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DEVELOPING SERVICES IN THE COMMUNITY FOR PEOPLE WITH MENTAL HANDICAP

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PEOPLE FIRST

DEVELOPING SERVICES IN THE COMMUNITY FOR PEOPLE WITH MENTAL HANDICAP:

A REVIEW OF RECENT LITERATURE

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King's Fund Centre
London

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CONTENTS

CHAPTER 1 - INTRODUCTION

> "Mentally handicapped children and adults should not be segregated unnecessarily from other people of similar age, nor from the general life of the local community."
> (DHSS, 1971, p.9)

There has been much talk in the last ten years of developing community-based services for mentally handicapped people. The expectation, since the 1971 White Paper "Better services for the mentally handicapped" has been that increasing numbers of mentally handicapped people - if given the support of appropriate services - would be able to live their lives within their local community, rather than segregated away in long-stay hospitals as before.

A decade later, despite the activities of the Development Team for the Mentally Handicapped in encouraging local initiatives in the development of good services (Development Team for the Mentally Handicapped, 1978; 1980), despite the efforts and excellent publications of the now defunct National Development Group (see p.132), despite the hard thinking and recommendations of the Jay Committee (Report of the Committee of Enquiry into Mental Handicap Nursing and Care, 1979) an ordinary life in the community is still a goal rather than a reality for thousands of mentally handicapped people, their families and those involved with them. The strains and pressures for families coping with mentally handicapped relatives at home remain immense. In the absence of universally available - and acceptable - family support services and community facilities, mentally handicapped people continue to be admitted to long-stay institutions, particularly at school-leaving age or in later adulthood, as elderly parents become too frail to go on coping alone. Meanwhile, the number of people discharged from hospital into the community each year remains small. The 1971 White Paper has clearly not produced the dramatic shift to community care anticipated at the time, for a variety of reasons. Townsend (1973) has argued that one factor contributing to this failure was the impossible attempt by both Labour and Conservative governments in the early 1970s to follow two contradictory policies simultaneously: on the one hand encouraging an increased role for hospitals in the total service for mentally handicapped people; on the other hand seeking to reduce it. (For a critique of the 1971 White Paper, see Tyne and Wertheimer, 1980). More recently, national economic problems and the ensuing public expenditure cuts have imposed further constraints on the expansion of the locally based services necessary to enable mentally handicapped people and their families to live comfortably in the community.

Fortunately, there has been another, brighter, side to this gloomy picture. At policy level, the government has confirmed its commitment to the idea of community based services for people with mental handicap in a number of publications from the DHSS (DHSS, 1980; 1981) and by its acceptance in principle of the model of community based care set out in the Jay Report (see p.5). At the level of finance, it has underlined this commitment with its establishment and expansion of joint funding provisions, and its discussion in the recent Green Paper "Care in the Community" (DHSS, July 1981) of more resources for community-based care to come. (For comments on the Green Paper, see Mittler, 1982; Campaign for Mentally Handicapped People, December 1981, and Independent Development Council for People with Mental Handicap, December 1981. For the Minister's recent decisions on the Green Paper see the British Medical Journal, vol.285, August 7, 1982, p.446; for reaction to them, see, for example, Community Care, August 5, 1982, p.1 & 3).

Meanwhile, though resources may have been in short supply, innovation and commitment have mushroomed. Drawing on the suggestions of the National Development Group, on initiatives taken in other countries, and on their own ideas, experiences and common sense, parents and professionals in different parts of the country have established imaginative, pioneering schemes and services - often on shoestring budgets - to meet the needs of mentally handicapped people and their families.

The purpose of this review is to outline these new developments, their strengths and their weaknesses, on the basis of the published material available about them, so that lessons learned in one part of the country may be shared with, and benefit, people elsewhere. Describing schemes that have operated successfully should demonstrate what is possible even in the current times of economic restraint. With the help of the details given and the references to where further information is available, it is hoped that those currently involved in planning and providing services will be able to learn about, and build upon, the experiences of others in really creating "better services" in the community for people with mental handicap.

The review is divided into nine chapters. Chapter One introduces its background, purpose and structure. Chapter Two asks "What kind of services do we want?". It briefly examines the principles, or philosophy, underlying an "ideal" service for people with mental handicap, and the essential elements of such a service. Chapters Three to Eight describe the ingredients of such a service - the kind of schemes that have developed to meet the needs of mentally handicapped people and their families in the community, at different stages of their life-cycle: in the first twelve months; during the pre-school years; at school age;

in adolescence and at school-leaving; during adulthood; in old age. The divisions are, of course, somewhat arbitrary, since the need for different services will vary from individual to individual, from area to area and often beyond one particular phase of any individual's life. Nonetheless, it seemed helpful to categorise the schemes discussed in this way. The final chapter of the review explores the implications of these developments for the professionals - and others - concerned. It looks at the implications for their training and at the new ways of working that are involved, and draws out some tentative conclusions.

The primary source of information for the review has been material published since 1975, though some earlier material has also been included where appropriate. About a thousand publications of different kinds - journal articles, research reports, conference proceedings, biographies, books, even newspaper cuttings have been used, supplemented occasionally by references to projects which are as yet unrecorded in the literature, but are of interest to those concerned with service developments. Some of the schemes described may, of course, have changed significantly since the publication discussing it was written. Where possible, details of where more up to date information may be obtained have been included.

At the end of the review, there are a number of appendices. Appendix 1 outlines the sources, methods and material used in putting the review together. Appendix 2 contains the addresses of useful organisations. Appendix 3 lists the publications referred to in the text. Finally, there is a detailed index (listing authors of publications quoted and topics, schemes and organisations discussed) to facilitate quick and easy reference to the appropriate sections of the review relevant to the reader's specific interests.

CHAPTER 2 - WHAT KIND OF SERVICES DO WE WANT?

2.1 Underlying principles

> "... all policies and every aspect of service provision, every day-to-day decision to provide or not provide a service, involves principles - even if the principle is simply that other groups are more important than mentally handicapped people."
> (King's Fund Centre, 1980, p.13)

An early, and explicit, statement of principles underlying thinking about mental handicap is set out in chapter three of the 1971 White Paper "Better services for the mentally handicapped." (DHSS, 1971). Fifteen general principles covering a wide range of important issues relating to service planning and provision were outlined. A primary emphasis, as Mittler (1979) observes, was on helping mentally handicapped people to take their place in society and to use the whole range of community services available to the general population, rather than special separate and segregated facilities. At the same time, however, there was recognition that additional provision might also be necessary to meet special needs.

The Jay Report extended the discussion on principles underlying service provision in its third chapter, on "Philosophy and model of care." (Report of the Committee of Enquiry into Mental Handicap Nursing and Care, 1979). The Committee decided at an early stage in its work to formulate and make explicit the broad principles which would provide the framework for its deliberations. It identified three sets of principles which underpinned its thinking:

"(a) Mentally handicapped people have a right to enjoy normal patterns of life within the community.

(b) Mentally handicapped people have a right to be treated as individuals.

