations are concerned, the Housing Corporation has adopted the policy of giving priority, in allocating funds for ordinary 'fair rent' housing, to those who include mobility or wheelchair units within their proposed developments.

We also draw attention to evidence that stereotyped assumptions appeared to play too great a role in the development and allocation of sheltered housing for the elderly. It seems that many old people could be equally or even more happy, if they wish to move from their previous home, in convenient and good quality ordinary housing - if it were available. Proposals to develop more sheltered housing need to be assessed in this perspective - not that more is not needed, but it should not be *assumed* to be the right answer in any particular case. It is an advance that the Housing Corporation allocation for housing for old people will not in future as in 1981/82 be available exclusively for sheltered housing. It is not clear why leasehold schemes for the elderly should be restricted to sheltered housing: they could usefully be applied also to convenient housing without special features.

Turning to housing association special projects, it would be helpful if Department of the Environment, Housing Corporation and voluntary organisations were to discourage repeated references to 'hostels' when what is meant is provision which can include group homes, cluster flats and many other variations: the staffed hostel is already an over-popular blueprint without extra encouragement. More important, those seeking to meet the needs of homeless people or particular client groups should consider most carefully whether a special project on a standard model is the solution most likely to enable an autonomous and normal life in any particular case. Health authorities, for example, may often prefer to sponsor individual patients to find a place in non-specialist accommodation, supported if necessary, in preference to a place in a standard hostel. Voluntary organisations will no doubt want to assess critically proposals from housing associations who may want to take advantage of allocations for 'hostels': it is up to voluntary organisations to call the tune as to what is most suited to the needs of the potential residents. Perhaps allocations of council or housing association fair-rented property, together with support services, might be more appropriate? Or a supported landlady scheme? Or a more self-contained form of supported accommodation than that proposed? Or perhaps the main local need is for non-specialist, rather than specialist projects? Voluntary organisations may find themselves better able to sort these questions out in inter-agency alliances, rather than by themselves.

We have also noted the importance of ensuring that a special project is linked to a source of permanent housing, lest the project becomes silted up with people who need not be there. Housing Corporation plans to favour ordinary fair-rent schemes which include units specifically earmarked for people moving on from special projects are to be welcomed. The Corporation might consider becoming progressively more strict in insisting that special project schemes for short- and medium-stay supported accommodation should, to qualify for funding, show evidence of available move-on and permanent housing.

Finally, not only non-specialist supported housing, but mixed communities of those who do and do not require support, should surely feature more prominently as community care develops. The proposed Community Care Fund should help this trend. The relevant statutory authorities are urged to give this consideration in applying their funds.

Emphasising Autonomy

A further, detailed aspect of questioning the special needs approach relates to style and attitude in delivering and designing services. It was noted earlier that perceptions of people as dependent clients can be self-validating and impede the growth of their confidence and self-reliance. This can be a pitfall of professionalism, and much work is needed in assessing how to achieve styles which emphasise autonomy rather than dependence. Where people do need help - with washing and using the toilet, with budgeting, with sorting out their life - the way in which it is provided can add to their independence. The philosophy of the Community Service Volunteers 'One to One' schemes is

that the helpers should do what the users require, the opposite of a service delivered by a professional to a dependent client.

The Crossroads schemes not only give carers some of the independence to which they are entitled; they also diminish the psychological dependence of disabled people on a single person, and do not replace it with another dominance relationship since the help given by Crossroads attendants is simply that requested by the carer or the disabled person themselves. In the same way good supported residences for single people try not to limit their residents' independence with regulations, and the staff can encourage independence. For example the report on the Lance project in Manchester states that,

> 'The Lance houses are run on lines designed to give residents the maximum of independence ... And residents have their own keys and keep their own hours. People are encouraged to find work or other occupation during the day and are expected to do their own housework.'[99]

Where staff do not adopt this philosophy places are more likely to become mini-institutions creating dependence in their residents. This is not simply a question of abstract ideals: NACRO's experience is that most ex-offenders, given encouragement and advice, are more successful at finding jobs and housing than professionals trying to act on their behalf.

Special Treatment in its Proper Place

Such are some specific proposals for modifying current forms of special treatment in the community and putting individuals first. These proposals complement the wider strategy put forward for meeting needs of people who are elderly, physically or mentally disabled, homeless, addicts or offenders, so that they take their places wherever possible as autonomous members of society, exercising choice, enjoying rights and contributing to others. The main challenge, in housing and in social support, is not simply to widen the range of responses to particular handicaps and disabilities but to attack the obstacles - defects in the framework of rights, resources, responsibilities, and perceptions - which stand in the way of treating people as, first and foremost, individuals with common human needs. Special treatment, whether in institutions or outside them, is too often a reflection of inadequate housing and social support services to citizens in ordinary homes. That is why sound general housing policies and a diversification of care and support to people in ordinary housing should feature more prominently on the agenda for developing good community care.

None of this is to imply that there is no place for institutions or special housing. Of course, we need well run hospitals, prisons, and supported accommodation including specialist hostels and group homes - but not for those who could live more normally. The recommendations that have been made, which are now summarised and addressed to the relevant agencies, are intended as a contribution towards the wide-ranging programme of measures which will be required if adequate community care policies are to be found and special treatment put in its proper place.

GROVE ROAD HOUSING SCHEME - SUTTON IN ASHFIELD

1. Origins and Aims

The inspiration for the scheme originated with physically handicapped people whose primary aim was to create the conditions whereby they could get married and lead lives integrated into the community, enjoying the same rights and responsibilities as ordinary citizens.

2. Objectives

The severity of their handicaps would, in the absence of family help, place the people concerned at risk of institutional care. Since the aim of the scheme is generally counter-institutional in character, brief reference to some of the basic features found in institutions for the physically handicapped is necessary as a preface to the main objectives:

(i) Institutions disable physically impaired people by taking them out of the community and aim to cater for their physical needs in batches, under the same roof and under the same regime.

Thus the scheme had to be physically blended into the local community and cater for handicapped tenant's needs in the privacy of their own homes and in a way which supported their individuality.

(ii) Institutions are provided ostensibly because local domicilary services, by themselves, are insufficiently comprehensive and flexible to meet the physical needs of severely handicapped people in the community.

Thus the community based alternative scheme had to embody a system of help sufficient to make up for the deficiencies in locally available services in meeting tenants physical needs.

(iii) Institutions have paid staff who organise and provide help which is theoretically available to inmates all the time whether or not it is wanted by, or appropriate to their real needs.

Thus the help provided in the scheme should correspond to the help needed. Handicapped tenants will best know their own physical needs, but since the dependency situation involves a relationship between the helper and the helped, the organisation of actual and anticipated care should be a co-operative effort. Payment for help given should not be controlled by any outside body.

(iv) Institutions are dependency oriented. Staff see themselves in a primary helping role and inmates as the dependent recipients of care. Comprehensive aids to individual independence are rarely provided - or, if provided, used - by either inmates or staff.

Thus the scheme should be oriented towards the independence of handicapped tenant's. Helpers should see themselves primarily in a supporting role. Aids and equipment should be provided, as available and appropriate.

(v) Institutions occasionally allow inmates opportunities to present limited views on aspects of organisation. But democratic participation in areas where inmates can usefully contribute is often actively discouraged.

Thus maximum opportunity should be afforded to all tenants to bring their personal resources into the scheme and actively participate and exercise effective control over a living situation which has potential for a strong sense of community.

3. **Concept**

The aim and objectives are planned to be realised through the provision of three ground floor flats specially designed and equipped for physically handicapped tenants, in conjunction with three first floor flats for able-bodied 'supporting families' who will co-operate together in supplementing locally available domiciliary services in meeting handicapped tenants needs.

4. **Co-operative Principles**

A substantial degree of co-operation between the initiators, the Housing Association's architect, the local authority, potential tenants and others has brought into being a building which embodies the above concept.

Continuing co-operation is seen to be necessary between the tenants representative body and the Housing Association, while the scheme is in operation. The function of each of the parties in matters such as tenant participation in management and the provision of services, should be clearly defined. It is felt the Association should accept the need to advise and support tenants through access to their specialised managerial/technical skills.

Full inter-tenant co-operation is prerequisite to the smooth running and long term stability of the scheme for the following reasons:

(i) To meet known and anticipated handicapped tenants needs within the context of a scheme which secures no one in particular full-time source of help - and where help will be required intermittantly over the course of the day.

(ii) To make maximum use of the opportunity to reduce pressure on supporting families, by spreading the load as efficiently as possible. This will increase flexibility of opportunitity for supporting families to pursue their own interests within the limitations of their undertaking to provide necessary support.

Co-operation between tenants and the local/area health authority services will be a continuing responsibility.

5. **Tenant Responsibility**

A high degree of co-operation at a number of levels - some particularly personal - will characterise the concept in operation.

It is considered essential that potential tenants should display an understanding of and commitment to the special undertakings and levels of co-operation in the scheme.

The Tenancy Agreement should incorporate a statement which makes plain tenants responsibilities for full inter-cooperation in maintaining a satisfactory level of help.

6. **Continuity of Help**

Given such a substantial degree of inter-tenant co-operation, disagreement between tenants could lead to breaks in the continuity of support. A framework within which disagreements can be approached has been suggested as a basis for democratic discussion within the Tenants Group (7.). The procedure which emerges will need to be agreed with the Housing Association.

The tiers of support listed overleaf indicate the extent of a fall-back in the event of care failure.

Continuity of Help (continued)

(i) Participation by physically handicapped tenants in the development of good design and the incorporation of the right aids and equipment in the scheme, will lead them to maximise their own potential for independence. Their own self-sufficiency will be the first line of support.

(ii) Home Helps and Community Nurses provided as part of the locally available domiciliary services.

(iii) Three supporting families co-operating to give help act covered by (i) and (ii) above.

(iv) Voluntary support co-ordinated through a 'local liaison committee' or a sub-committee of the Tenants Group. WRVS support has been agreed in principle by the local District Organiser.

(v) Relatives and friends, some of whom live close to the scheme.

(vi) Selective hire of an agency nurse in conjunction with financial help appropriate to the individual circumstances of handicapped tenants.

7. **Tenants Group**

Given the ability and desire of some tenants to participate more actively than others, it is nevertheless considered important that some degree of participation should be accepted by all tenants in matters relating to management/organisation of help in the scheme. Involvement in, and indentification with the scheme will be key features in the development of strong community spirit. A direct democratic basis to the Group's operations should be possible given the small number and proximity of the units - and this basis will help prevent control lying with a small minority.

The Association should accept the Tenants Group (or elected officers thereof) as the representative body in its official dealings and consultations with the scheme.

Some of the more important aspects of the Group's activities which can be forseen are:-

(i) To discuss the need for a Constitution which properly defines the Group's functions.

(ii) To act as the medium through which the organisations of day to day routines of help can take place.

(iii) To act as the medium of mutual education of common needs and difficulties arising out of the dependency situation.

(iv) Agree on a framework for the handling of possible intertenant (or external) disputes including provision for independent arbitration.

(v) To set up an agreed system of payment for help given and received.

(vi) To consider the need for setting up a Sub-Committee, involving links with local support sources.

(vii) To monitor the progress of the scheme.

CD/JH
25 July 1977

The Milton Keynes Community Care Service : Glyn Vernon

Introduction

The Milton Keynes Community Care Service is a project set up by the Spastics Society in Neath Hill, a perfectly ordinary housing estate in the new city of Milton Keynes in the South of England. 24 flats on Neath Hill have been specially designed for use by the physically disabled and most of the people living in them are severely disabled, some needing total care. The care needed by these people, such as myself, is provided by a team of part-time Care Assistants, prepared to do anything from toiletting to cooking meals, who work from a central point, an ordinary house on the estate, under the supervision of a Care organiser.

The flats are all connected to the central staff house by an Intercom system on which any of the residents can call help at any time day or night. The idea is to create an environment where handicapped people can live independent lives in a normal community.

General Points

Most of the residents in the Neath Hill Project come from more conventional Part Three accommodation and indeed, because of the way it has to be financed, Neath Hill itself is technically Part Three. Each flat is registered separately. This provides a secure financial base for the project. However, I must admit to feeling a certain vulnerability, living under Part Three. The Care Organiser is ultimately responsible for you, and this means that he or she has real power to impose herself or himself on the lives of the people living in the scheme. The present Care Organiser is very aware of this potential and carefully avoids falling into the trap but the very thought that it could possibly happen in the future is one of my few serious misgivings about the scheme.

The scheme does have other drawbacks, all of them stemming from the technicalities of Part Three, or from the original planning of the flats. For example, although the scheme takes married couples, because it is Part Three and everyone living in it has therefore to be disabled enough to qualify for local authority Sponsorship, both married people have to be fairly severely disabled. And because the flats are single bed-roomed, it would be a practical impossibility for any of the couples living there to have children!!!

However, within these technical limits, the scheme does provide a base from which people have every chance to integrate into the growing community of Milton Keynes. The City has been built during the last ten years, and every effort has been made to accommodate the needs of the disabled. For the most part this planning has been well done, with the result that whatever else one might think of this dream city, it is paradise for those of us who get around on wheels instead of legs. This means that disabled people flock to the place and wheelchairs being such a common sight, I believe the general population is more attuned to disability than in most places I have lived in. So any success or failure in successfully integrating is really down to the people themselves.

