DEVELOPING COMMUNITY-BASED RESIDENTIAL SERVICES FOR PEOPLE WITH MENTAL HANDICAP

A review of recent British initiatives based upon the principles of An Ordinary Life

DAVID TOWELL

King's Fund Centre
126 Albert Street
London NW1 7NF

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Introduction

'Be it ever so humble, there's no place like home'. So say the words of an old song. Like other popular sayings, this phrase captures something of significance to us all - the fundamental importance of home in our lives. The Oxford English Dictionary suggests why this should be so. Home is 'the place of one's dwelling or nurturing, with the conditions, circumstances and feelings which naturally and properly attach to it'. It is 'the seat of domestic life and interests'. It is 'a place to which one properly belongs, in which one's affections centre, or where one finds refuge, rest or satisfaction'. Reflecting on our own experiences it is clear that home and home-life meet a wide range of essential human needs. Home is typically the place where we eat, sleep and wash. It provides shelter and security. It offers opportunities for privacy (e.g. in making love) and freedom (e.g. in our choice of leisure activities). Home is where the relationships which provide us with friendship and affection are often sustained. It is these relationships which help us make links with the wider networks of people described by the terms 'neighbourhood' and 'community'. Home is also therefore important to our personal identities - defining our place in the world and our sense of personal worth. Finally, home is one place where we learn and grow as people.

These needs are important to all of us. In addition people with mental handicap are likely to have in varying degrees further needs which should be fulfilled within the context of their home life. Most obviously, precisely because of their handicap, they may need assistance in activities which otherwise might be undertaken unaided (like dressing) or help in coping with special problems (like physical disability). They are also likely

to require relatively intensive education in the knowledge and skills necessary for everyday life.

The aim of a residential service is to meet these needs: to provide a home and home-life for people who cannot find these independently. It requires two kinds of resources. The first are material - the buildings in which people live and furniture necessary to make them comfortable. The second are even more important - the people who staff the service and bring to it their home-making skills. Their tasks include both 'doing' and 'teaching': they assist their clients where necessary in carrying out the activities of daily living and teach them skills required for greater independence. Through their personal relationships with residents, they also foster the distinctive climate of friendship, support and mutual respect which we associate with a good home.

Residential services are of fundamental significance to the quality of life open to people with mental handicap, their identities and status in the community. Accordingly, in developing comprehensive local services, particular attention should be given to the residential component of provision. Decisions on this front will have widespread ramifications for how other elements of provision are organised and delivered. Giving prominence to residential services provides an overdue corrective to common practice in the past, which has neglected home-making as a service in itself but rather made it a subsidiary feature of more specialised services like therapy and training. In this situation, home-life, for example in mental handicap hospitals, has often been of very poor quality (Tyne, 1978). The arguments of this paper are also part of a wider challenge to traditional thinking in which a description of disability ('mental handicap') has been elevated into a label ('the mentally handicapped') which characterises whole groups of people. Such thinking

readily leads to a view of people with mental handicap as basically different from the rest of us, and to segregated services which confirm this difference (Shearer, 1981b). The starting point for this paper is that a home and home-life are things we all need although some people with mental handicap require assistance to cope successfully in a home of their own.

Prevailing types of provision

In the United Kingdom as in many other countries there have until recently been only two places in which people with mental handicap have usually lived: the family home or a large institution. In the most recent government review of mental handicap policies (DHSS, 1980 - all figures relating to England in 1977) over 70 per cent of more severely incapacitated children and 40 per cent of adults (aged 16-44 years) with severe handicap were living in their parental home. Of the remainder, among children 35 per 100,000 population under 16 years were living in hospital (this figure has since declined sharply) and 20 per 100,000 in local authority and other residential homes. Among adults, 125 per 100,000 aged 16 years or over were living in hospitals and 33 per 100,000 in local authority and other provision. In England there are still (in 1984) well over 35,000 adults with varying degrees of handicap living in large hospitals.

The last twenty years however have seen considerable expansion in a third type of residential provision through rather smaller and more local hospital, hostel or 'community' units. A pioneer was the Wessex Regional Hospital Board which in the late 1960s adopted a policy of establishing 25-place locally-based hospital units both for children and adults with severe

mental handicap (Kushlick, 1980). As the statistics above suggest, there has been growth too in local authority hostel provision typically for people with lesser degrees of handicap. Quite recently many health authorities have made plans to build multi-purpose community units (DTMH, 1978), often containing about 24 residential places.