> (c) Mentally handicapped people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals."
> (The Jay Report, 1979, p.35)

Each of these principles it interpreted more specifically to give guidance on key questions such as: where should mentally handicapped people live, what kind of living environment is required, and how should services be organised? It then described the kind of model of care that would follow from its thinking, and spelt out in valuable detail the component parts of such a model which would enable the needs of mentally handicapped people and their families to be met appropriately throughout their life cycle (pp.34 - 57).

More recently the Independent Development Council for People with Mental Handicap has also pursued the question of the principles underlying service plans and provisions. In its 'Statement of General Principles' (July,1981) it sets out its belief that services for mentally handicapped people should

> "affirm and enhance the dignity, self-respect and individuality of mentally handicapped people who are people first and mentally handicapped second
>
> pay due regard to what mentally handicapped people and their families want and be informed by their views
>
> enable mentally handicapped people to share in and contribute to community life, including family life
>
> assist mentally handicapped people to lead as normal a life as possible, where necessary providing extra help to enable them to do so."

The Statement then elaborates on the principles upon which services should be based to achieve these aims, for example, that help for mentally handicapped people and their families should be available in their own local community; that existing general services, rather than separate specialist services, should be used wherever possible; that residential provision should be based on ordinary housing; that mentally handicapped people should only be cared for in hospital if they are ill, when it would be appropriate for them to be admitted to local hospital facilities. As a first step, the Council recommends that mentally handicapped children and young people should not be admitted to mental handicap hospitals and those already there should be discharged to appropriate community facilities (IDC, July 1981).

Another valuable discussion of principles and philosophy, particularly in relation to residential services for mentally handicapped people, is given in "An Ordinary Life", (King's Fund Centre, 1980, pp.13 - 16). The philosophy put forward here, like that set out in the Jay Report and the IDC Statement, is grounded essentially in principles of normalisation, which Bank-Mikkelsen defined in 1969 as

> "letting the mentally retarded obtain an existence as close to normal as possible."
> (quoted in Wolfensberger, 1972, p.27)

In order to achieve this goal, mentally handicapped people must be helped to live in ways that are both normal and valued by the rest of society. Services based on normalisation principles will therefore seek to help handicapped people develop coping skills, appropriate ways of behaving, and the kind of appearance that is socially valued (e.g. nice haircuts and clothing and so on). The services themselves will need to be delivered in positive, non-stigmatising ways. Normalisation is, then,a complex principle, addressing not only the desired outcome of services (i.e. a 'normal' and positively valued life for handicapped people) but also the means whereby this should be achieved. For a more detailed discussion of the principle, its implications for specific problems and services and strategies by which it can be implemented, see Wolf Wolfensberger's classic "The principle of normalization in human services" (1972). An invaluable, and readable, guide to normalisation and practical ways it can be achieved is O'Brien and Tyne's recent paper for the Campaign for Mentally Handicapped People "The principle of normalisation - a foundation for effective services" (1981). The paper is particularly useful in providing examples of ways in which current services may devalue mentally handicapped people (e.g. by isolating them away from other people; by treating them as if they are children or less than fully human) and, perhaps more importantly, ideas on how normalisation may be approached in practice (e.g. suggestions on how a service can help enhance an individual's dignity and self-respect).

Increasingly, the need to work out and explicitly set down the essential principles guiding a service is being recognised both as a vital stage in service planning, and as an aid in later evaluating whether the services actually provided do reflect the original principles as intended.

A particularly useful tool in this respect is the checklist of standards produced by the National Development Group "Improving the quality of services for mentally handicapped people" (NDG, 1980). The checklist sets out in great detail the questions and issues that need to be addressed by all those agencies and individuals concerned with developing, improving or evaluating services for mentally handicapped people. The questions are grouped by topic under four principles which the NDG argue should underlie a comprehensive local service, the overriding principle being that:

> "Mentally handicapped people are entitled to the same range and quality of services as are available to other citizens, and to services designed to meet their special needs. Services for children should recognise their distinctive needs."

The checklist is produced in looseleaf form so that relevant sections can be easily photocopied and used by different organisations and individuals involved in mental handicap services in one locality. It is available free of charge (see p.132). (For details of other approaches to monitoring and evaluating services, see pages 124-5).

2.2 The elements of a model service

Developing better services for mentally handicapped people means translating underlying principles or philosophy into specific plans for the provisions required in a particular locality. A number of health and local authorities have now published comprehensive proposals of this kind, which move from an outline of the principles guiding their ideas to plans for the specific services entailed and the administrative and organisational arrangements these will imply. (See for example, Kent AHA & Kent CC, 1981; Newcastle City Council & Newcastle AHA (Teaching), 1981; Sheffield AHA (Teaching) & Sheffield Metropolitan District Council, 1981; Guy's Health District, 1981; University College, Department of Community Medicine, 1981; Wessex RHA, 1979; N.Western RHA, 1982).

Sometimes, the need for a drastic reorganisation of services has been suggested, to overcome the problems created by the current division of responsibility between health, social services, and other agencies like education and housing authorities and voluntary organisations of different kinds. The DHSS review of mental handicap services in England since 1971, however, argues that the disruption entailed by changes of this magnitude (for example, the creation of a single mental handicap service) would have to be weighed against any benefits that might ensue. It comments moreover, on the particular difficulties inherent in trying to secure substantial changes in responsibility for services at times of constraint or retrenchment. It concludes:

> "We would suggest, therefore, that consideration should be given to less radical changes aimed at reducing the areas of confusion and overlap between the responsibilities of authorities and at improving and encouraging joint working by health, social services and other agencies, including the private and voluntary sectors. This would entail looking at the elements going to make up a service for mentally handicapped people and their families, the extent to which it would be appropriate for each agency to contribute to the provision of these elements, the overall level of service required, and mechanisms for joint planning and making the best use of limited financial resources."
>
> (DHSS, 1980, p.100)

In many areas, developments in community-based mental handicap services have proceeded along these, more piecemeal, lines. Plans have, perhaps, been modest, but small-scale innovative schemes designed to enable mentally handicapped people to lead lives as close as possible to those of their fellow citizens have, nonetheless, flourished. In the pages that follow are outlined some of the variety of developments that have been taking place as part of this attempt to translate the principles of normalisation into practice, throughout the life cycle of the person with mental handicap.

CHAPTER 3 - THE FIRST YEAR

> "There is no nice, easy way of finding out that your child is mentally handicapped - only awful ways and slightly less awful ways."
> (McCormack, 1978, p.17)

The grief and trauma for parents of learning that their baby is handicapped has been vividly documented. (McCormack, 1978; Boston, 1981; Hannam, 1980; Hunter, 1980). Profound disappointment, despair, shock, anger and confusion are inevitable concomitants of the discovery that one's child is not - and never will be - "normal".

What can be done to help parents at this time? Clearly, different families will, to some extent, have different needs. But certain needs will be common to almost all - the need for information, for support and for practical advice - and in this section we review approaches to meeting each of these needs in turn.