However, very few of the people living in the Neath Hill Scheme, had previous experience of living in the community and it takes time to build up the necessary Social confidence and expertise required to take full advantage of the situation. But the signs are that a significant success is being achieved at Neath Hill.

Conclusion

I feel the ideal will only have been achieved when those living under the scheme are themselves tenants, with all the rights that entails. However, in order to achieve this ideal a fundamental change would have to take place in the way care is funded in England, and I suspect that in order for anything like this to occur, schemes like the one in Neath Hill would have to become the norm rather than the exception. Only when this happens, and the care is completely divorced from the accommodation, will the Disabled approach true integration.

Spinal
Injuries
Association

5 Crowndale Road London NW1 1TU 01-388 6840

QUOTES ON HOUSING TAKEN FROM THE TETRAPLEGIC SURVEY

"As I was unable to be looked after at home when I left Stoke I went to a Cheshire Home. The effect on my morale was terrible."

"The hardest thing was trying to remain living independently and bringing my children up who were six and nine years old at the time of the accident. After my husband left the difficulty was finding living in help. I have now overcome this during the last six months after finding out, through television, about Community Service Volunteers."

"Being tetraplegic has made me totally dependent on my mother, my social life is limited."

"I am lucky in that my mother has devoted her life to caring for me, but she is now 76 and I can see the time coming when I shall have to go into residential care."

"Housing and after care are two of the most important points in my opinion."

"It has broken my mother's heart and prematurely aged her - instead of having an able bodied caring daughter for her old age, the roles are reversed and we both worry about trying to care for each other."

"The main problem I find is the right sort of care and the time given. I am now due to move into a house in South London which will have four CSVs living in to assist in any way needed, organised by a charity called SHAD. When I move into the house I shall have total freedom to do all I want and need."

"I think a wife of complete tetraplegics should be classed as fully employed and insured against injry and have time off and holidays free from responsibility."

"The good things are that I met my wife, and am happy that I am living within a family rather than in a disabled unit where I was living before my marriage. Problems - getting somewhere to live when I decided to leave the disabled unit, i.e. finding a council prepared to put us on their housing list. Then the problem was trying to purchase the bungalow under the Right to Buy Act."

"The worst thing is getting about - I live in a village and I have to rely on my father to take me any place I want to go. I think my parents could do with some help from time to time or a place for me to go to give them a rest."

"Two major areas of concern are a. employment, which is difficult to obtain despite my qualifications and b. being reliant on my wife for personal care, when the opportunities for relieving this burden do not exist, at least to suit the convenience of me and my wife."

"Personal care is difficult to find and receive on a continuous basis. Relief help is almost impossible to find. It is impossible to fulfil roles in the accepted sense, e.g. being a wife and mother. The change requires a great deal of adaptability on the part of the disabled family and their family and friends. It seems to me that most of the above problems result from the fact that disabled people are not integrated into society."

"I have to live away from home and can only get home at weekends. I am due to go home for good when the council build an extension but that could be some time, and when I do it means my mum might have to give up her job, which she doesn't want and can't afford."

"I feel I could be more independent, but I hold down a demanding full-time job and would rather have assistance so that I can work than be fully independent and using all my time to get dressed and undressed. My distant dream is my own place one day - I live with my family at present. I believe I could cope in a well designed, gadget infested kitchen."

"The worst aspect of my life now is having to continually battle in my attempt to live a relatively normal and personal life in here, because although physically it is in many ways suitable for me, it is also the most patronising, undemocratic 'warehousing' institution imaginable."

METROPOLITAN BOROUGH OF STOCKPORT

SOCIAL SERVICES DIVISION

HILLGATE DEVELOPMENT

Through the Housing Corporation and the Collingwood Housing Association, a mixed development of houses, flats and accommodation for people with mobility problems, is currently being built on Higher Hillgate. The Housing Association have given the Social Services Division the opportunity of either taking the tenancies or nominating people for specific tenancies for accommodation which would be suitable for people with a range of physical handicaps. There are four bungalows for 2/3 people and a number of ground floor flats - possibly up to six - for people with limited mobility, but who might not require to be in a wheelchair all time. Because the development is a mixed development, there will also be families with children, as well as younger single people and older married couples.

Once final details have been approved, it is the intention of the Social Services Division to ensure that finance is made available through the Capital Programme to alter kerbs, etc., immediately adjacent to the development, so that wheelchair users can move freely to the shops on Hillgate.

The level of independence of the tenants will no doubt vary considerably. Where the tenants are a married couple, only one member of the family may be physically handicapped and therefore much of the individual and day to day caring tasks will be undertaken by the able-bodied member of the family. However, it is intended that a flexible support scheme will be available which will enable people with physical handicaps of a varying degree of severity to be accommodated in the scheme. Within walking distance, and for many people in wheelchairs within travelling distance, is the Millbrook Centre, and it may be appropriate, providing vacancies at the Centre are available, for some of the tenants to be offered day care, and the various facilities available at the Millbrook Centre in order that a full and satisfying set of daily experiences can be provided, and to prevent them from remaining in their own accommodation effectively isolated from all social interaction.

Because there could be up to ten people requiring assistance within a small geographical area, it becomes viable to consider providing support services specifically for this development. The staffing requirement is likely to be a Warden, who will be provided by the Housing Association, and who may be connected to the tenants by a simple alarm scheme; part-time Care Assistants will be employed to provide support at crucial periods of the day, i.e. getting up, washing and bathing assistance, and going to bed. It is unlikely that any of the tenants will require continuous assistance during the night.

In addition, many of the tenants will require some assistance from a Home Help who will undertake domestic duties. Nominations of tenancies in the rest of the development for key personnel is possible.

All tenants will be expected to hold the tenancy of the accommodation in their own name, although assistance with the payments of rent and other bills will be provided by the care staff; the tenants will be financially independent and will be required to make a contribution towards the support services which they receive. Tenants will be expected to furnish their own accommodation, with the exception of any who might move from full residential care to this scheme, and in

these instances it will be possible to provide assistance in furnishing accommodation in the same way that it is provided in group homes.

It is envisaged that the first tenancies will be available from August onwards, although the accommodation specifically designed for physically handicapped people will not be available until late Autumn. A detailed report requesting approval of the scheme will be sent to the Social Services Committee for their meeting in July. Finance is only available within the overall budget for services to physically handicapped people, and it is intended that the net cost of the scheme should be identified as a new cost centre with virement being applied to provide the necessary money to develop this new service.

Whilst tenancies for the whole of the scheme are shared jointly by the local authority and the Housing Association, Collingwood Housing Association have indicated that they are willing to allocate nomination of all tenancies for physically handicapped people to the Social Services Division.

Each tenant will be responsible for his/her own rent, and for heating and lighting etc. Each housing unit will offer accommodation suitable to the level of functioning of the individual client, i.e. rocker light switches in each unit, toilet facilities etc. There is an individual gas fired central heating system in each unit. Limited car parking facilities are available and this will be borne in mind when allocating tenancies.

A similar scheme, but for more dependent people, is also currently being built in Stockport, and will be available in about 18 months' time.

Initial nominations for tenancies should be made to Miss P. Cartwright on an SSD. 1 form, who will then arrange for suitable applicants to be given an application form for the Housing Association.

RJL/WAM
22.6.82

HOUSING & CARE SUPPORT
INFORMATION PACK

contents

1. Project 81 Housing/Care Programme Information Sheet.

2. Crossroads Care Attendant Scheme.

3. "SHAD" - Sheltered Housing Assistance for the Disabled Information Sheet.

4. PRESTON Scheme - North British Housing Association/Lancashire Social Services Information Sheet.

5. "Housing and Services for the Handicapped in Sweden" - Article.

6. "Housing Plus Support" CSV Independent Living Scheme article by Marion Janner.

7. Relevant Reference List prepared by Susan Kay.

8. "Housing and Community Care" Order Form and photocopies Chapters 18, 19, 20.

9. "Grove Road" Housing Scheme, Derbyshire - Information Sheet.

10. "Milton Keynes Community Care Scheme" - article by Glyn Vernon.

11. "The Kingston Project" leaflet.

12. Quotes on Housing - taken from Spinal Injuries Association Tetraplegic Survey.

13. "Hillgate Development" - Stockport Social Services Division.

14. "HABINTEG" Housing Association Limited - leaflet.

HOUSING & CARE SUPPORT CONFERENCE

30 September 1982

WORKSHOPS

GROUP A

Group Leader - Judith Gray, Community Physician, North Manchester Health Authority

Recorder - Nigel Smith, Regional Officer, North West Region, The Spastics Society

Miss K Bruce, Principal, Fourways Assessment Centre

Mrs D Garton, Rochdale MBC Housing Department

Mr D Griffiths, Mobility Information Service

Mr M Grimes, Property Services Officer, Wigan MB Council

Mrs E A Houghton, Fieldworker, Wigan Social Services

Mrs M Jackson, Family Housing Association

Mr Phil Mellor, Personnel Department, GMC

Mrs J Mulhee, Rochdale Housing & Disability Group

Mr A M Pate, Grosvenor Housing Society Limited

Mr A Roper, Senior Maintenance Officer, Wigan MB Council

Mr M Smith, Family Housing Association

Mr N Strowger, Chairman, Manchester Disabled Athletes

Mr Glynn Vernon, c/o Andy Wiggins

Mr Andy Wiggins, GMYA - Homelessness Project

Mrs M A Wright, Regional Housing Manager, Northern Counties Housing Association

GROUP B

Group Leader - Anne Miller, Chairman, Action for Research into Multiple Sclerosis (Manchester Group)

Recorder - Anita Hadfield, Senior Housing Welfare Officer, Oldham MD Council

Mr A Barker, Team Leader, Oldham Social Services

Mr A Bowden, Rochdale Housing & Disability Group

Mr J Chadwick, Residential Services Officer, Oldham

Mrs C Davies, Occupational Therapist

Mr Chris Drinkwater, Rochdale Voluntary Action

Barbara Frost, Family Housing Association

Mrs D Kimblin, Occupational Therapist

Helen Lee, HCIL

Mr G Littlemore, Deputy Director, Social Services, Rochdale

Eiluned Parry, Area Manager, Oldham Social Services Department

Sheila Rae, Family Housing Association

Mrs J Taylor, Senior Occupational Therapist, Oldham General Hospital

Councillor C Tucker, Chairman, Social Services MBC

Miss S Warrington, Oldham Advice Centre for the Handicapped and Disabled

Rosalie Wilkins, LINK

GROUP C

Group Leader - Peter [illegible], Chief Executive, [illegible] Valley
Regional Representative - [illegible] Area Team

Recorder - Mike Dobbin, Principal C
Services Division, Stockport

Mrs Wendy Elkin-Jones, Rehabilitation

Mrs M Bone, Tameside

Mrs Beryl Sutton, Secretary, Derbyshire Club

Mr Morgan Colledge, National Union of

Mr [illegible], Derbyshire

Mr Charles Tully, Presenter/Reporter, C

Miss Vera Blower, Rehabilitation Of

Mrs M Gleaves, Occupational Therapist,

Dr J B McCann, Community Physician,

Mrs Anne Brown, Rehabilitation Officer, S

Miss Clare Wyatt, Secretary, Tameside Associ

Mrs Yvonne Sherwin, Rehabilitation Officer

Mrs Andrea Dickson, Social Services North

Mr Paul Hanson, Senior Social Worker, Vita

Mr Chris Whitehall, Personal Housing Manager
Housing Services.

GROUP D

Group Leader - Jane Wagstaff, Manchester, Manchester

Recorder - Jane Greenwood, Regional Organiser,

Mrs Pat [illegible], Personnel and General Workers

Mr Alf Finch, [illegible] Chief Executive, Bradford Council of

Mrs M [illegible], Equipment and Resource Officer, Bradley

Mr John Cannon, Planning and Resource Manager, Stockport

Mrs Lorna Voisey, Volunteer Director, Stockport

Mr Jim Kenyon, Personnel Assistant, Tameside

Mr Leslie Jones, Head Porter, Macclesfield Ad

Miss A [illegible], Occupational Therapist, Tameside

Mr R [illegible], Housing Manager,

Miss [illegible], Community Nurse, Rochdale

Mr A [illegible], Rochdale MBC Housing D

Councillor D Tucker, Chairman, Social Services

GROUP C

Group Leader - Peter Norman, Director, Irwell Valley Housing Association Ltd; NW Regional Representative on National Federation of Housing Associations

Recorder - Mike Jobbins, Principal Officer, Residential & Day Care Services, Social Services Division, Stockport

Mrs Wendy Birch-Jones, Rehabilitation Officer, Stockport Social Services

Mrs M Bone, Tameside

Mrs Beryl Born, Secretary, Primus Club

Mr Norman Colledge, National Union of the Deaf

Mr K Davies, Co-ordinator, Derbyshire Coalition of Disabled People

Mr Martin Duffy, Presenter/Reporter, Granada

Miss Wendy Elsworth, Rehabilitation Officer, Stockport Social Services

Mrs M Hanson, Occupational Therapist, Stockport Aids Centre

Dr J K McCann, Community Physician, Stockport AHA

Mrs Anne Roberts, Rehabilitation Officer, Stockport Social Services

Mrs Clara Scott, Secretary, Tameside Association of Handicapped and Disabled

Mrs Yvette Steward, Rehabilitation Officer, Stockport Social Services

Mrs Andrea Thomas, Social Services, North Area, Stockport

Mr Paul Tranter, Senior Social Worker, Withington Younger Disabled Unit

Mr Chris Withnell, Regional Housing Manager, Collingwood Housing Association Ltd; Housing Institute.