The last decade in the U.K. has also seen a variety of innovations by public and voluntary agencies which provide the antecedents for a fourth type of provision. Following ordinary child care practice, some children with mental handicap requiring an alternative to the parental home have been fostered. A similar approach has been adopted in the 'family placement' of adults. Drawing on the example offered by psychiatric services, there have been experiments in providing 'group homes' for small numbers (e.g. 3-5) of adults with limited external staff support. Reflecting arrangements designed to secure more independent living for people with physical disabilities (Shearer, 1982), there has been modest growth too in schemes which seek to combine ordinary housing and care.

These piecemeal innovations have paralleled larger-scale developments in other countries, notably Sweden (Grunewald, 1983), Canada (Neufeldt, 1983) and the United States, explicitly based on the principle of normalisation (O'Brien and Tyne, 1981). Particularly influential in the British context has been the working model of comprehensive service provision offered by ENCOR - the Eastern Nebraska Community Office of Retardation (Thomas et al, 1978). Learning from these developments, a coherent philosophy on which to design residential services has been advanced nationally by the Committee of Enquiry into Mental Handicap Nursing and Care (The 'Jay Committee', 1979) and since received widespread endorsement. This new 'model of care' has been reflected in

regional development strategies, notably in Wales (Welsh Office, 1983) and the North West (North Western Regional Health Authority, 1982), and is increasingly reflected in local services at the 'leading edge' of current provision (Shearer, 1984).

Through its An Ordinary Life programme, the King's Fund Centre has played an important role in supporting these British initiatives. Over the past five years we have worked with policy-makers, professionals and consumer representatives to clarify ideas and identify practical steps required to establish comprehensive local residential services for people with all kinds of mental handicap. We have produced a series of reports addressing key issues arising in these endeavours, so far examining service design for adults and children, staff training, related employment and day services, the wider context of community care and leading examples of current provision (King's Fund Centre: An Ordinary Life Working Group 1980, 1982; Shearer, 1981a; Shearer, 1983; Ward 1984; Gathercole, 1984; Ward, 1982; Shearer, 1984). Drawing on this work, the rest of this chapter focusses attention on experience of this fourth type of residential provision - based on the principles of An Ordinary Life.

An Ordinary Life: Principles into practice

The An Ordinary Life programme was launched with the aspiration to see people with mental handicap 'in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their own community'. Like all visions of future services, this aspiration reflects principles which must be made explicit if they are to be used in service design and evaluation. These principles include:

- People with mental handicap have the same human value as anyone else and the same human rights;

- More specifically, all people with mental handicap have a right to live like others within the community and where necessary are entitled to the extra help which will enable them to do so;

- People with mental handicap are developing human beings and services should assist them towards the greatest possible independence;

- People with mental handicap should be involved as far as possible in decisions which affect their own lives;

- Services should therefore affirm and enhance the dignity, self-respect and individuality of people with mental handicap who are people first and mentally handicapped second;

- Services should support the social networks which people with mental handicap have already established and thus contribute to continuity in personal relationships;

- Services should be local, accessible and comprehensive;

- Existing general services available to the rest of the community (like ordinary housing) should be used, rather than separate specialist services, wherever possible.

How can these eight principles be translated into practice?

For Children. Children with mental handicap, like other children, should be expected wherever possible to live in their parental home. Among younger children this is typically the case even for those with severe handicap and problem behaviour. However there is considerable evidence (Bayley 1973; Wilkins 1979) of families (especially mothers) making great efforts to sustain this situation with little support in many localities either from neighbours or professional services. What is possible therefore depends both on parental willingness and the services available. Parents of young children need information, the opportunity to share experiences with other parents, and support from professionals, for example, in the form of early introduction to home teaching schemes. As the children grow, they need nursery schools, play facilities and holiday opportunities. Many parents also need respite either in the form of 'sitting in' and 'care attendant' services (Inskip, 1981) or through short-term care of the child by placement with other families (Oswin, 1984).

Even where these and more specialist support services are available, there are some children who need an alternative to the family home. Others currently growing up, for example, in large institutions require more suitable placements. Each locality has to provide services carefully designed to meet the needs of individual children. Following the principles set out above, the two main kinds of provision are likely to involve either living with another family (i.e. through long-term fostering or adoption) or living with a small group of other children with mental handicap in staffed housing local to their own family.