3.1 The need for information

Breaking the news

Reports from parents suggest overwhelmingly that information about their child's handicap should be given to them as soon as possible after birth, or when it is first suspected (Hewett, 1975; Armstrong, Jones, Race & Ruddock, 1980). Unnecessary additional distress and anxiety can result from parental doubts and uncertainty when professional diagnosis is unduly delayed, or conveyed without adequate sensitivity (Cunningham, 1979; Warnock Report, 1978). Mental Handicap - the first twelve months (a project paper produced by the Association of Professions for the Mentally Handicapped) contains useful suggestions from both parents and professionals on how the initial diagnosis to parents may best be handled. (APMH, 1981a). It recommends that the appropriate professional to break the news is the paediatrician, and stresses that both parents should be informed together. (Cunningham, 1979, reviewing research on how parents were informed of their child's handicap reports that in fact only 20-30% of parents surveyed were told together. In 50-60% of cases one parent was left to inform the other). Some parents feel that the professional who will be the family's "keyworker" in the future - e.g. a social worker or health visitor - should also be present. (The idea of a "keyworker" is discussed further on p.15 below). Others feel that coping with additional professionals at this point is not easy for parents - they should simply be made aware of their existence and future supportive role. Rod Ballard (1976) provides a good insight into parents' needs at this time and the kind of information most helpful to them. The APMH paper recommends that a written report be given to parents after this initial interview, summarising what the paediatrician has said and giving details of future sources of help, including the name and phone number of their keyworker. A written report like this is useful to parents who might otherwise - in their initial shock and numbness - retain little memory of the contents of the original interview. Detailed suggestions on the content and form of such a letter are given in Appendix A of the paper. In St. Thomas' health district a copy of the letter is sent to the health visitor, which ensures she is informed about the child's condition from the outset, and certainly before she herself makes contact with the family (APMH, 1981a). The initial interview with parents should be followed up within a few days, according to the APMH paper, to enable them to ask questions once the initial shock has subsided.

Stokes (1975) provides more details of the range of information parents should ideally receive from professionals immediately after the initial diagnosis - not only a written report of the consultant's views (perhaps together with an immediate appointment with their GP or a social worker who will help interpret it), but also the names and qualifications of all the professionals who have seen the child; evidence that deficits of hearing, vision, orthopaedic development etc. have been considered; reading lists and pamphlets about welfare benefits and allowances; information on or introduction to local voluntary or parent groups and a planned, written campaign for the forthcoming period before the next review so that parents can feel involved in their child's development right from the start. Useful guidelines on breaking the news and the kind of information most helpful to parents at this time are also given by Cunningham (1979). For a brief summary of research evidence on informing parents about their child's handicap, see also "The Family with a Handicapped Child: a review of research", a leaflet produced by the National Children's Bureau (National Children's Bureau, 1981).

Breaking the news about a child's handicap is not an easy task for professionals any more than it is for parents, as Marks (1980) points out. Atkins (1977) and Sinson (1978) both stress that the professionals involved - in this case social workers and health visitors - may lack expertise in, and experience of, dealing with this situation, a point borne out by Harada's survey of the experiences of 40 midwives in handling abnormal births. (Harada, 1981). Some suggestions for improving the training of doctors and nurses in this area are given by Rawlings (1975).

Information about resources

In addition to information about their child's condition, parents also need information about resources, services and organisations which may be of use to them. "Guidance for parents" - a leaflet produced by Line 81 (see p.132) - gives information on how to get help from professionals and on useful organisations and publications. A more detailed guide to benefits and services for all people with disabilities is the annual Disability Rights Handbook. (The Disability Alliance, 1981). A free list of the national organisations relating to mental handicap, with a brief description of their activities and services offered is produced by the Voluntary Council for Handicapped Children (VCHC, Factsheet 5, August 1980).

In some areas, local groups (statutory or voluntary) have compiled leaflets or pamphlets setting out useful information on benefits, services and organisations for distribution to parents of handicapped children in the area. (See, for example, Bristol CMH; NSMHCA, S.W.Region; Ealing Social Services Department, 1982; Darnbrough and Kinrade, 1981). In other areas, such a service is still lacking, and parents may remain unaware of welfare benefits or voluntary organisations which might be of help (Boston, 1981). Often the lack of information available to parents is reflective of a lack of information on the part of the professionals themselves. Here, the establishment of local advice and information centres (O'Gorman, 1976; Parfit, 1977) may be a vital means of providing professionals and perhaps parents, with the kind of information that they need. (For details of Avon's mobile information service, contact Mental Handicap Information Service, see p.132).

3.2 The need for support

Support from other parents

A valuable source of support for parents, particularly in the first days after the discovery of their child's handicap may be contact with other parents of mentally handicapped children. The best known of such early support schemes is that which has been operating successfully in Southend for more than ten years, in which parents of children newly diagnosed as handicapped are offered an immediate opportunity for contact with parents who have had the same experience. (Crowe, 1975). Similar schemes - sometimes called "pilot parents" as in the United States - are now developing elsewhere in the country (Shaw, 1979). The Royal Society for Mentally Handicapped Children and Adults operate a similar scheme in which trained voluntary welfare visitors offer parents help, support and advice of whatever kind is needed. (Ross, 1975). Self-help parents groups - which are discussed in more detail below (see p. 17) - may also provide a source of ongoing support for parents from others who are similarly placed.

Support from a "keyworker"

In the last few years, it has been recognised that it is best for both parents and professionals alike if one particular professional is designated the "named person" or keyworker for that family (see, for example, the Warnock Report, 1978). This practice should, ideally, ensure on the one hand that no family is deprived of services on the assumption that other professionals - perhaps from different agencies - are already in contact with them, and on the other hand, that families are not deluged with endless visits by different professionals, conceivably offering different, even conflicting advice. The lack of communication between professionals involved with the same family is well illustrated by Lloyd Bostock (1976) and is discussed in the Court Report (Report of the Committee on Child Health Services, 1976).

The named person could be from one of a number of professions, though there is some evidence that parents react more positively, particularly in the early years, to a health visitor rather than a social worker, as the latter may be seen to indicate some kind of failure on the part of the family to cope (APMH, 1981a). It is, however, vital that the health visitor has some kind of specialist training in mental handicap, or parents may well feel her scanty knowledge of handicapping conditions makes her visits of limited value only (Sinson, 1978). The role of the health visitor in this field is discussed further on pp.22-23 and 110-111 below.

The role of the keyworker is to provide parents with the practical advice and information needed; to put them in touch with other professionals or agencies as appropriate; and to offer support and counselling. The latter may take the form of individual sessions, which seek to help the parents both through the initial stages of reaction to their child's handicap and through later difficulties,and/or the form of parent groups or workshops where support is provided additionally via other parents, while advice and information is also imparted. More information on parent groups and workshops is given in the section that follows; for a discussion of parent counselling, see Cunningham (1979); Attwood (1981), and Wing (1975).

3.3 The need for practical advice

Practical advice on how to cope with their child's condition, how to promote his physical, social and intellectual development and on aids which will be of assistance, may be given to parents both from other parents and from professionals, either on an individual or a group basis.