GROUP D

Group Leader - June Maelzer, Chairman, Manchester Access Committee

Recorder - Zena Homewood, Regional Organiser, Community Service Volunteers

Mr Jack Askins, Transport and General Workers Union

Mr Vic Finkelstein, Chairman, British Council of Organisations of Disabled People

Mrs W B Forster, Bury and District Disabled Advisory Council

Mr John Glenholme, Housing and Environmental Services, Bury

Marion Janner, Volunteer Director, Community Service Volunteers

Mr Eric Kenyon, Principal Architect, Cheshire County Council

Mrs Levine, Bury and District Disabled Advisory Council

Miss A McFarlane, Kingston upon Thames Association for the Disabled

Mr R Philips, Regional Housing Manager, North British Housing Association Ltd

Pauline White, Community Action Project

Mr Nicholas Peter Westington, Housing and Environmental Services, Bury

Mr Andy Zuntz, Rochdale MBC Housing Department

Technical Officer, Housing Corporation

GROUP 1

Group Leader - Sara Lundin, Director of Housing

Secretary

Recorder - Roger Arnold, Director of Housing, Preston

Mrs Alison Carver, Housing Officer, Wigan

Mrs J Davey, Crewe & Nantwich Housing Authority

Louise De Jong, [illegible]

Mrs A Hancock, Housing Advisory Officer

Mr A Jolley, [illegible] Yorkshire Association

[illegible] Homes Council for [illegible]

Ms Amy Kearney, Community Action Pro[illegible]

Mrs J M Mill, Head Occupational Therapist

Mr T B Price, Architect, DOE

Anne Rands, Owner, Warrington Cheshire Fo[illegible]

Mr H Vare, Development Officer, Blackpool

Mr Gerard Wood, Area Head Practice of the

Mrs D Worthington, Housing Manager, Groves

Mrs L Yates, Social Worker, Preston North Team

GROUP 2

Group Leader - Roy Southern, Assistant District [illegible]

Secretary

Recorder - [illegible] Area Specialist Housing Nurse

Mrs Zara Arnfield, [illegible]

Mr B Baker, Community Action Project

Mrs I Black, Chairman, Trafford & Halton A[illegible]

Mr Brennan, Assistant Chief Housing Officer

Ms C Ford, Support for Work Skills

Mrs A Oates, [illegible]

Mrs [illegible], Visiting Nursing Officer

Mrs [illegible], Specialist Person Supervisor

Ms C [illegible]

[illegible]

[illegible]

[illegible]

Mrs [illegible], [illegible]

Mr [illegible], Housing Corporation, Manch[illegible]

Mrs [illegible], Housing Officer, [illegible]

Mrs [illegible], Housing, Ellesmere [illegible]

GROUP E

Group Leader - Ken Lumb, Representative of Union of Physically Impaired Against Segregation

Recorder - Roger Arkell, Director of Development, North British Housing Association Ltd, Preston

Miss Alison Carver, Housing Officer, Midlands Area, Improvement Housing Association

Mrs J Davey, Grosvenor Housing Society Ltd

Louise De Raeve, SHAD

Mrs A Gardner, Housing Advisory Officere, North Cheshire Housing Association

Mr A Goldthorpe, Yorkshire Association for the Disabled

Mr E Humphrey, Hyndburn Council for the Disabled

Mr Rick Hennelley, Community Action Project

Miss J M Mills, Head Occupational Therapist, Liverpool Social Services

Mr T B Parker, Architect, DOE

Anne Parks, General Manager, Cheshire Foundation Housing Association

Mr H Ward, Development Officer, Blackpool Division, Lancs Social Services

Mr George Wood, National Federation of the Blind

Mr G Worthington, Housing Manager, Grosvenor Housing Society Ltd

Mrs E Yates, Social Worker, Preston North Team

GROUP F

Group Leader - Roy Southern, Assistant District Adminstrator, South Manchester Health Authority

Recorder - Eileen Milnes, Spastics Society National Executive Council

Mr John Armitage, SHELTER

Mr P Baker, Community Action Project

Mrs J Black, Chairman, Trafford & Salford Association Spina Bifida & Hydrocephalus

Mr W Bowman, Assistant Chief Housing Officer, Trafford MB Council

Mr C Ford, Support for North Staffs

Mrs A Gatis, YWCA

Mrs H Handley, Divisonal Nursing Officer, Trafford AHA

Mr Ken Heyes, Disabled Persons Supervisor, GMC

Mr D Henshaw, TFCD

Mrs Kathryn Johnson, Voluntary Organisations Officer, Trafford Social Services Department

Mr J D Lang, Secretary, CRHA Ltd

Mr Phil Mason, HCIL

Miss M Marsh, Volunteer Organiser, Trafford Social Services Department

Mrs M Piper, Senior Specialist Officer (Adults), Trafford Social Services Department

Mr J Standford, Housing/Access Offficer, ACCESS

GROUP 3

GROUP G

Group Leader - Bob Lewis, Assistant Director, Social Services Division, Stockport

Recorder - Paul Crowther, Development Officer, Irwell Valley Housing Asociation Ltd

Mrs P B Banning, Principal Officer, Salford Social Services

Mrs C Bentley, Senior Officer, Aids and Adaptations, Salford Social Services

Elaine Bennell, Occupation Therapist

Mr P Cornille, General Secretary, The Cripples Help Society

Ms M Hines, Claycross Inter-Help Coop

Mrs Anne Godfrey, City of Salford Housing Department

Mrs J Goodwin, Schemework Officer, The Housing Corporation

Mr Kevin Hyett, Salford CVS Disability Sub Committee

Sister Morgan, Salford Area Health Authority

Dr Joan Munro, Community Physician

Dr Jill Rowland, Community Physician, Salford Health Authority

Mrs N K Smith, Head Occupational Therapist, Hope/Ladywell Hospitals

Miss J A Stanway, Senior Occupational Therapist

Miss S M Tipton, Director, St Vincents (Manchester) Housing Association Ltd

GROUP H

Group Leader - Don Simpson, Borough Housing Officer, Rochdale

Recorder - Patrick Mbatha, Registrar in Community Medicine, South Manchester HA

Mr M Annan, Chief Executive, Collingwood Housing Association Ltd

Mrs J K Bowerbank, Sister-in-Charge, Withington Younger Disabled Unit

Mrs S Kay, Derbyshire Social Services Department on secondment Warwick University

Dr A E Jones, MOEH Manchester

Mr M Kent, Senior Housing Manager, Mosscare Housing Association

Mr D Leaman, BCODP Housing Group

Mr P Mittler, Information Officer, SERIS

Mrs A Plumb, Union of the Physically Impaired Against Segretation (Womens Section)

Mrs Angela Roden, Deputy General Secretary, GM CVS

Dave Rogers, GMYA/PHAB

W J Shaw, Principal Assistant, Domicilary Services Division, Manchester Social Services

Mr Frank Tranter, Chairman, Manchester Disability Forum

Mr John Taylor, Principal Housing Officer

Mrs V J Tibbelts, Development Officer, St Vicents (Manchester) Housing Association Ltd

Mrs S Wareing, Organiser of Wardens, Domillary Services, Manchester Social Services

Juliet Woulfe, Manchester Diability Forum

It is hoped that in the near future the Rochdale Housing and Disability Group, in conjunction with St. Vincents Housing Association, will have 3 or 4 flats for rental, suitable for wheelchair users. They will be part of a mixed housing scheme, situated at Sudden, with ample facilities nearby, (such as Post Office, Shops and Library).

The flats on the ground floor will be designed and equipped to suit the needs of the disabled tenants.

An important part of the scheme is the idea of "supporting tenants" who will occupy the flats directly above the "wheelchair flats" and provide help to the disabled tenants, in addition to what is already available from local services, e.g. District Nurses, Home Helps and Crossroads Care Attendant Scheme.

We invite anyone who is interested in the scheme, or would like more information to write to or 'phone Chris Drinkwater at Rochdale Voluntary Action, 15§ Drake Street, Rochdale. (Tel. 31291/522798).

Published by: Rochdale Housing and Disability Group.

New housing idea for disabled people in Rowdale

HABINTEG HOUSING ASSOCIATION - INTEGRATED WHEELCHAIR HOUSING WITHIN A NON-HANDICAPPED COMMUNITY.

NORMAN SUMMERS, DIRECTOR

Housing for the disabled is a theme which has achieved increasing prominence during the International Year of the Disabled Person, and any improvement in awareness of the needs of the handicapped, and in the solution of relevant problems is to be welcomed. It is extremely important, however, to avoid over-simplification in assessing the requirements of the handicapped, and in assuming that the provision of wheelchair or mobility accommodation is in itself the complete answer to the problems.

A number of good solutions have evolved through the initiative of disabled individuals, and through housing associations and local authorities, and these allow not only for the specialized daily living requirements, but also provide the opportunities for a full social life. Some broad examples of these are:-

a) Purpose-built wheelchair flats, designed and managed on the initiative of disabled persons to individual requirements with directly-linked standard accommodation for persons providing support. This is a most satisfactory solution for disabled couples who are able to manage the revenue finance within a chosen environment, the capital finance and expertise having been supplied from housing association sources. A similar solution has also been found by one or two disabled people through the adaption of existing premises to provide accommodation for themselves, either as individuals, or small compatable groups, with 'in house' accommodation for persons giving support.

b) Many successful adaptions have been carried out by local authorities and private individuals to existing properties which improve the quality of life for a wheelchair user. Again this works very well for those who's premises are suitable for alteration and possible extension, and who wish to remain in the same location, (often living within a family group).

c) Purpose-built wheelchair housing has been introduced into housing association and local authority normal housing schemes. It is encouraging to see that such provision is being made, and in general terms is most suitable for disabled persons living within a family group able to provide the supportive and social needs. For individuals, however, unless they are capable of a high level of independance, it can produce a degree if isolation.

d) Sheltered housing schemes invariably contain some units designed for wheelchair users, and very sensibly meet the needs of the elderly permanently disabled and those who have acquired disability.

It will be seen that the provision that has been outlined so far, meets specific catagories of need. In order to meet these, and at the same time to allow for an even wider range of requirements within a given location, Habinteg has formulated a policy which provides a mix of a number of sizes of wheelchair accommodation, integrated into a normal community, and backed by a residential support service.

Habinteg Housing Association was formed some 12 years ago by the Spastics Society, which saw the need for housing provision within a normal community, not only for spastic persons, but for all handicapped people with or without families who had no choice other than grossly inadaquate housing, or alternatively institutional care. Although strong links with the Society are still maintained, Habinteg is, of course, autonomous, is registered with the Housing Corporation and is a registered charity. At the present time the Association has over 600 houses, flats and bungalows in management, of which approximately 150 are designed for wheelchair users, and a further 500 in the course of planning and development. Schemes are developed on a national basis and cover most regions of England. There is also participation in a project in Wales, and a few years ago a sister organization, Habinteg (Ulster) Ltd, was established in Belfast, which now has schemes in management and development in Northern Ireland.

With this concept of design for independent living, disabled persons have freedom of choice and the right to make their own decisions, and this is achieved by good design within the accommodation, coupled with an environment which provides facilities for social integration with the surrounding community. The following is a broad outline of the principles involved:-

Accommodation

On each scheme at least 25% of dwellings are designed for wheelchair users in sizes to accommodate single persons, couples and families according to local demand. These units are not grouped together, (despite possible advantages in architectural and financial terms), but are interspersed within the total scheme, thus avoiding the creation of separate communities. The balance of the housing which is tenanted by non-handicapped persons and families in housing need, is designed to mobility standards with wider doors and level access at ground floor level.

This has a number of advantages, the most important of which is to enable a person in a wheelchair to visit any other dwelling within the scheme. It also benefits elderly frail persons, (to whom the Warden cover can be extended case of need), mothers with very young families, and indeed, the non-handicapped generally.

Whilst it is essential to allow correct space standards for wheelchairs, it is equallyimportant to achieve a satisfactory relationship between rooms and circulation area to ensure unhampered movement around the dwelling. In planning the shape and wall-space in individual rooms it is noted that in addition to normal furniture there will probably be at least one wheelchair in the sitting-room and again in the dining area. Bedrooms are sufficiently large to allow adequate wardrobe space with wheelchair access, and, where space permits, access to both sides of the bed.