Shearer (1981a) has reviewed the growing British experience of these options, especially for children with severe handicap. Both local authority social services departments and, on their behalf, specialist placement

agencies can arrange fostering and adoption with people who should of course be appropriately housed and receive the full range of support services and welfare benefits. The largest provider of residential services for children with mental handicap in Britain is a charity, Barnardo's, which has pioneered creation of dispersed networks of staffed houses (Kendall, 1983). This approach has also been adopted in schemes designed to bring children out of mental handicap hospitals, as in the NHS project in Northumberland where three rented council houses each provides a home for three or four local children supported by care staff (Northumberland Area Health Authority, 1981; KFC, 1984b).

In a variety of similar projects (Shearer, 1981a) children and young people, some with severe behavioural, sensory or physical difficulties, are also living more ordinary lives. For a very small number of these children (some of whom have been further handicapped by the absence or inappropriateness of past provision) experience suggests that support in ordinary houses will only be possible through especially well designed and intensively staffed services.

For adults. If children with mental handicap grow up in ordinary houses in their own community, as adults they should have the opportunity to continue this form of home-life. Where young adults live in their parental (or substitute family) home, they should have the opportunity - like other adults - to move with appropriate preparation to a home of their own. Applying the eight principles, a comprehensive residential service for adults aims to provide a flexible range of housing and support options which meet individual client needs in ways designed to help each person live as full a life as possible in the locality of their choosing.

A variety of ordinary housing (some adapted for people with physical handicap) is required, dispersed throughout the community, together with a wide range of support services. Ideally each local catchment area should include the following options:

(i) continuing residence, where both client and parents choose this, in the parental home but with domiciliary support and other services available as necessary;

(ii) placement in another family home in a way analagous to fostering schemes for children (see Gathercole, 1981b);

(iii) a staffed home, where up to three or four people with mental handicap live in a house with continuing staff support appropriate to their needs (see Ward, 1983);

(iv) a co-residence arrangement where one or more people with handicap share a flat or house with one or more other people who offer support as part of the deal (see Mansell, 1977);

(v) a group home where two or more people with handicap share their own flat or house, possibly with volunteer or visiting staff support (see Gathercole 1981a; Malin, 1984);

(vi) independent housing or flats available in the same way as housing for those without handicaps to people who can manage domestic life unassisted or with visiting support only (see Shearer, 1982).

A comprehensive residential service integrates these options into a system that is responsive to individual needs and where it is usually staff rather than residents who move as the need for support in particular homes changes. A good example is provided by the 'Wells Road Service' (Bristol and Weston Health Authority, 1983). In part of Bristol, residential services on this pattern are being developed for a total population of 35,000, among whom 77 adults with severe mental handicap have been identified, together with 40 others who originate from the locality but currently live in institutions elsewhere. A constellation of dispersed homes is being established to meet the requirements of this population (schematically illustrated in Figure 5.1).

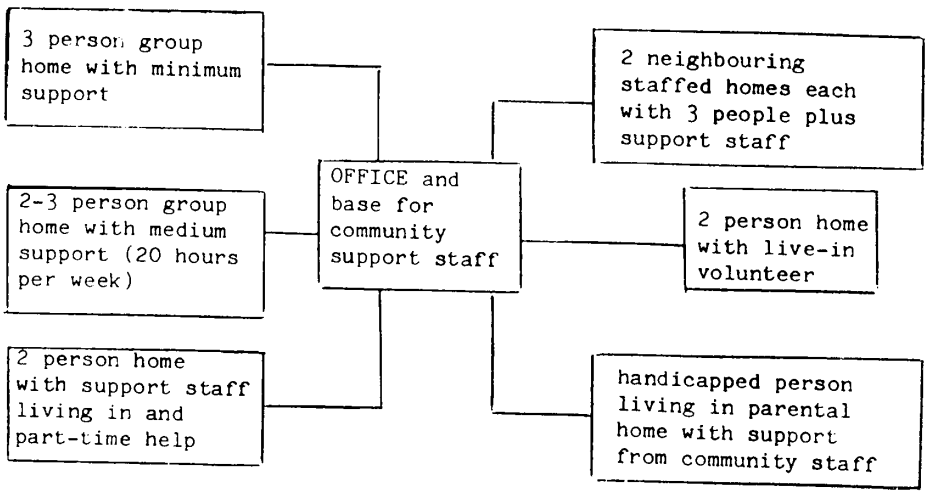

Figure 5.1: Part of a dispersed constellation of local residential options.