Advice from other parents

The new parent can often glean invaluable bits of practical advice from other parents - tips borne out of hard-learned experience, and of which the professional may well be unaware. This kind of practical advice may be shared by parents either individually - e.g. via pilot parent schemes - or in self-help parent groups. Such groups may serve a number of useful functions - providing a forum for discussion, enabling parents to express their feelings about their child's condition to a sympathetic and supportive audience, helping them resolve their own problems on the basis of the suggestions and experiences of other parents, and acting as a meeting place to which different professionals may be invited, according to the parents' particular needs. It may even develop into a springboard for action to obtain better facilities and services. Although such groups are often formed at the outset on the initiative of concerned professionals, once established it is usually for the parents to work out how their group will operate. There are some useful accounts of the establishment and operation of parents' groups in the literature. A number of articles discuss the successful Southend Group Therapy Scheme (Crowe, 1975; Mellor, 1975, 1980; Pugh & Russell, 1977; Pugh, 1981) and there are several accounts by social workers - and others - of groups which they have helped to establish (Line 81, 1981;

Cole, Greatorex and Preston, 1980; Carter, 1976; Sinson, 1978; Area 5 Action Group, 1981). The experience of the Southend - and other schemes - suggests that groups comprising parents with children of similar age and handicap - e.g. Down's babies or infants - may be particularly useful. (For accounts of Down's Infants Groups, see Wordsworth, 1979; Sinson, 1978; Kabon, 1975).

Advice from professionals

Parent workshops

Parent workshops organised by professionals for a number of parents at a time provide a more economical means of channelling professional advice and expertise to parents than the traditional one-to-one relationship. The workshops can cover a variety of important topics relevant to parents concerning the management of their child, perhaps using different professionals as resources each week. The workshops may have the additional benefit of putting parents in touch with others like themselves, who may, moreover, be able to offer useful information, borne of personal experience, beyond that contributed by the professionals. The literature on parent workshops is discussed more fully on pp.34-36 below.

Home visiting schemes

The value of home visiting or early intervention schemes of various kinds in guiding parents on the best methods of promoting their child's development has become increasingly recognised in the last few years. The best known of these schemes is Portage. The basic principles of Portage and its operation in Wessex and South Glamorgan are clearly described in Gillian Pugh's excellent booklet "Parents as partners" (Pugh, 1981). Portage is essentially a home visiting scheme in which parents of mentally handicapped children are trained by a home teacher how to effectively teach their children particular skills and tasks. The scheme is based on the premise that parents are keen to maximise their child's development, and that given training they can easily learn to do this. The home teacher - who may be a teacher, a nursery nurse, a health visitor or even someone without a professional background, but with training in Portage - first assesses the child. On the basis of this assessment the mother and teacher together will choose, and practise, suitable tasks for the mother to teach the child during the forthcoming week. The results are recorded on an activity chart. Each home teacher will visit perhaps a dozen families a week for an hour and a half on each visit. The home teachers will themselves have weekly staff meetings where they can pool their problems. A supervising teacher - perhaps a psychologist - will co-ordinate the whole programme.

Experience of Portage suggests that it does bring significant gains in achievement to the children involved (though such gains are notoriously difficult to determine with precision - see Clements, Bidder, Gardner, Bryant & Gray, 1980; Smith, Kushlick & Glossop, 1977). Moreover, as parents become increasingly skilful, they may take on more responsibility for devising a suitable programme for their child. The involvement of the home teacher may then gradually be reduced. In South Glamorgan, for example, Pugh reports that some families were now working on the basis of a monthly visit from their home advisor. It is even possible that trained and experienced parents might themselves in turn become trainers for other parents entering the programme. In any event, Portage does not require vast injections of funds to implement. Revill and Blunden (1977 and 1978) report that Portage was introduced in South Glamorgan and Dyfed largely using existing resources and professionals. On the basis of their experience in developing and evaluating Portage schemes they have now produced a comprehensive manual on how to set up and operate a scheme. (Revill & Blunden, 1980). In Wessex, additional funding was originally made available to establish a Portage scheme. The initial training in Portage, however, was deliberately limited to three days, so that the scheme would be a practical possibility from an economic point of view. (Pugh, 1981).

As Pugh points out, Portage may offer advantages over parent workshops in certain respects. Home visiting cuts out problems and expenses of travel for parents, especially in rural areas. It may be more accessible to less literate parents than the lecture base of workshops, and the advice given will be directly tailored to the needs and life style of the individual child in his or her own home. A potential disadvantage is that Portage may reinforce rather than reduce a mother's isolation. In Glamorgan parents were found to be split almost equally between those who wanted the support of a parents' group and those who did not. In Cardiff, where travel is less of a problem, some parents have therefore gone ahead to form groups themselves - one for parents of cerebral palsied children, one for those of Down's Syndrome children, and others are planned. (For more details, and some evaluation of the Wessex scheme, see Smith, Kushlick & Glossop, 1977; on schemes in Wales,see Barna, Bidder, Gray, Clements & Gardner, 1980; Clements, Bidder, Gardner, Bryant & Gray, 1980; Revill & Blunden, 1979; Jones, 1980; and Wishart, Bidder & Gray, 1980. Cameron, 1982, gives a useful overview of the development of a variety of Portage schemes in different parts of the country.)

Other early intervention schemes

A number of other early intervention schemes based on home visits, but operating on a less structured basis than Portage, have run successfully in other parts of the country. As with Portage, their basic rationale is to provide consistent advice and support to the family in the child's natural environment - the home.

In Avon, such a scheme operates for Down's Syndrome babies. Within days of diagnosis, the family is introduced to its keyworker, who will be involved with the child until school age. In this first meeting - either at home or in hospital - points from the initial interview between parents and paediatrician will be discussed. The worker outlines the kind of positive help that can be given and offers the chance of contact with other parents of handicapped children. About two weeks later a second visit is made. More detailed advice on early stimulation and exercises is given. Visits are then made every two to six weeks depending on the family's needs. In this way, the problems associated with over-visiting by a number of different professionals is avoided, and there is continuity in the practical and emotional support given right from the start. (APMH, 1981a).

In the Exeter area, a home visiting scheme is run from Honeylands, a multi-service and resource centre for handicapped children (discussed further on p. 31 below). The scheme is staffed by thirteen developmental therapists from a variety of backgrounds - nurses, physio-, speech and occupational therapists, psychologist - and includes a mother without professional training. Therapists are matched to families by a social worker and paediatrician after a home interview and review of the child's presenting problem.

Each child is visited weekly for a year, then less often. The aim is to give parents information and guidance on the child's condition and ways to promote his development, and to establish a practical support system for the family. The programme is less structured than Portage, with an emphasis on seeing the family and its needs as a whole, rather than simply putting extra pressure on it to work intensively with the child. Interesting points about this scheme are the range of backgrounds of the therapists employed, and the use of a multi-disciplinary support team to provide them with back up, insights and information from other disciplines besides their own. More details of the scheme are to be found in the overview given by Pugh (1981) and in a number of reports by others on different aspects of the scheme. (See, for example, Burden, 1978 and 1980; Rayner, 1980; Carlyle, 1980; Pugh & Russell, 1977). An article by Key, Hooper and Ballard (1979) provides an interesting commentary on the scheme from the viewpoint of a mother with a handicapped child who had not received a home visiting service.