The kitchen is designed with a considerable degree of flexibility, avoiding the need to await the selection of a tenant before building in fixtures. With variable height sinks, worktops, hobs and ovens, and with both adjustable and mobile storage, only minor adjustments may be necessary to suit most types of handicap. This also provides for any subsequent change in tenancy or circumstance at no extra cost.

Bathrooms and W.C.'s are designed to allow easy access to the bath and washbasin, and for transfer from wheelchair to W.C. An extension seat is provided to the bath, to facilitate transfer and a hand-shower is fitted as standard. There are a minority of cases where a "drive under" shower is indicated, and all bathrooms on recent schemes are therefore provided with a drain outlet with a slightly dished floor so that, at minimal cost, the bath can be removed and the bathroom then becomes a shower-room.

Specific additional items such as grab-rails, hoists, remote operation window gear, etc., are added to individual requirements where necessary. Such items are acquired through Social Services where possible, or otherwise funded from charitable sources. This also applies to raised planters and additional paving to gardens when these cannot be funded through development finance.

Environment

The selection of a site, and its location is of equal importance to the thoughtful design of the accommodation. The priority of need usually indicates a location within a city, town, or close to a district centre, and this can present problems in availability and cost of suitable land. Invariably however, a solution is ultimately found through perseverance, and the co-operation of local authorities.

The site itself will preferably be level, although three-storey flats have been built on sloping sites, and the contours used to provide wheelchair access to all floors, in addition to the normal lift access. Within the scheme itself, whatever building form is used, there is the freedom of complete circulation for wheelchair-users. The actual location of the site will be determined by the availability of public facilities for the disabled. Food shops, post office, public transport and a public house should ideally be within level wheelchair distance of the site, and every effort made to have kerbs and hazards modified.

In conclusion, an attempt has been made to outline in broad terms Habinteg's approach to the wider provision of housing disabled persons within the community. There are still problems which could be eased, particularly in terms of finance. For instance, space standards could be improved, particularly in bedrooms, bathrooms and kitchens, and a higher level of revenue allowances are needed for adequate resident warden (Community Assistant) cover, together with the essential communication system. In this International Year of the Disabled Person may we hope that those responsible for determing cost-effectiveness will come to the understanding of the true and necessary requirements of the handicapped in their daily life, and not consider essentials as merely "desirable".

INTRODUCTION

P81 is an approach to Independent Living put forward by a group of disabled people mostly resident at the Le Court Cheshire Home.

The members of the P81 Management Committee are:-

John Evans - Chairman
Philip Mason - Secretary
Philip Scott - Treasurer
Liz Briggs
Peter Wade - Trustee Cheshire Foundation
Neil Slatter - Spinal Injuries Association Management Committee
Tad Polkowski
John Lambert
Julian Crowder - Le Court Management Committee
Graham Thomas - Le Court Management Committee

All the foregoing are severely disabled.

Ann Parkes - General Manager, L.C.F. Housing Association
Judith Cowley - Senior Advisor Disability & Rehabilitation, Hampshire

This group is wholly responsible for all operations of the scheme.

Our concern is with those severely disabled people who cannot exist without daily personal care assistance, ie. help with washing, dressing, toiletting, cooking, etc.. This need has, until very recently, meant one of two alternatives: care from parents/spouse or care from staff in an institution.

We hope to help change this situation by making it possible for severely disabled people to live where and how they choose, something that is taken for granted by the able-bodied.

P81 has been in existence for three years. We have been working with our fellow disabled friends, statutory authorities, concerned charities and the Housing Corporation to try and enable severeley disabled people to move into homes of their choosing, provided by a housing association, and with personal care needs being met by Domicillary Care provided by the Local Authority.

These aims involve changing attitudes and practices. This is beginning to happen:- "Care in the Community", a DHSS Consultative Document, July 1981, "Most people who need long term care can and should be looked after in the community. This is what most of them want for themselves..." However, in practice there is little evidence of this approach.

Our major task has been and will continue to be the practical details involved in implementing this. It is up to us to demonstrate how one actually brings about INDEPENDENT LIVING. That is, enabling the disabled person to realise their aspirations in a manner compatible with the means and resources available.

Besides the obvious humanitarian arguements, there are sound economic reasons for the change. This aspect is most heavily featured in the promotion of Independent Living in the USA. Gini Laurie commented in the Rehabilitation Gazette, 1973:- "Millions of dollars are being wasted in maintaining severeley disabled people in hospitals and nursing homes all over the world. A majority of these could live happily and productively in the community for a fraction of the cost of any institution if some assistance were provided."

To be succesful we had to become as well informed as the experts and so we embarked upon an extensive research program in the UK, Denmark, Sweden, Holland and the USA. (Our Chairman John Evans, went on a six week tour of the USA looking at their Independant Living Movement.) Besides increasing the knowledge and experience of the group, we have had many opportunities to share our endeavors both nationally, (Naidex 81) and internationally, (EEC Independent Living Seminar, Brussels. VIF Conference, Munich.)

The idea that severely disabled people should be removed to residential institutions in order to obtain the personal care they require is still prevelant. In Britain this remains the dominant opinion and practice amongst the Medical and Caring Professionals aided by the Concerned Charities. From the earliest days we have had to combat this opinion.

We have met with representatives of the Social Services in Hampshire and have obtained an agreement in principle from the Director of Social Services, that they will seek to provide the Care Support necessary for a severely disabled person to live independently in the community within this area.

We have also arranged through a housing association, the purchase of a bungalow in Cowplain, Hampshire, for one of our severely disabled members, who will rent the property and so be able to move out of Residential Care iminently. This we trust will be the first of many such successes.

The housing association has also purchased another property in Southampton to house two more members and some able bodied tenants. In this instance, according to the wishes of the future occupants, it is intended that the property be sub divided into bed-sits, while other areas are communally shared.

The Future.

Our primary task will be to establish those members of our group who wish to live outside the Residential Institution (four people at this time), in homes of their choosing with the appropriate Care Support. We shall also continue our researches and offering our expertise and experience to any who seek it.

It is hoped that the operation of P81 will be something that other severely disabled people can copy, forming a bridge from Institutional Care to Independent Living and also, helping as many as possible to avoid having to enter such establishments in the first place.

.....

66 BELLEVILLE ROAD
LONDON SW11 6PP

Shad

SHELTERED HOUSING ASSISTANCE FOR THE DISABLED.

OPENING OF 31 ELMBOURNE ROAD

Background

SHAD arose out of the experience of Stephen Burton who has lived in his own house in Battersea for the last five years. Stephen, who is confined to a wheelchair with severe physical disabilities, persuaded Wandsworth Council to convert and adapt one of their council houses for him, and arrange with Community Service Volunteers to have four volunteers living with him, taking care of his physical needs, helping in looking after his house, and taking Stephen to his business and social appointments.

The obvious success of his way of life, led to the setting up of SHAD, so that other men and women with similar disabilities had the opportunity to live in their own houses, enabling them to lead independent and full lives, working or studying as members of the community.

The first SHAD project: Wandsworth

Because of the support of Wandsworth Council, this London borough was chosen for the first SHAD project. Together with Threshold Housing Association, SHAD initially chose three sites, with a further three houses to be added later. The disabled tenants will be chosen on rigorous criteria – they will be severely disabled women or men confined to wheelchairs who are capable both emotionally and intellectually of running their own household. The volunteers helping the tenants will be supervised and supported by SHAD's Volunteers Organiser, an essential part of the project.

The Wandsworth Project is managed by a local committee, consisting of representatives from SHAD, Social Services, Threshold Housing Association, a SHAD tenant, Occupational Therapist and other individuals from the community. The Management Committee will be responsible for selecting tenants, employing the Volunteers Organiser, choosing further sites with Threshold and securing the necessary finances.

The opening of the first SHAD house in Wandsworth, marks the end to a long period of planning and the start proper to SHAD's Wandsworth Project.

CHARITY NO. 276890

Shad

Sheltered Housing Assistance for the Disabled: Wandsworth

C/O 465 GARRATT LANE SW18

31 Elmbourne Road

The ground floor of the house was converted by Threshold Housing Association to wheelchair standards. It includes such things as a lift, adjustable washbasins, low level kitchen units, bath hoist and ramped access, to meet the needs of a person with severe physical disabilities.

Volunteers and Volunteers Organiser

Four volunteers will live with Tony, each staying for periods of 4-6 months. They will look after his physical needs, share the housework and take Tony to the various places he chooses to visit. The volunteers will be supported and co-ordinated by SHAD Volunteers Organiser, Louise de Raeve who was appointed in January. She will be responsible for helping Tony and his volunteers to settle into their new situation, and working out how best to maintain a smooth-running household ie. allocation of work, other projects, free time etc. Because this situation can be very demanding on everyone, it is important that there is opportunity for other interests. So as part of their stay, the volunteers will be involved with secondary activities in the community, arranged by the Volunteers Organiser and other agencies in the borough.

Initially volunteers will come through Community Service Volunteers but as the Project grows, the Volunteers Organiser will recruit volunteers locally.

Finance

The capital costs involved in converting the property were secured by Threshold Housing Association. Joint Finance by Wandsworth Council and the Area Health Authority has been provided to meet the essential running costs of the scheme - for such things as the volunteers upkeep, travel and spending money.

Further Plans

There are two further schemes at the planning stage, with sites located by Threshold. Finance for the running costs has been assured by Wandsworth Council for the first and promised for the second. SHAD has plans to increase the number of houses involved to six, and is looking at ways of meeting the running costs of these schemes, before Threshold can identify possible sites.

THE NORTH BRITISH HOUSING ASSOCIATION LIMITED

HOUSING FOR THE PHYSICALLY HANDICAPPED AT WATLING STREET ROAD, PRESTON

1. INTRODUCTION

The North British Housing Association Limited have for many years developed schemes specifically for the elderly and more recently the mentally disordered. Prompted initially by The International Year for Disabled Persons, attention was drawn within the Association to the needs for the physically handicapped within the community. This interest was heightened by a request from the Greater Manchester Council for Voluntary Services to Housing Authorities working within the North West, to consider providing a housing scheme for physically disabled on a similar basis to the Milton Keynes version of the Swedish 'Fokus' scheme.

2. SCHEME CONCEPT

The Association was proposing to develop a housing scheme of 131 dwellings at Watling Street Road, Preston. The scheme is on a flat site and in a location which had many advantages for the disabled. Realising the opportunity offered by the development, six ground floor flats were identified for re-design to render them suitable for occupation by a wheelchair confined person.

Care support would be provided by Community Service Volunteers (CSV's) who would be resident on site. A large family dwelling was identified for re-design to produce furnished single person accommodation.

To allow reasonable integration, all remaining dwellings with ground floor accommodation are to be built to mobility standards to allow entry for visiting by disabled persons. Hence the scheme proposed is aimed at permitting severely disabled persons to live, with the necessary support, within and as part of the community.

3. PARTIES TO THE PROJECT

Early consultations between the three parties to the project, N.B.H.A., C.S.V. and Social Services Department, were concerned in securing funds to meet operational costs for the project from the Social Service budget. Approval from the Social Services Committee was secured at an early date, due in part to a general acknowledgement that financial savings could be made should clients currently in residential units, being supported financially by Social Services, be included in this project.

The annual cost of theC.S.V. support, including the cost of theC.S.V. accommodation will be met by Lancashire Social Services Department, supplemented by payments from the six residents from their special allowances.

Once funds had been secured for this project, consultations were arranged on a regular basis to establish and maintain links and to define areas of responsibility.

4. IDENTIFICATION OF CLIENTS

Total nomination rights were granted to the Social Services department by N.B.H.A. with regard to the identification and selection of clients for the six units contined within the scheme.

Social Services department are to adopt the following criteria when selecting clients, firstly the scheme should accommodate Prestonians, secondly the principle aim of the project is to take persons out of residential units, be they Local Authority Part III institutions, or independent homes provided by such foundations as the Cheshire Homes. The next category of person for consideration would be those identified by a field Social Worker and who is currently living within the Community and who is likely to be admitted into Part III or similar type accommodation within the near future. A typical example would be a single physically handicapped person living with aged parents.

Prior to offering any client a unit it is proposed that for a period of some two to three weeks, the prospective client attend Sharoe Green House, where a short 'rehabilitation' programme has been devised to assist persons who previously may have very little experience of anything but instituionalised life. The short rehabilitation programme covers such topics as home management, budgeting, cooking etc.

5. DEGREE OF CARE

Care support would mainly be provided by the Community Service Volunteers who will be resident on the scheme. Dependent upon the needs of individual clients it is envisaged that, initially, a team of eight CSV's will be required and these will be resident in one house on the development. A 24 hour emergency communication system is to be installed which will link the disabled persons dwellings and the CSV accommodation. The CSV work on a one to one programme working with individuals rather than being attached in a more general way to organisations or institutions. The CSV view the disabled persons as the expert in their own care, and act in the main as working extensions, doing on behalf of their client all the things which they are unable to do for themselves.

The care support needs of individual clients would be met by the CSV on a 'rota' basis, supplemented as necessary and appropriate by the Social Services Department and Area Health Authority.