In this service the office provides a contact point and administrative centre for the whole scheme. It is a base for the service coordinator, psychologist and community staff who support people in their own or parental homes. The first two staffed homes offer residential support to a total of six adults with severe mental handicap and in the early days of the scheme provided for assessment and initial training of new clients moving into the local service.

Key issues in local service development

While these examples show what can be achieved, the tasks involved in developing local services are far from straightforward. There is space here only to note the main issues (referencing other sources for more detailed discussion).

(i) Establishing commitment to basic principles

The starting point for developing good services is clarification of the principles which inform service design (The 'Jay Committee', 1979; O'Brien and Tyne, 1981). As An Ordinary Life argues (KFC, 1982) a coherent set of principles provides a basis for mobilising the support of local people who will be influential in securing progress and ensuring that opportunities for service development are systematically exploited. (See also Harlow CMH/CVS 1981 and North Western RHA, 1982).

(ii) Planning comprehensive services

The planning process is concerned with converting these principles into detailed strategies for developing comprehensive local services. Arrangements are required which bring the relevant health, local authority and voluntary organisations into partnership (National Development Group, 1976; Newcastle City Council and Area Health Authority, 1981) and encourage widespread participation of people with an interest in future services. Planners have to define catchment areas for local services and identify the needs of the people to be served (KFC, 1982). Residential services have to be planned together with other elements of a comprehensive service (IDC, 1982; Welsh Office, 1978; Guy's Health District, 1981).

(iii) Acquiring appropriate housing

In Britain housing for people with mental handicap can be rented from public housing authorities or private landlords, provided by housing associations, or purchased in the private market by the statutory authorities. Ordinary housing provision (including flats and bedsitting rooms) is required, selected to meet the requirements of individual clients and adapted (e.g. to accommodate physical handicap) as necessary (Centre on Environment for the Handicapped, 1981; Heginbotham 1981; 1983).

(iv) Staffing the residential service

The most important investment is the staff: home-makers who 'do' and 'teach' and managers who provide the framework for these activities (Tyne, 1982). A local service needs to recruit and retain people with appropriate attitudes and relevant experiences, develop staff skills in home-making tasks and encourage commitment to the principles on which the service is based (Ward, 1984).

(v) Financing the service

The 'capital' costs of housing can be met through the public housing authorities, housing associations (whose government grants also permit some contribution to staffing), from health and social services budgets and occasionally through voluntary contributions (Royal MENCAP, 1982). Staff costs can be met by health, social services or the reallocation processes designed to foster 'Care in the Community' (DHSS, 1983). Social Security payments to clients can contribute to rent and running costs. Comprehensive local services require funding from a variety of these sources in order to achieve 'cost dispersal' (Heginbotham, 1983).

(vi) Operational policies and management arrangements

A vital aspect of planning is the production of operational policies which define in detail how the residential service is intended to be run (Felce et al, 1977). Management arrangements are required which foster coordination between this and other elements of the local service, and ensure implementation of the operational policies. Managerial tasks include recruitment and training of staff, their deployment to meet changing client needs, and continuing support for front-line staff in maintaining standards and avoiding isolation (McKnight 1980).

(vii) Staff training

The definition of roles and the training of staff to perform those roles are essential for the success of new services. Partly because of weaknesses in the statutory training arrangements, innovative services must invest heavily in tailor-made training and development programmes. This includes training for senior staff in setting up local services (South East Thames R.H.A., 1983) and opportunities for these and other staff to explore the values underlying operational policies as well as improve their specific skills (Shearer, 1983).

(viii) Individual programme planning

A fundamental requirement for effective delivery of services is the individual programme plan (Blunden, 1981): a written statement of each client's strengths and needs, the specific goals being pursued and the programme of intervention through which these goals are to be achieved. The IPP is established and reviewed regularly through consultation among the people usually involved with each client, with

participation of the client and relatives. It is the basis for organising daily activities so as to create learning opportunities in the home environment and elsewhere. The IPP is particularly important in ensuring a consistent and individualised approach to serving people with profound or special needs (Firth and Firth, 1982; NWRHA 1983).