Pugh (1981) also gives an account of the Manchester home visiting scheme, in which health visitors with additional specialised training - lasting three weeks - visit parents of Down's Syndrome children at six weekly intervals, providing practical informational and guidelines on promoting the child's development. Again, the approach is much less structured than with Portage. The scheme developed from an earlier research project at the Hester Adrian Research Centre which revealed that parents of Down's Syndrome children needed support, help and information about handling their child from a sympathetic but knowledgeable person for the first two years after the initial diagnosis. Health visitors were welcomed by parents but were unable to provide the specific help required because they lacked the necessary specialist training. Once health visitors were provided with such training they were able to provide families with young mentally handicapped children with the kind of regular service of support and stimulation which parents felt they needed. For a more detailed discussion of this project and the training of health visitors involved, see Pugh (1981), also Cunningham and Sloper (1977). The project is also summarised briefly in the factsheet "Home-based intervention programmes" produced free by the Voluntary Council for Handicapped Children. The factsheet gives an over view of a number of schemes with additional references for those interested in more detailed information (VCHC, no.10, 1979).

For a discussion of the respective advantages and disadvantages of parent workshops versus home visiting schemes, see Sandow & Clarke (1978) who describe a home intervention scheme with parents of severely handicapped pre-school children (aged 18 months or over); also Wood and Berry (1980), who review the literature on training parents of mentally handicapped children and argue that hospital based teaching is more economic and possibly better than that based in the home. Another review of some of the literature on the use of parents as therapists of mentally handicapped children is provided by Gath (1979). Gath comments on the problems of evaluating such ventures, and notes some evidence that too much visiting and support by the professional may be counter productive by increasing the parents' dependency, so that initial gains may be followed by some degree of fall-off (Sandow & Clarke, 1978; Sandow, Clarke, Cox & Stewart, 1981). She concludes, however, that although well-designed research in the area is sparse, the results of actively involving parents in promoting the development of their mentally handicapped children have been encouraging. An interesting and rare account of home based treatment from the parental viewpoint can be found in the report by Meg and Roger Fish on the programme carried out by them in conjunction with psychologists in Bromsgrove to deal with the behaviour problems of their son, Mark. (Fish, 1975).

Other services

A number of other services which may have an important role to play during the first year of the child's life - or indeed later on - have not been discussed in this chapter. For information on adoption of mentally handicapped children, see Shearer (1981), British Institute of Mental Handicap (1980), or contact Parents for Children, or British Agencies for Adoption and Fostering Resource Exchange (see p.131). For information on fostering schemes, see Shearer (1981); Voluntary Council for Handicapped Children Factsheet no.12 (1980); British Institute of Mental Handicap (1980). For details about individual programme plans - a valuable system for ensuring a regular review of the particular goals, objectives and service needs of each mentally handicapped person from childhood onwards, with a resulting written plan of action for all concerned until the next review, see Carle, 1981 b; Blunden, 1980; Houts and Scott, 1975 a. Daycare facilities for handicapped children and short term relief for their parents are reviewed in the chapter that follows.

CHAPTER 4 - THE PRE-SCHOOL CHILD

> "... there was some evidence that parents were more depressed a year after the birth of their handicapped child - which could have had some correlation with the drop-off of support services and home visits as the children reached their first birthday."
>
> (Russell, 1980/1, p.8, commenting on research by Gath, 1978)

Although mentally handicapped children and their parents continue to need the help and support of different professionals and resources throughout the early years, there is evidence that delivery of such services may in fact decline after the first months following diagnosis. The Hester Adrian Research Centre team, for example, observed that in the case of the Down's Syndrome children they studied, visits from professionals like health visitors tended to fall off at about six months and be virtually non-existent by a year (Cunningham & Sloper, 1977). Yet this was often a particularly trying time for parents:

> "During the first six to ten months many Down's infants develop fairly normally, and in fact some parents found themselves thinking and hoping that they did in fact have a 'high grade' or very able Down's baby. However, as developmental milestones such as sitting up and crawling are reached, the impact of the handicap begins to manifest itself again .... at this stage the rate of development appeared to slow down considerably when compared to normal infants, and many mothers seemed to enter a new phase of depression and confusion."
>
> (Pugh, 1981, pp.65-66)

For older parents, whose child's handicap has been less easy to identify, the pre-school years may be difficult for different reasons, as they confront the uncertainty and anxiety resulting from delayed diagnosis. In some such cases, where handicap has been secretly suspected and feared, eventual diagnosis may bring a certain relief,as Nichola Schaefer reveals in her vividly human account of life with her own severely handicapped daughter. (Schaefer, 1978). Nonetheless, support, information and advice are greatly needed and continue to be just as important for parents of pre-school children as they are in the baby's first year. Many of the schemes, services and resources described in the previous section continue to be vital. Indeed, Portage and other home schemes, parent groups and workshops and the support of a keyworker should ideally continue to be available at least until the child's school years, so long as they meet the parents' and child's needs in ways that are appropriate and acceptable to them. In addition, however, pre-school children and their mothers will benefit from other services: for the child, opportunities to play and mix with other children; for the mother, support and respite, and continuing access to information, advice and resources of different kinds. Some examples of positive developments in community services for pre-school children and their families are outlined below.

4.1 Mixing with other children

Mentally handicapped children, like other pre-school children, benefit from contact with their peers, and from the stimulation of different surroundings, toys and equipment available in mother and toddler groups and playgroups. For many mothers the contact with other mothers involved provides a welcome break from possible isolation at home with their handicapped child.

Different kinds of play opportunities are available in different areas, organised by a variety of agencies, from local authorities to parents themselves. (A useful list of organisations, publications and manufacturers involved in play and toys for handicapped children is available free from the Voluntary Council for Handicapped Children - VCHC, Factsheet 7, 1980). In some areas, there are play groups catering exclusively for handicapped children (see, for example, Wimpory, 1976). In other areas, there are opportunity groups catering deliberately for a mixture of handicapped and non-handicapped children, thus providing important models and early experiences for both. Opportunity groups may well provide a base for other services for the child and its family also, for parent groups and workshops, for example, or a toy library. Lovell (1973) and Way (1975) describe the Yeovil opportunity group and service developments associated with it; Scott (1980) gives an account of a weekly group in Redhill which has the added bonus of a social worker available at every session for any parent in need of advice. Other professionals - health visitors, community nurses, teachers and therapists - attend regularly; parents' workshops have developed, a toy library visits alternate weeks and adults from the local ATC are regularly involved in looking after the children. (For more information on local opportunity groups contact MENCAP or the Pre-School Playgroups Association - p.132). Mother and infant groups like the one described by Janice Sinson in Leeds may also combine the benefits of a playgroup for the children with support and information for their mothers. In that (Down's Syndrome) group, a range of discussions and activities on topics of interest to them was organised by the mothers, with the support of Sinson (a psychologist working for the Leeds Society for Mentally Handicapped Children), while their children played. The group was successful with both mothers and children, providing much needed stimulus, guidance and previously lacking information. A useful spin-off of this particular venture was its educative role for local health visitors, whose visits had previously not been felt to be useful by the mothers concerned. A trip to the group became a regular feature of health visitor training in the area, and other health visitors also began to drop in on the group regularly. (Sinson, 1977, 1978).