6. ADAPTATION WORKS CARRIED OUT IN UNITS

The six ground floor units identified for the project are scattered within the development, all units have been designed to meet the wheelchair housing criteria and other related design circulars [DOE/WO Circular 74/74 120/74 and HDD Occasional Paper 2/74].

Furthermore, each unit (except one where planning permission was refused) is to be provided with a carport, this is aimed at assisting clients mobility.

The detailed design of the dwellings has been carried out in close liaison with an occupational therapis, social workers and individual wheelchair users. The final 'fitting out' of the dwellings will be designed around the particular needs of the identified occupants.

7. FURTHER INFORMATION

Further information on the scheme can be obtained by contacting one of the following:-

Bernard Gallagher, Regional Housing Manager, The North British Housing Association Limited, Unicentre, Lord's Walk, Preston PR1 1DP.

David Halpin, Lancashire Social Services Department, Moor Lane Day Centre, Moor Lane, Preston.

HOUSING AND SERVICE FOR THE HANDICAPPED IN SWEDEN

An account of what the Fokus Society does to promote integrated living conditions for the severely disabled persons by Sven-Olof Brattgard, Folke Carlsson, Arne Sandin.

The Fokus Society and Its Objectives

The 1960's was a decade of greatly improved facilities for the rehabilitation and education of severely handicapped children and teenagers. However, this has not been matched by a similar effort to provide physically impaired young people with housing and services. Up to now many of these persons have to spend their lives in isolation and idleness at nursing homes or institutions for the chronically sick whenever their parents have been unable to look after them. The mere suggestion that they might manage homemaking on their own used to be widely considered unthinkable.

In 1964 the Fokus Society was established in Sweden. It's objective is to help the younger ambulant impaired (those who are partly or wholly dependent upon technical aids and personal assistance in order to facilitate moving about, personal hygiene, dressing and undressing, shopping, cooking and transportation), with housing services and guaranteed care so that they can live in their own homes under the same conditions as other people and not be reduced to isolation and idleness at nursing homes and sanatoria or have to stay on at the parental home, with all the burdens that this implies.

What Fokus had in-mind was to include apartments for the young handicapped in ordinary rental housing. They would be designed to enable the handicapped person to manage independently as far as possible. The dwelling units would be intended for single as well as multiple occupancy even though emphasis would be put on one-person apartments. Personal assistance would be available on a 24 hours basis. There would be direct access from the apartments to common-use spaces. Eligibility for accommodatiuon would extend to handicapped persons from all over Sweden.

The apartments were to be centrally placed in ordinary residential areas and in ordinary structures mixed with apartments for the non-handicapped. By locating the apartments in communities with relatively good employment opportunities and full-fledged education programmes, it would be easier for the handicapped person to get and hold onto a job.

The Fokus Society seeks to encourage work contributions and provide capabilties to enable the tenants to avail themselves of public resources on the labour market. Fokus interprets its mission in terms of helping the handicapped person in his whole situation, the better to enable the tenant to lead his life without unnecessary restrictions.

In line with this objective, Fokus has formulated certain basic principals as follows:-

* The handicapped person shall have the right to choose his dwelling irrespective of where he lives.
* The handicapped person shall be permitted to live in an ordinary residential environment and use his dwelling under the same conditions as others.
* The handicapped person shall feel secure on the strength of access to personal service.
* The handicapped person shall be given all necessary support to enable him to choose, obtain and retain employment.
* The handicapped person shall be given opportunities to engage in meaningful pursuits.

Target: The Severely Disabled - A Small, Neglected Group

Hence the primary target group at which Fokus aimed consisted of younger persons suffering from severe locomotor disabilities, a group that must have technical equipment and personal assistance in order to cope with the activities of daily life (ADL), such as dressing and undressing, visits to the lavatory, cooking, shopping, etc.

Guidelines for the design of dwellings and the close-in environment were drawn for Fokus by a special task force consisting of architects, rehabilitation experts, consulting engineers (heating, ventilation, sanitation and electricity) and handicapped persons. The task force sought to plan specially designed dwelling units which permitted maximum flexibility to accomodate individual needs. It was also called upon to plan the common-use facilities that might be needed: rooms for use in emergencies, for the care of clothing, for washing-up etc. This part of the project included the design of an emergency signal system that could be used by the handicapped.

The task force presented the first draft of a conceptual scheme in the spring 1967. This proposal was then reworked into finalized shape in the following year. Its title: Principles of the Fokus Housing Units for the Severely Disabled. This manifesto has formed the basis for planning the different Fokus units. It is published in German and English versions.

With the task force report as the starting point, work began on the design of flexible kitchens and bathrooms. Interior fittings such as cabinets and work counters are manufactured to Fokus specifications by designated suppliers. In Germany, for instance they are produced by Berufsforderungswerk Hamburg G.m.b.H. Here Fokus does not confine itself to quality control of the production process, but all regularly informs the produce of the experiences that are gained.

Fokus undertakes to select tenants for the apartments. In addition, the local executive committee are brought in to ensure that service personnel are available.

A fundamental principle of Fokus planning is that every tenant shall have his own apartment. A single "all-purpose" room, even if equipped with kitchen facilities and the like, cannot be accepted as a long-term solution of the handicapped persons housing problem. All units are planned for the severely disabled from the outset. The recommendations drawn up earlier by the Fokus planning group have been followed.

Fokus has apartments for families as well as individuals, Some dwelling plans, especially those for one-person accommodations, provide for an "all-activities room". The rationale here is to have a dwelling which puts the tenant at the centre of activity on every occasion, enabling him to keep in touch with everything that happens round him, whether he be in bed, sitting in the kitchen or lounge on a sofa or armchair. All interior fittings are detachable, which permits the tenant to shape his dwelling as he sees fit.

All interior fittings are adjustable for height, both in the kitchen and bathroom. Maximum livability put in the handicapped's hand, regardless of whether he is tied to a wheelchair or uses crutches.

Various technical amenities are built into the apartments. Thus the electrical controls are assembled in small movable boxes that can be placed next to the bed, in the kitchen or on the wheelchair. In the latter instance, the switching is radio-controlled so that the handicapped person can move freely in the room. When the installed equipment is activated by the switching device, the tenant can open doors, call for help, talk in the house telephone, turn the lights on and off and so on. All apartments are connected to on-duty personnel by intercom. As a rule, too, the tenants have their own telephones.

All Fokus dwelling units adjoin common-use spaces. Those facilities are open to all tenants, handicapped as well as non-hanicapped. There are recreation rooms with TV sets and communal dining rooms with kitchen for those who prefer to eat in the day's

main meal in the company of others. Separate rooms are usually set aside for physical training and exercise, each containing items of equipment suited to individual capabilities. There are craft activity rooms, likewise fitted with specially designed equipment.

An adjunct of most Fokus units is a hygienic department, which has bathing equipment especially adapted to the severely disabled, Many places also come with a sauna. Separate provision is usually made for a clothing-care room in which suitable designed washing machines, dryers and mangles are installed, Plans are in hand to build garages for wheelchairs used outdoors. Wherever feasible parking stalls for car are provided as an integral part of the structure. In other cases garaging consists of carports equipped with electrical car-heaters.

Service personnel are provided with staff rooms as well as with an office or on-duty room.

Fokus has striven to obtain central locations for its apartments wherever possible. This makes it easier for the tenant to take part in community activities, develop interpersonal relations, do his own shopping, etc.

The Full-Care Service - Scope and Organistion

Once a severely disabled person has been provided with a dwelling adapted to his handicap, it is just as important for him to enjoy a function-worthy personal service. The handicapped tenant in a Fokus unit will have that need met by the Society's staff, over and above the service he may obtain from the public home-help programme.

Many handicapped persons, especially the severely disabled, may need round-the-clock service for all functions which relate to life's daily rounds. The most salient needs have to do with dressing and undressing, help with personal hygiene, getting food and shopping. Moreover, the handicapped person who lives in his own dwelling needs help with cleaning, bedmaking, laundry etc. Provided those tasks are not too heavy, many of them can be performed by home helps or by another service organisation. However, owing to the need of the severely handicapped for 24 hour sevice as well as the size of assisting staff required, this programme differs from that traditionally associated with home nursing. That is why we have elected to call our programme with full care service.

The starting point for any assessment of the need for such service must be what the handicapped person can do on his own and the time it takes him to do it. Consideration must also be given to all technical arrangements that can reduce the need for service and make the handicapped less dependent on others for help.

Service for the handicapped is cast in organisation modes that differ slightly from one locality to another. This reflects the different philosophies prevailing among county councils and municapilities. The basic principle has been to allot the handicapped person as many hours of help from a home samaritan as though he lived in a so-called interpersed invalid dwelling. County councils and municapilities have generally maximised the number of hours at four per day. For the severely handicapped with whom Fokus is concerned that is not enough. The vast majority must have access to personnel who can help them at different times of the day. To be able to meet that need, the Fokus units employ personnel who are on duty round the clock. This enables the handicapped person to recieve help whenever he wishes whether it is to go to the toilet, get undressed for bed or have his sleeping position changed. Fokus employees also assist home helpers whenever two people are needed to do heavy lifting or the like. Moreover, the home-help programme cannot easily find the manpower needed to work on weekends, which means that Fokus personnel must assume the greater part of the workload.

Several reasons prompted Fokus to adopt a full-care service, which may be defined as a system of personnel assistance and service during certain hours, which access to on-dury personnel in between. Most important of all, the tenants themselves have found this

arrangement to be appropriate. The handicapped person has someone who takes more direct care of his dwelling and his service needs, someone who takes where he keeps his clothes, what he wants to eat and so on. This makes it unnecessary to initiate every new assistant in all the details.

Another reason is that they system based on personnel who comes from outside counteracts tendencies towards "institutional thinking", i.e. by analogy with commitment to a hospital, nursing home or the like.

A third reason is that this system prevails on the handicapped person to assume responsibility for himself. He knows how many service hours he can get and must allocate them properly.

An important aspect of the full-care service is the attitude of personnel. Fokus staff must be open-minded and avoid all tendancies to treat the handicapped person as a patient. It is also necessary to show respect for the handicapped's right to independence and to management or his private affairs.

A major function for the severely disabled is the ride service. A well-functioning ride service is necessary if the handicapped person is going to be able to engage in different activites offered by the community and to get into contact with others. The ride service is being built up. Although in operation at all localities where Fokus is active, it has not yet developed in some places to the desired extent. One trouble with the ride service is that it is available in several localities only at limited times of the day.

Earlier Situation of the Tenants

An analysis of the situation for handicapped persons before they moved to Fokus apartments discloses that about 34% came from the neighbourhood, while 66% were from other localities. Most of the handicapped, 48%, had formerly lived with their parents, while 24% had been at institutions, nursing homes, chronic-care clinics or the like.

After moving into the Fokus units the handicapped took greater part in work and studies. Here, however, there was a time lag, which reflected the difficulties of finding jobs during the short period that the programme had been in operation. Even so, 45% were in employment or eudcation one year after moving in.

The Fokus dwellings made it possible for more handicapped to move together to form together families with handicapped or non-handicapped persons. 36% of the tenants cohabitated or were married.

Of the handicapped tenants 77% were tied to wheelchairs. More than half needed help with dressing and undressing, and one-third with the daily hygiene. Nearly one in five (28%) needed help to change sleeping positions during the night.

Thus the handicapped tenants in Fokus apartments comprise a group of severely disabled, who are utterly dependent on a full-care service that functions round the clock. The Fokus programme has enable them to live a more active and independent life under secure conditions. Moreover, the programme also permits the handicapped person to settle down wherever he likes, He is no longer shut in by provincial boundaries. He may dispose of his dwelling on the same terms as others and personal service is guaranteed to him. As a result he is also given new opportunities for employment, education and lesiure activities.

As a tenant of Fokus the handicapped person derives special benefits. For some tenants the Fokus apartment becomes a step in the rehabilitation process leading to a more ordinary dwelling. Because of the Society's nationwide activity, a tenant is also enabled to move from the Fokus locality to another, which brings him closer to friends and relatives or to places with better job openings. During the vacation season, moreover, a Fokus tenants may switch flats temporarily with a handicapped person at another locality. Both then enjoy access to the home welfare service at the new "holiday

resort". The tenant may also provide guest accommondation over a weekend or so to another handicapped person, who likewise qualifies for service.

Problems of the Severely Disabled: A Community Concern

The Fokus programme, together with the investigations that Fokus has sponsored, proves that the severely disabled in need of constant care are a small, neglected group. Most of them have been handicapped from birth, which accounts for deficiencies in their education, and after finishing school many have been reduced to living on disability pensions.

Each year 40 or so handicapped persons in Sweden may be expected to enter a situation which generates the need of a dwelling with service according to the Fokus system. So far their problems have not received attention from the body politic, which is more inclined to deal with the most acute cases by commitals to nursing institutions or chronic-care clinics. None the less, Fokus has shown with its programme that arrangements to house and care for severely disabled persons are indeed feasible at very reasonable expense. These persons need no longer be constrained to stay on in parental homes or become inmates of institutions. These handicapped, too, deserve the right and the opportunities to a home of their own. Although the Fokus solution opens new vistas for the severely disabled, it is also an advantageous solution for the community.