(ix) Using community resources

Community-based residential services provide the opportunity for people with mental handicap to participate in local life through contact with neighbours and use of amenities available to other people. There is evidence of negative attitudes, at least among a minority of the public, to people with mental handicap moving into a neighbourhood (Locker et al, 1979) although these attitudes may change as familiarity weakens traditional stereotypes (McKnight, 1980). A further task for staff is to promote social integration within the local community.

(x) Quality assurance and advocacy

Even well designed services require mechanisms which sustain the quality of provision and highlight any need for improvements. Management includes the positive monitoring (Houts and Scott, 1975) necessary to provide staff with constructive feedback about how well services are meeting explicit goals and standards. There are also benefits in encouraging external monitoring, for example by consumer representatives (Wolfensberger, 1977). Among the tools available, PASS (programme analysis of service systems, Wolfensberger and Glenn, 1975) is particularly useful in assessing the consistency of services with the normalisation principle.

Making choices and moving forward

In most parts of Britain there remain major deficiencies in services available to people with mental handicap and in public sector resources allocated to meet their needs. Local people face important choices in deciding how best to change this situation. This paper has examined an emerging model of residential provision which aims to meet the needs of all people with mental handicap through ordinary housing in the community. This approach will typically be in competition with other proposals, most commonly - particularly in relation to people with severe handicap - the model of the small institution with perhaps 24 'beds'.

In deciding between the alternatives, five key questions need to be considered:

- How far does the proposed option reflect the values and principles which local people believe should inform service design?
- To what extent will proposed services meet the preferences of consumers in so far as these can be determined?
- What does operational experience and research evidence suggest about the effectiveness of particular services in providing high quality of life and promoting individual development of clients?
- In achieving required levels of effectiveness, what are the relative costs incurred by different types of provision?
- How well can the different options adapt to new ideas and changing needs as local services develop?

This paper has made clear the principles upon which An Ordinary Life services are built. Such services are consistent with expressions of preference by people with mental handicap and although some parents may

have initial doubts (McKnight, 1980), there is evidence of increasingly positive views among families where this option can be seen in practice. British experience of providing these services is still limited although reports from the pioneering areas are largely encouraging. Evaluative research is now underway. Early results from Wessex show that 'substantial improvements in the quality of life of severely and profoundly mentally handicapped adults can be brought about by moving them from institutional settings to those which are smaller, based in the community, equipped as autonomously functioning houses and staffed by a single category of care staff who have been given specific training on behavioural principles of teaching and interaction' (Felce, 1983). It can indeed be argued that only An Ordinary Life services are likely to achieve an adequate level of effectiveness, while available evidence (NWRHA, 1982) suggests that the public sector costs of well-staffed insitutions and services based on ordinary housing are broadly comparable. It is also apparent that the more a service avoids investment in specialist buildings, the more likely it is to prove flexible to changing demands.

Even where the choice among different options for a residential service have been made, however, there are still major challenges in making progress. Resource constraints, policy ambiguities, organisational complexities and diffuseness in professional leadership all constitute problems for local service development (Towell, 1982). At a time of retrenchment in public expenditure, there is tension between providing alternative community-based services for people living in the large institutions and offering appropriate services to the larger numbers of people still living in their parental homes (IDC, 1981). In both situations professionals will have to work sensitively with parents in planning moves for their offspring. The traditional allocation of resources for mental

handicap services can lead to the paradox of the NHS assuming the functions of other public agencies, for example in providing housing. Experience in the United States (Landesman-Dwyer 1981) also suggests that unless the development of community-based services is managed with considerable skill, the whole enterprise may lead to disillusionment and conflict.

Nevertheless bold strategies are emerging to confront these challenges. The government's 'Care in the Community' initiative (DHSS, 1983) is providing financial arrangements which promote the relocation of services based in large institutions. In Wales, government has gone further (Welsh Office, 1983) in adopting a clear strategy for local authority leadership in implementing new patterns of provision. Among English regions, the North Western RHA (NWRHA, 1982; 1983) had been at the forefront in promoting genuinely community-based services, while South East Thames RHA (see Glennerster and Korman, 1983) has given particular attention to how existing large institutions can be made redundant.

These large-scale strategies can only work when combined with the local initiative required from professionals and others to build coalitions for progress among the interested parties and seize any opportunities available to implement change (KFC, 1982; IDC 1984). At the end of the day, whether people with mental handicap are offered good services in their own communities will depend on the enthusiasm and skill of local people and their success in mobilising political support.

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