In a few areas, play facilities for handicapped children co-exist under the same roof as a range of specialist help, for example, physio and speech therapists, and social workers. Such multi-purpose resource centres - like Honeylands in Exeter and Balidon House in Yeovil - are described in more detail below (p. 31). Play facilities may also provide the necessary opportunity for detailed assessment of a child's condition, as for instance, at the Ryegate Centre in Sheffield (Bailey, 1978; Jones, Ruddock & Heron, 1981); the Child Development Centre at Charing Cross Hospital - where handicapped children are observed while playing with the 'normal' children of hospital staff in the day nursery (Pugh, 1977); at the Mary Sheridan Assessment Centre described by Appleyard and Baird (1975), and at Children's Centres elsewhere.

To follow the principles of normalisation, mentally handicapped children should ideally have access to the same pre-school facilities as other children, rather than separate, segregated facilities. In different areas, this might mean the chance of attending an ordinary playgroup, nursery school or day nursery, according to the provisions available in a locality, and the needs of the individual families concerned. Obtaining access to ordinary pre-school facilities for their mentally handicapped child, however, may be an enormous struggle for parents and necessitate a good deal of effort in educating playgroup leaders about handicap. Extra resources may also be helpful if integration is to work successfully from the viewpoint of both children and staff. In the Barnardo's Chorley project, for example, two volunteers helped to support each mentally handicapped child attending a local playgroup. (Shearer, 1978). A number of publications relating to handicapped children in playgroups are available from the Pre-School Playgroups Association which has also developed short training courses for playgroup leaders on handicap. (Contact the PPA, see p.132).

Some handicapped children are able to attend local nursery schools or classes. The advantages and disadvantages of this are reviewed briefly by Mittler (1979). The main problem, he suggests, is that of reconciling the undoubted social advantages of mixing with normal children with the danger of neglecting specific educational and developmental needs which might be better met by a more specialist approach. He also cites the research carried out for the Warnock Committee which showed that nursery teachers, while welcoming a small number of handicapped children, badly needed advice in methods of working with them. (Clarke, Riach & Cheyne, 1977).

Mittler (1979) also discusses the value of nursery units attached to special schools which are able to provide more specialist help than nursery classes in ordinary schools. The main drawback with such units of course, is the lack of opportunity to mix with other, non-handicapped children. Interestingly, this disadvantage no longer applies in some parts of Manchester. An excess of places in special nursery units has allowed them to become integrated. Non-handicapped children now attend nursery classes at special schools.

An alternative form of provision for the mentally handicapped child is day-fostering, which may be particularly appropriate where the family is under great stress. Day fostering of the child with a suitable person in the local community combines the advantages of opportunities for play and mixing with other people for the child, with some respite for the mother. Day fostering is essentially similar to the familiar service offered by child minders for, usually, non-handicapped children, though extra guidance and training for the foster person on the child's condition and management may well be necessary. To date there appears to be little documentation of day fostering schemes, though Somerset Social Services Department is reported to have made successful use of such a service (NDG, No.2, 1977) and the possibility of establishing such a scheme is being actively explored in South and North Tyneside (Community Care, Feb.12, 1981; Bromley and Lister, 1980).

Meanwhile, facilities for all pre-school children remain very limited in many areas, and for handicapped children even more so.

What is more, parents may remain unaware of those facilities that are available in their locality (Hannam, 1980). Such a situation confirms both the need to attach a keyworker to each family to ensure that information of this kind is passed on and to ensure that the keyworker herself is aware of existing facilities through the provision of adequate training, and of information services and handbooks.

4.2 Access to information, advice and resources

Family support centres

One way of ensuring that parents and professionals alike have access to information about local services and resources is to establish an informal resource centre of some kind. Such centres may provide an information bank and a contact point for parents of mentally handicapped children wanting support or advice. Different centres may house a wealth of different activities and services, with the supreme advantage to the client of being housed beneath one roof. Two notable examples of such multi-disciplinary provision are Honeylands in Exeter and Balidon House in Yeovil, both of which are now well documented in the literature and will be described only briefly here.

Honeylands, developed within a district general hospital paediatric service, offers day and short term residential care assessment, physiotherapy and speech therapy facilities, a playgroup and toy library amongst other services for children from birth to puberty. There are also a number of informal groups dealing with special problems of feeding, behaviour or handling twins. Parents are encouraged to make whatever use of the variety of services available they want and they are continuously involved in any decision making that is carried out in connection with their children.

The emphasis is on enabling parents to develop the skills and confidence they need to help their children achieve their maximum potential in an informal, multi-disciplinary setting. The unit also supports the home visiting programme described earlier (p.21). (For more detailed information on Honeylands see Goddard & Rubissow, 1977; Rubissow, 1976; Brimblecombe, 1976 a; Hyde, 1979. A summarising account of these is given in the excellent booklet "Shared Care", Pugh & Russell, 1977).

The services at Balidon House, by contrast, developed originally out of a voluntary opportunity playgroup, with later support from the health, education and social services. The House now offers a comprehensive service for the assessment and management of handicapped children, from infancy to school-leaving age. The original opportunity group provides a good basis for observation of the children at play. Also based at Balidon House are the local assessment centre, child and family guidance and school psychological services, with physiotherapists seconded from the district hospital. The work of the unit is co-ordinated by two senior social workers (Evans, 1975; Way, 1975), Pugh & Russell (1977) again provide a useful summarising account.

A number of areas now boast centres providing advice and information for parents in an informal setting. Pugh & Russell (1977) describe the Special Families Centre in Tower Hamlets which provides an information and support service for parents, informal groups, clubs, play sessions and a toy library. They also give an account of the Parents Advisory Centre in Coventry, which was set up to provide advice, stimulation and parental support during the pre-school years. Parents are encouraged to get involved in the creation of programmes to encourage educational and social development in their children. The Centre has a large toy library which provides the material for home activities. (For more details of the Special Families Centre and the Parents Advisory Centre, see Pugh & Russell, 1977).

Another multi-purpose family support centre was opened in Camden in December 1979, with support from KIDS, a voluntary organisation concerned with handicapped children. The Centre provides a meeting place for parents and professionals. It offers information on benefits and facilities in the area and operates a home-based learning service similar to Portage. It provides a range of activities for children during the school holidays, and on Saturdays is open to the whole family - including brothers and sisters - which has resulted in the formation of ad hoc 'fathers' groups'. The project is a pilot one and, it is hoped, will act as a model for similar services in other districts. (Fuller details on the KIDS - Family Support Centre in Camden are given in Wyman & Russell, 1980/1).

Not all areas are able to fund and support relatively large-scale resource centres like those discussed above, particularly in the current economic climate. Nonetheless, individual elements of the services may be reasonably easy to provide. Toy libraries, for example, are of clear importance in giving parents access to toys and games appropriate to their child's condition and stage of development, and may also provide a useful meeting place for parents. Shearer (1978) supplies some helpful hints on opening a toy library; Head (1976) gives an account of one particular toy library for handicapped children,

and some of the other services (for example, courses for parents, and advice on welfare benefits) which developed as a result. For information on how to set up and run a toy library, contact the Toy Libraries Association (see p.133).
Information may also be made available, through leaflets or some kind of information service, without the establishment of a full-scale resource centre, perhaps based on a toy library (Shearer, 1978; Head, 1976) or a playgroup of some kind.