The communtiy must also assume responsibility to satisfy the legitimate demands of the severely handicapped group here at issue, demands for homes they can call their own as well as for guaranteed service.

One to One

now known as the INDEPENDENT LIVING SCHEME

For more than 20 years Community Service Volunteers has provided young people with opportunities for full-time voluntary community work. Traditionally, placements are with groups in institutions or with organisations. A recent development is the One to One scheme in which volunteers work with physically handicapped people in their own homes, enabling them to lead independent, near-normal lives in the community with CSVs to compensate for their physical disabilities. Volunteer director Marion Janner describes the aims and scope of the One to One scheme and its implications for housing services.

CSV's One to One volunteers work for a minimum of four months, extendable to six, in return for pocket money, board and lodging and travelling expenses. Along with a monthly £45.00 per volunteer placement fee to CSV, these expenses are generally met by the volunteer user's local social services department, or other appropriate statutory or voluntary organisation, through which all One to One applications must be channelled. The volunteer user might contribute to the cost of having volunteers out of their salary or attendance allowance.

Because all One to One "projects" are people, with a wide variety of lifestyles, ages and disabilities, it is difficult to generalise about volunteers' working and living arrangements. However, about half of the One to One volunteers do not live in the volunteer user's home, but in a local setting such as a staff flat in an old people's home. Permutations of living arrangements, both existing and potential, will be discussed later in the article.

The volunteers are young — mainly between 18 and 22 — unqualified and untrained in matters concerning disability, and most have never worked with physically handicapped people before. However, the physical care aspect of One to One work is almost never a problem, either for the volunteer or the user. Many of the benefits of this arrangement (which of course is not suitable for every physically handicapped person) lie in precisely this feature. The volunteer acts as a "facilitator", as if they were a working extension of the CSV user, performing the physical tasks that the disbled people cannot manage for themselves. These include elements of physical care (often erroneously perceived as nursing duties) such as dressing, washing and toileting, and may involve housework, driving and acting as amenuensis. The volunteers may also be needed to provide social support for the volunteer user, particularly if their placement is part of the rehabilitation process — perhaps after a recent, disabling accident, or after many years in an institution.

The aim of the scheme for the users is to enable them to lead the independent lifestyle they choose, preferably the one they would pursue were they not disabled. As they have people acting as their arms and legs — generally two or more volunteers working a rota for each user — at least theoretically, there are almost no activities which are barred to them. In practice, however, even the most willing and strapping of volunteers might be daunted by the prospect of several flights of steep stairs! This scheme is sufficiently flexible to encompass people with very different needs and lifestyles. Whether they are students, elderly people, people living with their families, single parents or single people, they will all share the desire to remain in, or perhaps move into, their own homes in the community, and to continue the activities they want to, be they professional, domestic, or recreational.

CSV, it should not be forgotten, is an organisation concerned with volunteers, and it would be wrong to ignore the volunteers' aims or motivations. Again, it is difficult to generalise, since they too come from very different backgrounds: perhaps they have four months to spare before taking up their first job and they want to participate in a way that they are unlikely to be able to do in the future, whether because of limitations of time or finance, or they may want experience relevant to a social work qualification. Many apply to be CSVs because they do not know what they want to do in the future, and this is one way of enabling them to do interesting and enjoyable work which is also of considerable and very tangible benefit to others.

Given this background, various implications for appropriate housing become apparent. What are the main housing criteria for the volunteer users? The answer to this is probably a wish to live as normal a life as possible, in an ordinary (suitably adapted) house or flat, in an ordinary street of their choice.

In order to be able to do this, they need the support of carers, in this case volunteers. They need the volunteers to be near enough to them to be on call for any unexpected eventualities, but they also need there to be sufficient distance between to provide everyone with some privacy and independence.

This consideration is also very important to the volunteers. A One to One relationship is necessarily an intense one, and its insularity needs to be diffused. The emotional demands, in particular, on the volunteers, mean that they need to have their own rooms for their off-duty times. One of the main problems when their rooms are simply others in the volunteer user's house, is that it is difficult for the volunteers to draw a distinction between working and off-duty hours. Another is that it makes it difficult for the volunteers to regard their rooms as their own territory, rather than an integral part of the volunteer user's home.

Volunteers also want their accommodation to be close to, but separate from, the volunteer user's, for the sake of convenience. Given the choice, most volunteers would rather have a walk of seconds, rather than minutes, to their work; everyone, including social services departments, appreciates savings in transport costs and the increase and safety that is afforded when volunteers' accommodation is close by.

The ideal housing situation, therefore, for physically handicapped people who need constant assistance from carers, has been found to be an independent, self-contained, house or flat attached to the volunteer user's. This may be next door, or above the user's accommodation, and preferably physically accessible to them. Alternatively, volunteers may also be housed a few doors or streets away. This may be particularly appropriate if there is a core of volunteers acting as carers for several people living nearby.

This latter arrangement is very similar to the Fokus housing schemes in Scandinavia, and the existing English version — at the Spastics Society, Neath Hill, in Milton Keynes. However, there are limitations to those schemes where a central group of care attendants support disabled people living in wheelchair housing, integrated with mobility housing. A brief outline of some of the difficulties may help to illuminate alternative features in the One to One scheme.

1 Fokus-type schemes provide a fuller degree of support for the more severely handicapped than those housing schemes which make no provision for carers. However, their care attendants only provide "in-house" care. This inevitably restricts what the disabled person can do outside their home.
2 Physically handicapped people also have their choice of accommodation limited by the location of particular schemes.
3 Some care attendant schemes in Europe place additional restrictions on the disabled people by first making them request the help they need in advance, because the care attendants are situated some miles from their homes.
4 They may only do the things that the clients cannot do for themselves, so even if it takes a client three hours to prepare a meal, their ultimate ability

precludes care attendants from helping with the tasks.

5 Finally, an aspect of living in this type of housing scheme, which their residents find most unpalatable, is the fact that it is classified as Part III accommodation (or its European equivalent). The financial as well as social implications of this need not be elaborated on here.

Of course, the One to One scheme is not without its own difficulties. One of the main administrative ones is that there is often no "community care" budget out of which the local authorities can pay for the volunteers. This produces various administrative delays or anomalies such as volunteers being financed out of such categories as "home helps", or even "aids (without an e) and adaptations".

Problems also arise when the prospective volunteer user is in residential care and being financed by a local authority different from that of the institution. If he or she wishes to move out to live independently in that area, their home authority is generally not prepared to pay for their house or the costs of their volunteers. Their new local authority is often very reluctant to accept responsibility for providing this finance. Their financial commitments to the disabled people living in their area can be seen as multiplying considerably if the residents of the institution become independent residents in their communities.

However, disabled people want the same range of choice of accommodation as the able-bodied. Maybe they want to live in a flat or a house, in the town or in the countryside, alone, with friends, with family, in group homes, in a residential institution or in an integrated housing scheme. Their housing needs cannot be seen in a vacuum, bu must be related to the wider neighbourhood in which they live. They need access to neighbours' homes, shops, offices, public transport, and all other amenities. Obviously, this is more feasible when the housing scheme is being designed from scratch, but these benefits are then offset by limitations of separateness.

In order to have a realistic choice of accommodation, disabled people need to have viable alternatives. Some alternative care arrangements have been discussed already. The two main relevant services other than One to One in England, are Crossroads and the Leonard Cheshire Family Support Service. Both are run on the basis of relieving carers for a certain number of hours each week, by doing the tasks they would otherwise do, such as physical care, shopping and housework. This provides a very important and flexible service, especially for people who do not need constant physical help in order to live independently. But, like the Fokus and similar schemes, these two services provide only "in-house" care, and are mainly for disabled people living with their families, or some other form of existing support.

To conclude, here are three contrasting housing arrangements for disabled people using One to One CSVs. One volunteer user lives with her young son in a three-bedroom adapted house on a council estate in Moss-side, Manchester, with the support of three CSVs. There are bedrooms for the user and her son, and for the one volunteer who sleeps in the volunteer user's house. The volunteers have an off-duty base in a flat in a local authority old people's home several miles away. The most serious disadvantage this arrangement poses is the alarming number of assaults that have been committed on the volunteers when they have been travelling between their flat and their work. As these volunteers are all female, their vulnerability is dramatically increased.

This risk has been completely eliminated on a project in Birmingham, where the accommodation was designed and executed by a local housing association. The volunteer user and her husband live downstairs, and the volunteers have a self-contained flat upstairs. The main drawback of this particular design is that while it is very convenient for the volunteers to get to the volunteer user, she cannot visit them, since there is no lift to get her wheelchair upstairs.

Another type of living arrangement which is quite common is when volunteers and user share the one house. This has its drawbacks, as neither party has a bolt hole, and communal living often creates tensions. Additionally, this does tend to compromise the user's feeling of independence. Recently, we have started a project where the living arrangements are probably the most satisfactory. In this case the volunteers live in an adjacent unit to the disabled person, and both units are accessible to the CSV user. When the disabled person is renting accommodation, for example, from a housing association, then they have the tenancy on their own unit, and the local social services department which sponsors the CSV takes the tenancy on the CSV's living unit.

For too long the now politically fashionable move to community care has been almost synonymous with mothers or wives staying at home to care for the disabled member of the family. The One to One scheme is one response to an enormous need for flexible schemes which enable all sorts of people with many types of disability to live in whatever type of accommodation they feel is most appropriate for them. Our experience has shown that where there is a need for constant support from carers who are not relatives, there is a concommitant need for suitable housing arrangements which gives the disabled person and the carers both proximity to, and privacy from each other. As local authorities and housing associations recognise this need and design and build accordingly, many more people will be able to enjoy the benefit of an independent life in the community.

Left: The volunteer performs the physical tasks that the disabled person cannot manage for themselves. (Photograph: Iftikhar Awan)

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Highly recommended

GROVE ROAD HOUSING SCHEME - SUTTON IN ASHFIELD

1. Origins and Aims

The inspiration for the scheme originated with physically handicapped people whose primary aim was to create the conditions whereby they could get married and lead lives integrated into the community, enjoying the same rights and responsibilities as ordinary citizens.

2. Objectives

The severity of their handicaps would, in the absence of family help, place the people concerned at risk of institutional care. Since the aim of the scheme is generally counter-institutional in character, brief reference to some of the basic features found in institutions for the physically handicapped is necessary as a preface to the main objectives:

(i) Institutions disable physically impaired people by taking them out of the community and aim to cater for their physical needs in batches, under the same roof and under the same regime.

Thus the scheme had to be physically blended into the local community and cater for handicapped tenant's needs in the privacy of their own homes and in a way which supported their individuality.

(ii) Institutions are provided ostensibly because local domicilary services, by themselves, are insufficiently comprehensive and flexible to meet the physical needs of severely handicapped people in the community.

Thus the community based alternative scheme had to embody a system of help sufficient to make up for the deficiencies in locally available services in meeting tenants physical needs.

(iii) Institutions have paid staff who organise and provide help which is theoretically available to inmates all the time whether or not it is wanted by, or appropriate to their real needs.

Thus the help provided in the scheme should correspond to the help needed. Handicapped tenants will best know their own physical needs, but since the dependency situation involves a relationship between the helper and the helped, the organisation of actual and anticipated care should be a co-operative effort. Payment for help given should not be controlled by any outside body.

(iv) Institutions are dependency oriented. Staff see themselves in a primary helping role and inmates as the dependent recipients of care. Comprehensive aids to individual independence are rarely provided - or, if provided, used - by either inmates or staff.

Thus the scheme should be oriented towards the independence of handicapped tenant's. Helpers should see themselves primarily in a supporting role. Aids and equipment should be provided, as available and appropriate.

(v) Institutions occasionally allow inmates opportunities to present limited views on aspects of organisation. But democratic participation in areas where inmates can usefully contribute is often actively discouraged.

Thus maximum opportunity should be afforded to all tenants to bring their personal resources into the scheme and actively participate and exercise effective control over a living situation which has potential for a strong sense of community.

3. **Concept**

The aim and objectives are planned to be realised through the provision of three ground floor flats specially designed and equipped for physically handicapped tenants, in conjunction with three first floor flats for able-bodied 'supporting families' who will co-operate together in supplementing locally available domiciliary services in meeting handicapped tenants needs.

4. **Co-operative Principles**

A substantial degree of co-operation between the initiators, the Housing Association's architect, the local authority, potential tenants and others has brought into being a building which embodies the above concept.

Continuing co-operation is seen to be necessary between the tenants representative body and the Housing Association, while the scheme is in operation. The function of each of the parties in matters such as tenant participation in management and the provision of services, should be clearly defined. It is felt the Association should accept the need to advise and support tenants through access to their specialised managerial/technical skills.

Full inter-tenant co-operation is prerequisite to the smooth running and long term stability of the scheme for the following reasons:

(i) To meet known and anticipated handicapped tenants needs within the context of a scheme which secures no one in particular full-time source of help - and where help will be required intermittantly over the course of the day.

(ii) To make maximum use of the opportunity to reduce pressure on supporting families, by spreading the load as efficiently as possible. This will increase flexibility of opportunitity for supporting families to pursue their own interests within the limitations of their undertaking to provide necessary support.

Co-operation between tenants and the local/area health authority services will be a continuing responsibility.

5. **Tenant Responsibility**

A high degree of co-operation at a number of levels - some particularly personal - will characterise the concept in operation.

It is considered essential that potential tenants should display an understanding of and commitment to the special undertakings and levels of co-operation in the scheme.

The Tenancy Agreement should incorporate a statement which makes plain tenants responsibilities for full inter-cooperation in maintaining a satisfactory level of help.

6. **Continuity of Help**

Given such a substantial degree of inter-tenant co-operation, disagreement between tenants could lead to breaks in the continuity of support. A framework within which disagreements can be approached has been suggested as a basis for democratic discussion within the Tenants Group (7.). The procedure which emerges will need to be agreed with the Housing Association.

The tiers of support listed overleaf indicate the extent of a fall-back in the event of care failure.

Continuity of Help (continued)

i) Participation by physically handicapped tenants in the development of good design and the incorporation of the right aids and equipment in the scheme, will lead them to maximise their own potential for independence. Their own self-sufficiency will be the first line of support.

ii) Home Helps and Community Nurses provided as part of the locally available domiciliary services.

iii) Three supporting families co-operating to give help act covered by (i) and ii) above.

iv) Voluntary support co-ordinated through a 'local liaison committee' or a sub-committee of the Tenants Group. WRVS support has been agreed in principle by the local District Organiser.

v) Relatives and friends, some of whom live close to the scheme.

vi) Selective hire of an agency nurse in conjunction with financial help appropriate to the individual circumstances of handicapped tenants.

7. **Tenants Group**

Given the ability and desire of some tenants to participate more actively than others, it is nevertheless considered important that some degree of participation should be accepted by all tenants in matters relating to management/organisation of help in the scheme. Involvement in, and indentification with the scheme will be key features in the development of strong community spirit. A direct democratic basis to the Group's operations should be possible given the small number and proximity of the units - and this basis will help prevent control lying with a small minority.

The Association should accept the Tenants Group (or elected officers thereof) as the representative body in its official dealings and consultations with the scheme.

Some of the more important aspects of the Group's activities which can be forseen are:-

i) To discuss the need for a Constitution which properly defines the Group's functions.

ii) To act as the medium through which the organisations of day to day routines of help can take place.

iii) To act as the medium of mutual education of common needs and difficulties arising out of the dependency situation.

iv) Agree on a framework for the handling of possible intertenant (or external) disputes including provision for independent arbitration.

v) To set up an agreed system of payment for help given and received.

vi) To consider the need for setting up a Sub-Committee, involving links with local support sources.

vii) To monitor the progress of the scheme.

CD JH
25 July 1977

Spinal
Injuries
Association

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QUOTES ON HOUSING TAKEN FROM THE TETRAPLEGIC SURVEY

"As I was unable to be looked after at home when I left Stoke I went to a Cheshire Home. The effect on my morale was terrible."

"The hardest thing was trying to remain living independently and bringing my children up who were six and nine years old at the time of the accident. After my husband left the difficulty was finding living in help. I have now overcome this during the last six months after finding out, through television, about Community Service Volunteers."

"Being tetraplegic has made me totally dependent on my mother, my social life is limited."

"I am lucky in that my mother has devoted her life to caring for me, but she is now 76 and I can see the time coming when I shall have to go into residential care."

"Housing and after care are two of the most important points in my opinion."

"It has broken my mother's heart and prematurely aged her - instead of having an able bodied caring daughter for her old age, the roles are reversed and we both worry about trying to care for each other."

"The main problem I find is the right sort of care and the time given. I am now due to move into a house in South London which will have four CSVs living in to assist in any way needed, organised by a charity called SHAD. When I move into the house I shall have total freedom to do all I want and need."

"I think a wife of complete tetraplegics should be classed as fully employed and insured against injry and have time off and holidays free from responsibility."

"The good things are that I met my wife, and am happy that I am living within a family rather than in a disabled unit where I was living before my marriage. Problems - getting somewhere to live when I decided to leave the disabled unit, i.e. finding a council prepared to put us on their housing list. Then the problem was trying to purchase the bungalow under the Right to Buy Act."

"The worst thing is getting about - I live in a village and I have to rely on my father to take me any place I want to go. I think my parents could do with some help from time to time or a place for me to go to give them a rest."

"Two major areas of concern are a. employment, which is difficult to obtain despite my qualifications and b. being reliant on my wife for personal care, when the opportunities for relieving this burden do not exist, at least to suit the convenience of me and my wife."

"Personal care is difficult to find and receive on a continuous basis. Relief help is almost impossible to find. It is impossible to fulfil roles in the accepted sense, e.g. being a wife and mother. The change requires a great deal of adaptability on the part of the disabled family and their family and friends. It seems to me that most of the above problems result from the fact that disabled people are not integrated into society."

"I have to live away from home and can only get home at weekends. I am due to go home for good when the council build an extension but that could be some time, and when I do it means my mum might have to give up her job, which she doesn't want and can't afford."

"I feel I could be more independent, but I hold down a demanding full-time job and would rather have assistance so that I can work than be fully independent and using all my time to get dressed and undressed. My distant dream is my own place one day - I live with my family at present. I believe I could cope in a well designed, gadget infested kitchen."

"The worst aspect of my life now is having to continually battle in my attempt to live a relatively normal and personal life in here, because although physically it is in many ways suitable for me, it is also the most patronising, undemocratic 'warehousing' institution imaginable."

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Now in operation

1. INTRODUCTION

The North British Housing Association Limited have for many years developed schemes specifically for the elderly and more recently the mentally disordered. Prompted initially by The International Year for Disabled Persons, attention was drawn within the Association to the needs for the physically handicapped within the community. This interest was heightened by a request from the Greater Manchester Council for Voluntary Services to Housing Authorities working within the North West, to consider providing a housing scheme for physically disabled on a similar basis to the Milton Keynes version of the Swedish 'Fokus' scheme.

2. SCHEME CONCEPT

The Association was proposing to develop a housing scheme of 131 dwellings at Watling Street Road, Preston. The scheme is on a flat site and in a location which had many advantages for the disabled. Realising the opportunity offered by the development, six ground floor flats were identified for re-design to render them suitable for occupation by a wheelchair confined person.

Care support would be provided by Community Service Volunteers (CSV's) who would be resident on site. A large family dwelling was identified for re-design to produce furnished single person accommodation.

To allow reasonable integration, all remaining dwellings with ground floor accommodation are to be built to mobility standards to allow entry for visiting by disabled persons. Hence the scheme proposed is aimed at permitting severely disabled persons to live, with the necessary support, within and as part of the community.

3. PARTIES TO THE PROJECT

Early consultations between the three parties to the project, N.B.H.A., C.S.V. and Social Services Department, were concerned in securing funds to meet operational costs for the project from the Social Service budget. Approval from the Social Services Committee was secured at an early date, due in part to a general acknowledgement that financial savings could be made should clients currently in residential units, being supported financially by Social Services, be included in this project.

The annual cost of theC.S.V. support, including the cost of theC.S.V. accommodation will be met by Lancashire Social Services Department, supplemented by payments from the six residents from their special allowances.

Once funds had been secured for this project, consultations were arranged on a regular basis to establish and maintain links and to define areas of responsibility.

4. IDENTIFICATION OF CLIENTS

Total nomination rights were granted to the Social Services department by N.B.H.A. with regard to the identification and selection of clients for the six units contined within the scheme.

Social Services department are to adopt the following criteria when selecting clients, firstly the scheme should accommodate Prestonians, secondly the principle aim of the project is to take persons out of residential units, be they Local Authority Part III institutions, or independent homes provided by such foundations as the Cheshire Homes. The next category of person for consideration would be those identified by a field Social Worker and who is currently living within the Community and who is likely to be admitted into Part III or similar type accommodation within the near future. A typical example would be a single physically handicapped person living with aged parents.

Prior to offering any client a unit it is proposed that for a period of some two to three weeks, the prospective client attend Sharoe Green House, where a short 'rehabilitation' programme has been devised to assist persons who previously may have very little experience of anything but instituionalised life. The short rehabilitation programme covers such topics as home management, budgeting, cooking etc.

5. DEGREE OF CARE

Care support would mainly be provided by the Community Service Volunteers who will be resident on the scheme. Dependent upon the needs of individual clients it is envisaged that, initially, a team of eight CSV's will be required and these will be resident in one house on the development. A 24 hour emergency communication system is to be installed which will link the disabled persons dwellings and the CSV accommodation. The CSV work on a one to one programme working with individuals rather than being attached in a more general way to organisations or institutions. The CSV view the disabled persons as the expert in their own care, and act in the main as working extensions, doing on behalf of their client all the things which they are unable to do for themselves.

The care support needs of individual clients would be met by the CSV on a 'rota' basis, supplemented as necessary and appropriate by the Social Services Department and Area Health Authority.

6. ADAPTATION WORKS CARRIED OUT IN UNITS

The six ground floor units identified for the project are scattered within the development, all units have been designed to meet the wheelchair housing criteria and other related design circulars [DOE/WO Circular 74/74 120/74 and HDD Occasional Paper 2/74].

Furthermore, each unit (except one where planning permission was refused) is to be provided with a carport, this is aimed at assisting clients mobility.

The detailed design of the dwellings has been carried out in close liaison with an occupational therapis, social workers and individual wheelchair users. The final 'fitting out' of the dwellings will be designed around the particular needs of the identified occupants.

7. FURTHER INFORMATION

Further information on the scheme can be obtained by contacting one of the following:-

Bernard Gallagher, Regional Housing Manager, The North British Housing Association Limited, Unicentre, Lord's Walk, Preston PR1 1DP.

David Halpin, Lancashire Social Services Department, Moor Lane Day Centre, Moor Lane, Preston.

INTRODUCTION

P81 is an approach to Independent Living put forward by a group of disabled people mostly resident at the Le Court Cheshire Home.

The members of the P81 Management Committee are:-

John Evans	Chairman
Philip Mason	Secretary
Philip Scott	Treasurer
Liz Briggs	
Peter Wade	Trustee Cheshire Foundation
Neil Slatter	Spinal Injuries Association Management Committee
Tad Polkowski	
John Lambert	
Julian Crowder	Le Court Management Committee
Graham Thomas	Le Court Management Committee

All the foregoing are severely disabled.

Ann Parkes	General Manager, L.C.F. Housing Association
Judith Cowley	Senior Advisor Disability & Rehabilitation, Hampshire

This group is wholly responsible for all operations of the scheme.

Our concern is with those severely disabled people who cannot exist without daily personal care assistance, ie. help with washing, dressing, toiletting, cooking, etc.. This need has, until very recently, meant one of two alternatives: care from parents/spouse or care from staff in an institution.

We hope to help change this situation by making it possible for severely disabled people to live where and how they choose, something that is taken for granted by the able-bodied.

P81 has been in existence for three years. We have been working with our fellow disabled friends, statutory authorities, concerned charities and the Housing Corporation to try and enable severeley disabled people to move into homes of their choosing, provided by a housing association, and with personal care needs being met by Domicillary Care provided by the Local Authority.

These aims involve changing attitudes and practices. This is beginning to happen:- "Care in the Community", a DHSS Consultative Document, July 1981, "Most people who need long term care can and should be looked after in the community. This is what most of them want for themselves..." However, in practice there is little evidence of this approach.

Our major task has been and will continue to be the practical details involved in implementing this. It is up to us to demonstrate how one actually brings about INDEPENDENT LIVING. That is, enabling the disabled person to realise their aspirations in a manner compatible with the means and resources available.

Besides the obvious humanitarian arguements, there are sound economic reasons for the change. This aspect is most heavily featured in the promotion of Independent Living in the USA. Gini Laurie commented in the Rehabilitation Gazette, 1973:- "Millions of dollars are being wasted in maintaining severeley disabled people in hospitals and nursing homes all over the world. A majority of these could live happily and productively in the community for a fraction of the cost of any institution if some assistance were provided."

To be succesful we had to become as well informed as the experts and so we embarked upon an extensive research program in the UK, Denmark, Sweden, Holland and the USA. (Our Chairman John Evans, went on a six week tour of the USA looking at their Independant Living Movement.) Besides increasing the knowledge and experience of the group, we have had many opportunities to share our endeavors both nationally, (Naidex 81) and internationally. (EEC Independent Living Seminar, Brussels. VIF Conference, Munich.)

The idea that severely disabled people should be removed to residential institutions in order to obtain the personal care they require is still prevelant. In Britain this remains the dominant opinion and practice amongst the Medical and Caring Professionals aided by the Concerned Charities. From the earliest days we have had to combat this opinion.

We have met with representatives of the Social Services in Hampshire and have obtained an agreement in principle from the Director of Social Services, that they will seek to provide the Care Support necessary for a severely disabled person to live independently in the community within this area.

We have also arranged through a housing association, the purchase of a bungalow in Cowplain, Hampshire, for one of our severely disabled members, who will rent the property and so be able to move out of Residential Care iminently. This we trust will be the first of many such successes.