A major advantage of multi-purpose centres, of course, is that they provide parents with an obvious contact point for meeting both with other parents and with professionals, in an informal and non-threatening situation. Nonetheless, it is clearly possible to provide an adequate meeting place in much less grand surroundings, as, for example, in Barnardo's Chorley project (Shearer, 1978).

Parent workshops

Parent workshops (mentioned above on p.18) are a useful channel of advice and support to parents in their child's pre-school years, and beyond. The objectives of such workshops and their usual pattern of operation are well summarised in the free factsheet on the topic produced by the Voluntary Council for Handicapped Children (VCHC, Factsheet 9, 1979). The workshops generally aim to give parents a teaching model which they can use when looking at their own child's behaviour and learning. Over a course of eight or more 2-hour sessions the workshops provide information and support to parents and discuss, and advise on, the management of individual children. Some have made use of developmental charts to help parents assess their own child's development, and most have divided the weekly sessions between lectures on specific topics and report back sessions on how well the tasks set the previous week have progressed. The factsheet goes on to describe briefly various parent workshops which have taken place in different parts of the country and provides references to further reading material for those interested in discovering about individual schemes in more detail.

Pugh (1981) gives a fuller, and very useful, overview of parent workshops, tracing their history and development from the early workshops at the Hester Adrian Research Centre in Manchester (Cunningham & Jeffree, 1975) and summarising the findings of those who have subsequently run workshops - and reported on them. She stresses a number of points common to the variety of workshops she describes; for example, the need to carefully plan and structure the workshop yet to retain sufficient flexibility to respond to individual needs as they arise; the value of a multi-disciplinary approach, involving a wide range of different professionals. Several other useful points are made - for example, that workshops catering for parents of children of similar developmental age and handicap are more effective than those covering a very heterogeneous group and that, since parents may well contribute a wealth of information themselves, care must be taken by tutors not to intimidate parents with their professional expertise.

There is now a fairly extensive body of useful literature on the operation of parent workshops, written by the professionals involved. Hattersley and Tennant (1981) give a detailed account of workshops run in Worcestershire (see also Hattersley, Tennant & Hattersley, 1976; Tennant & Hattersley, 1977; Holland and Hattersley, 1980); Attwood describes parent workshops in Croydon which led on subsequently to the formation of several self-help groups (Attwood 1977, 1978); Callias (1976) reports on an early NSMHC experiment in parent group training; Firth and Newton (1979) describe workshops run in Rotherham. Many of these accounts display a refreshing concern to ensure that the workshops do in fact give parents what they want. Attwood (1977) reports on mothers' reactions to the workshops (obtained via a questionnaire), as do Tennant & Hattersley (1977); Cocks & Gardner (1978) describe a more detailed approach to evaluating the effectiveness of the workshops, not only via a questionnaire to parents, but by visits to the family to actually observe whether parents were using skills they had learned at home, and if so, how successful they were proving. (See also Bevington, Gardner & Cocks, 1978). A sample programme of parent workshops run from Normansfield in the summer of 1980 is given in Appendix 2 of the Normansfield Annual Report 1981. (Kingston & Richmond Area Health Authority, 1981). For details of the Parental Involvement Project set up by workers at the Hester Adrian Research Centre, which was in many ways the precursor of later parent workshops, see the account in Pugh & Russell (1977). Out of this project came a range of games, resource materials and books which describe and draw on the projects' findings and present them in ways appropriate for parents' use - for example, 'Let me Speak' (Jeffree & McConkey, 1976) and 'Let me Play' (Jeffree, McConkey & Hewson, 1977) and for use by teachers (Jeffree, McConkey & Hewson, 1977). Details of the Parental Involvement Project are also given in McConkey & Jeffree (1975), and Jeffree, McConkey & Hewson (1975).

4.3 Support and respite for parents

Support

As well as access to information, advice and instruction on ways of helping and managing their children, parents - particularly mothers who generally shoulder the brunt of the burden of care (Wilkin, 1979) - will need support and help from professionals and others in their own home. The need for such support is ongoing, probably throughout the child's life, though the nature, intensity and duration of the support required will vary enormously between families, and within families at different stages of the child's life-cycle. As we have already noted (p. 25) there seems, however, to be some danger that professionals may assume that the support that they recognise as crucial in the early months following diagnosis is no longer so necessary - may even be safely withdrawn - once this initial period of shock and adjustment is negotiated. The dropping off of visits and services to the pre-school child may then leave the parent bereft of support and guidance and prone to depression, particularly as the child increasingly fails to meet normal developmental milestones like crawling and walking.

An illuminating study by Wikler et al lends weight to the view that parents' needs for support do indeed continue throughout the child's life and, perhaps more importantly, illustrates how professionals are consistently likely to underestimate the chronic and ongoing, as opposed to acute and shortlived, nature of parents' needs. (Wikler, Waslow & Hatfield, 1981).

The attachment of a <u>keyworker</u> to each family (p. 15) would ideally go some way towards alleviating this problem. In theory, a keyworker would develop a sufficiently good relationship with a family for parents to find little difficulty in asking for support when it was needed. In practice, demands on professional time may well render regular visitng of families, in the apparent absence of particular problems, impractical. Then, when specific problems do arise, parents may feel inhibited or uncertain about asking for help from a relative stranger.

In some areas, however, the attachment of a particular professional on a regular and long term basis to a mentally handicapped child and its family has been successfully achieved. The most notable example perhaps, is in the Barnardo's Chorley Project, described in detail in a useful pamphlet by Ann Shearer (Shearer, 1978) and more briefly in several articles elsewhere. (Shearer, 1978 a & b; Harvey, 1980). In the Chorley Project, every family with a mentally handicapped child was visited regularly by a social worker, whose task was seen, as far as possible, as helping to provide parents with the kind of services they themselves felt would be useful, for example, holiday playschemes, and sitting-in services (see p. 59 and p. 41 below) in addition to the more usual functions of social work support and advice.

Respite for parents

A particular problem confronts parents of mentally handicapped children in securing time away from their offspring. Whereas friends, neighbours and relatives may be obliging about babysitting for "normal" children during the day, so that mothers can shop and keep appointments without always having toddlers in tow, and in the evening, so that parents may enjoy time out together and leisure activities of different kinds, such help may be less forthcoming when the child is handicapped, particularly if behaviour and communication difficulties and problems with feeding, sleeping and toiletting are involved. Parents for their part may feel understandably reluctant to ask acquaintances for such help. As a result, parents may go for years without ever spending time together away from the demands of their child. (Birmingham Multi-Handicap Group, 1981). Traditionally, the only solution to the problem has been the - usually limited - provision of short term institutional care for such children, on an emergency basis, or, less often, to give parents some planned respite from care. Although short-term care is in great demand by parents, particularly for children of school age or beyond (see p. 46), there are understandable anxieties about expecting a small mentally handicapped child to cope with time away from both familiar home surroundings and family, given the increasing recognition in recent years of the potentially adverse effects of such experiences on "normal" pre-school children (e.g. during hospitalisation). Maureen Oswin's valuable report on short term care for mentally handicapped children (Oswin, 1981 b). argues cogently against the use of short term residential care for under fives except in particular extreme circumstances. A far preferable alternative is to provide relief care in the child's own home. The Leonard Cheshire Foundation's booklet "Family support services for physically and mentally handicapped people in their own homes" (Inskip, 1981), is a useful guide to setting up and operating a respite scheme for parents, and includes suggestions on funding and details of the training that might be useful to people working with families of mentally handicapped children. A sample form drawn up by parents of mentally handicapped children to show their likes, dislikes and habits, for use in such a scheme is included in the booklet.