The housing association has also purchased another property in Southampton to house two more members and some able bodied tenants. In this instance, according to the wishes of the future occupants, it is intended that the property be sub divided into bed-sits, while other areas are communally shared.

The Future.

Our primary task will be to establish those members of our group who wish to live outside the Residential Institution (four people at this time), in homes of their choosing with the appropriate Care Support. We shall also continue our researches and offering our expertise and experience to any who seek it.

It is hoped that the operation of P81 will be something that other severely disabled people can copy, forming a bridge from Institutional Care to Independent Living and also, helping as many as possible to avoid having to enter such establishments in the first place.

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HOUSING AND SERVICE FOR THE HANDICAPPED IN SWEDEN

An account of what the Fokus Society does to promote integrated living conditions for the severely disabled persons by Sven-Olof Brattgard, Folke Carlsson, Arne Sandin.

The Fokus Society and Its Objectives

The 1960's was a decade of greatly improved facilities for the rehabilitation and education of severely handicapped children and teenagers. However, this has not been matched by a similar effort to provide physically impaired young people with housing and services. Up to now many of these persons have to spend their lives in isolation and idleness at nursing homes or institutions for the chronically sick whenever their parents have been unable to look after them. The mere suggestion that they might manage homemaking on their own used to be widely considered unthinkable.

In 1964 the Fokus Society was established in Sweden. It's objective is to help the younger ambulant impaired (those who are partly or wholly dependent upon technical aids and personal assistance in order to facilitate moving about, personal hygiene, dressing and undressing, shopping, cooking and transportation), with housing services and guaranteed care so that they can live in their own homes under the same conditions as other people and not be reduced to isolation and idleness at nursing homes and sanatoria or have to stay on at the parental home, with all the burdens that this implies.

What Fokus had in mind was to include apartments for the young handicapped in ordinary rental housing. They would be designed to enable the handicapped person to manage independently as far as possible. The dwelling units would be intended for single as well as multiple occupancy even though emphasis would be put on one-person apartments. Personal assistance would be available on a 24 hours basis. There would be direct access from the apartments to common-use spaces. Eligibility for accommodatiuon would extend to handicapped persons from all over Sweden.

The apartments were to be centrally placed in ordinary residential areas and in ordinary structures mixed with apartments for the non-handicapped. By locating the apartments in communities with relatively good employment opportunities and full-fledged education programmes, it would be easier for the handicapped person to get and hold onto a job.

The Fokus Society seeks to encourage work contributions and provide capabilties to enable the tenants to avail themselves of public resources on the labour market. Fokus interprets its mission in terms of helping the handicapped person in his whole situation, the better to enable the tenant to lead his life without unnecessary restrictions.

In line with this objective, Fokus has formulated certain basic principals as follows:-

* The handicapped person shall have the right to choose his dwelling irrespective of where he lives.

* The handicapped person shall be permitted to live in an ordinary residential environment and use his dwelling under the same conditions as others.

* The handicapped person shall feel secure on the strength of access to personal service.

* The handicapped person shall be given all necessary support to enable him to choose, obtain and retain employment.

* The handicapped person shall be given opportunities to engage in meaningful pursuits.

Target: The Severely Disabled - A Small, Neglected Group

Hence the primary target group at which Fokus aimed consisted of younger persons suffering from severe locomotor disabilities, a group that must have technical equipment and personal assistance in order to cope with the activities of daily life (ADL), such as dressing and undressing, visits to the lavatory, cooking, shopping, etc.

Guidelines for the design of dwellings and the close-in environment were drawn for Fokus by a special task force consisting of architects, rehabilitation experts, consulting engineers (heating, ventilation, sanitation and electricity) and handicapped persons. The task force sought to plan specially designed dwelling units which permitted maximum flexibility to accomodate individual needs. It was also called upon to plan the common-use facilities that might be needed: rooms for use in emergencies, for the care of clothing, for washing-up etc. This part of the project included the design of an emergency signal system that could be used by the handicapped.

The task force presented the first draft of a conceptual scheme in the spring 1967. This proposal was then reworked into finalized shape in the following year. Its title: Principles of the Fokus Housing Units for the Severely Disabled. This manifesto has formed the basis for planning the different Fokus units. It is published in German and English versions.

With the task force report as the starting point, work began on the design of flexible kitchens and bathrooms. Interior fittings such as cabinets and work counters are manufactured to Fokus specifications by designated suppliers. In Germany, for instance they are produced by Berufsforderungswerk Hamburg G.m.b.H. Here Fokus does not confine itself to quality control of the production process, but all regularly informs the produce of the experiences that are gained.

Fokus undertakes to select tenants for the apartments. In addition, the local executive committee are brought in to ensure that service personnel are available.

A fundamental principle of Fokus planning is that every tenant shall have his own apartment. A single "all-purpose" room, even if equipped with kitchen facilities and the like, cannot be accepted as a long-term solution of the handicapped persons housing problem. All units are planned for the severely disabled from the outset. The recommendations drawn up earlier by the Fokus planning group have been followed.

Fokus has apartments for families as well as individuals, Some dwelling plans, especially those for one-person accommodations, provide for an "all-activities room". The rationale here is to have a dwelling which puts the tenant at the centre of activity on every occasion, enabling him to keep in touch with everything that happens round him, whether he be in bed, sitting in the kitchen or lounge on a sofa or armchair. All interior fittings are detachable, which permits the tenant to shape his dwelling as he sees fit.

All interior fittings are adjustable for height, both in the kitchen and bathroom. Maximum livability put in the handicapped's hand, regardless of whether he is tied to a wheelchair or uses crutches.

Various technical amenities are built into the apartments. Thus the electrical controls are assembled in small movable boxes that can be placed next to the bed, in the kitchen or on the wheelchair. In the latter instance, the switching is radio-controlled so that the handicapped person can move freely in the room. When the installed equipment is activated by the switching device, the tenant can open doors, call for help, talk in the house telephone, turn the lights on and off and so on. All apartments are connected to on-duty personnel by intercom. As a rule, too, the tenants have their own telephones.

All Fokus dwelling units adjoin common-use spaces. Those facilities are open to all tenants, handicapped as well as non-hanicapped. There are recreation rooms with TV sets and communal dining rooms with kitchen for those who prefer to eat in the day's

main meal in the company of others. Separate rooms are usually set aside for physical training and exercise, each containing items of equipment suited to individual capabilities. There are craft activity rooms, likewise fitted with specially designed equipment.

An adjunct of most Fokus units is a hygienic department, which has bathing equipment especially adapted to the severely disabled, Many places also come with a sauna. Separate provision is usually made for a clothing-care room in which suitable designed washing machines, dryers and mangles are installed, Plans are in hand to build garages for wheelchairs used outdoors. Wherever feasible parking stalls for car are provided as an integral part of the structure. In other cases garaging consists of carports equipped with electrical car-heaters,

Service personnel are provided with staff rooms as well as with an office or on-duty room.

Fokus has striven to obtain central locations for its apartments wherever possible. This makes it easier for the tenant to take part in community activities, develop interpersonal relations, do his own shopping, etc.

The Full-Care Service - Scope and Organistion

Once a severely disabled person has been provided with a dwelling adapted to his handicap, it is just as important for him to enjoy a function-worthy personal service. The handicapped tenant in a Fokus unit will have that need met by the Society's staff, over and above the service he may obtain from the public home-help programme.

Many handicapped persons, especially the severely disabled, may need round-the-clock service for all functions which relate to life's daily rounds. The most salient needs have to do with dressing and undressing, help with personal hygiene, getting food and shopping. Moreover, the handicapped person who lives in his own dwelling needs help with cleaning, bedmaking, laundry etc. Provided those tasks are not too heavy, many of them can be performed by home helps or by another service organisation. However, owing to the need of the severely handicapped for 24 hour sevice as well as the size of assisting staff required, this programme differs from that traditionally associated with home nursing. That is why we have elected to call our programme with full care service.

The starting point for any assessment of the need for such service must be what the handicapped person can do on his own and the time it takes him to do it. Consideration must also be given to all technical arrangements that can reduce the need for service and make the handicapped less dependent on others for help.

Service for the handicapped is cast in organisation modes that differ slightly from one locality to another. This reflects the different philosophies prevailing among county councils and municapilities. The basic principle has been to allot the handicapped person as many hours of help from a home samaritan as though he lived in a so-called interpersed invalid dwelling. County councils and municapilities have generally maximised the number of hours at four per day. For the severely handicapped with whom Fokus is concerned that is not enough. The vast majority must have access to personnel who can help them at different times of the day. To be able to meet that need, the Fokus units employ personnel who are on duty round the clock. This enables the handicapped person to recieve help whenever he wishes whether it is to go to the toilet, get undressed for bed or have his sleeping position changed. Fokus employees also assist home helpers whenever two people are needed to do heavy lifting or the like. Moreover, the home-help programme cannot easily find the manpower needed to work on weekends, which means that Fokus personnel must assume the greater part of the workload.

Several reasons prompted Fokus to adopt a full-care service, which may be defined as a system of personnel assistance and service during certain hours, which access to on-dury personnel in between. Most important of all, the tenants themselves have found this

arrangement to be appropriate. The handicapped person has someone who takes more direct care of his dwelling and his service needs, someone who takes where he keeps his clothes, what he wants to eat and so on. This makes it unnecessary to initiate every new assistant in all the details.

Another reason is that they system based on personnel who comes from outside counteracts tendencies towards "institutional thinking", i.e. by analogy with commitment to a hospital, nursing home or the like.

A third reason is that this system prevails on the handicapped person to assume responsibility for himself. He knows how many service hours he can get and must allocate them properly.

An important aspect of the full-care service is the attitude of personnel. Fokus staff must be open-minded and avoid all tendancies to treat the handicapped person as a patient. It is also necessary to show respect for the handicapped's right to independence and to management or his private affairs.

A major function for the severely disabled is the ride service. A well-functioning ride service is necessary if the handicapped person is going to be able to engage in different activites offered by the community and to get into contact with others. The ride service is being built up. Although in operation at all localities where Fokus is active, it has not yet developed in some places to the desired extent. One trouble with the ride service is that it is available in several localities only at limited times of the day.

Earlier Situation of the Tenants

An analysis of the situation for handicapped persons before they moved to Fokus apartments discloses that about 34% came from the neighbourhood, while 66% were from other localities. Most of the handicapped, 48%, had formerly lived with their parents, while 24% had been at institutions, nursing homes, chronic-care clinics or the like.

After moving into the Fokus units the handicapped took greater part in work and studies. Here, however, there was a time lag, which reflected the difficulties of finding jobs during the short period that the programme had been in operation. Even so, 45% were in employment or eudcation one year after moving in.

The Fokus dwellings made it possible for more handicapped to move together to form together families with handicapped or non-handicapped persons. 36% of the tenants cohabitated or were married.

Of the handicapped tenants 77% were tied to wheelchairs. More than half needed help with dressing and undressing, and one-third with the daily hygiene. Nearly one in five (28%) needed help to change sleeping positions during the night.

Thus the handicapped tenants in Fokus apartments comprise a group of severely disabled, who are utterly dependent on a full-care service that functions round the clock. The Fokus programme has enable them to live a more active and independent life under secure conditions. Moreover, the programme also permits the handicapped person to settle down wherever he likes, He is no longer shut in by provincial boundaries. He may dispose of his dwelling on the same terms as others and personal service is guaranteed to him. As a result he is also given new opportunities for employment, education and lesiure activities.

As a tenant of Fokus the handicapped person derives special benefits. For some tenants the Fokus apartment becomes a step in the rehabilitation process leading to a more ordinary dwelling. Because of the Society's nationwide activity, a tenant is also enabled to move from the Fokus locality to another, which brings him closer to friends and relatives or to places with better job openings. During the vacation season, moreover, a Fokus tenants may switch flats temporarily with a handicapped person at another locality. Both then enjoy access to the home welfare service at the new "holiday

resort". The tenant may also provide guest accommondation over a weekend or so to another handicapped person, who likewise qualifies for service.

Problems of the Severely Disabled: A Community Concern

The Fokus programme, together with the investigations that Fokus has sponsored, proves that the severely disabled in need of constant care are a small, neglected group. Most of them have been handicapped from birth, which accounts for deficiencies in their education, and after finishing school many have been reduced to living on disability pensions.

Each year 40 or so handicapped persons in Sweden may be expected to enter a situation which generates the need of a dwelling with service according to the Fokus system. So far their problems have not received attention from the body politic, which is more inclined to deal with the most acute cases by commitals to nursing institutions or chronic-care clinics. None the less, Fokus has shown with its programme that arrangements to house and care for severely disabled persons are indeed feasible at very reasonable expense. These persons need no longer be constrained to stay on in parental homes or become inmates of institutions. These handicapped, too, deserve the right and the opportunities to a home of their own, Although the Fokus solution opens new vistas for the severely disabled, it is also an advantageous solution for the community.

The communtiy must also assume responsibility to satisfy the legitimate demands of the severely handicapped group here at issue, demands for homes they can call their own as well as for guaranteed service.