Family support schemes of this kind - where a paid worker - or care attendant - will offer support and respite to a family by caring for their handicapped relative within the family home - could clearly provide a much needed support system to parents of mentally handicapped children from an early stage, as the following extract from the booklet explains:

> "We know that many mothers of both physically and mentally handicapped children would welcome closer support from the time the handicap is identified. A service could start by providing a care attendant for such a family. Initially she would probably go along for one afternoon a week and quietly forge links of friendship with the family and build up confidence. As confidence grows, the parents will be ready to leave the child for increasingly long periods with the care attendant, either in their home or at her home. In many cases we hope that a visit to a care attendant's home will take the place of a short-term "holiday" admission to a residential home."
> (Inskip, 1981, p.28)

The Cheshire Foundation booklet emphasises the importance of starting small with any family support service - "one family helped is better than none" - and of tailoring it to meet local needs, as they are experienced by the consumers the service is designed to help:

> "Remember at all times, and at all stages of planning and development, that the service exists for the clients. They know better than anyone what they most need. Consult them as fully and as early and as frequently as possible."
> (Inskip, 1981, p.28)

(Further information on this and similar respite, care attendant schemes is given on p. 51 below.)

The "Plus two" service operated by the Barnardo's Chorley Project also provides respite to parents of mentally handicapped children, but through the help of specially recruited volunteers, rather than part-time paid workers as in care attendant schemes like the ones discussed above.

The service aims to offer an extra pair of hands to the families concerned, in babysitting, escorting children to playgroup or inviting the children into the volunteer's own home. (Shearer, 1978).

In other areas "sitting-in schemes" of various kinds have been developed by a range of different agencies. In the Isle of Wight the AHA and County Council began such a service in 1978 (Dickens, 1979; Parents Voice, March 1979); Coventry Social Services Department developed an experimental service, to allow parents an evening out, using trained and experienced home helps as babysitters as far back as 1975 (White, 1975); the Gloucester Centre in Peterborough provides a similar free service using members of the Centre's staff (North, 1979). In Northampton a sitting-in service is organised through the local branch of APMH (APMH Newsletter, October 1981, p.5) and in Cardiff a sitting-in service was offered by students via Cardiff Universities Social Services (Drinkwater, 1980). In York a similar service was developed jointly by parents and volunteers in conjunction with York Community Council's Fuller Life Action Group and the Student Unit. The scheme has been supported by York Social Services Department since it started in 1978. PACT (Parents and Children Together) links families with a handicapped child to volunteers willing to babysit. The scheme's co-ordinator initially matches family to appropriate volunteer. Families and volunteers are then free to make contact with each other as and when they want. (VCHC, Factsheet 13, 1980).

Respite for parents may also be provided through short-term care for their children given by local families. These schemes are discussed below on p. 46.

Other services

Home visiting and early intervention schemes for pre-school handicapped children are discussed in Chapter 3 (pp.18-24). The effect on siblings of having a handicapped child in the family is reviewed briefly in Chapter 5 (p.54). For information on alternative residential provision for mentally handicapped children who are not able to live in their family home, see p.62.

CHAPTER 5 - THE SCHOOL-AGE CHILD

> "The greatest help was the special school.... To have David away from home between nine and four was our greatest relief."
>
> (Hannam, 1980, p.35)

> "...the health visitor kept on at me to go and see the headmistress and I sort of put it off and put it off, I didn't want to go... I didn't know what to expect and I suppose the longer I kept him away, well, I could imagine to myself that he was normal, but I knew he wasn't ..."
>
> (Mother about admission of her son to special school, in Hannam, 1980, p.135)

Starting school - at whatever age - can bring new stresses to mentally handicapped children and their families. For some parents, there may be the fight to get their child accepted into the ordinary local primary school. For others, the entry of their child into the special education system may underline once more their child's "differentness" from his siblings and peers, and perhaps mark the beginning of segregation from ordinary life in the local community. The stress may be particularly marked if the child has been happily integrated with non-handicapped children hitherto, in an ordinary playgroup, day nursery or nursery school.

Starting school may also pose problems for families who have been involved in home visiting schemes like Portage. Mothers particularly are likely to miss the regular contact with an interested professional, and the consistent availability of ideas, support and guidance on managing and teaching their child, which the schemes provide. On the other hand, for the families in the areas where early intervention schemes are non-existent, and pre-school facilities sadly lacking, the onset of full-time education may bring welcome daytime relief for mothers and the first organised and sustained teaching their children have yet received.

A discussion of the kinds of school education ideally required by mentally handicapped children, of new developments, ideas and ways of thinking, is beyond the scope of this review. (For an overview of some key issues involved see Mittler, 1979; the Warnock Report, 1978, and Hegarty, Pocklington & Lucas, 1982 a & b). In this section, the focus is rather on schemes and services to help the child and his family outside school hours- to meet their needs for information, guidance and support; respite and relief; leisure activities and social contacts.

5.1 Information, guidance and support for parents

Since mentally handicapped children benefit more than most from a consistent approach to their treatment and handling, there is much to be said for ensuring that any guidance and support needed by parents is made available through links between home and school. As Hanvey (1981) points out, however, there is wide variation in the degree to which teachers involve parents in special schools, both between and within local authorities and even within the same school. In some schools links are forged and information and advice given through parent workshops of the kind already described (p.34). Such workshops provide a valuable means for teachers to convey to parents some of the basic guidelines for promoting their children's development adopted within the school, thus encouraging a consistency of approach outside school hours also. Equally important, they may also furnish a means whereby parents may feel able to question and challenge the professionals' point of view, by discussing the methods of management they have themselves used successfully at home, and perhaps pointing out problems in suggestions made by professionals, for example, their lack of relevance to the child's home environment.

In a few schools, the ideas behind Portage have been extended to help school-age (as opposed to the usual pre-school) children. In the past, as Pugh (1981) points out, there have sometimes been problems in the parent/teacher relationship for parents who have, through a Portage scheme, become closely involved in promoting their child's development and planning future goals, and then have found their enthusiasm viewed with suspicion by teachers. Pugh reports that in the South Glamorgan area:

> "some schools are now coming to see the value both of working out specific objectives for individual children, and of the potential of working more closely with parents, and the Portage project could well provide a much needed injection of curriculum development. Two schools have in fact already integrated the Portage approach into their curriculum and are running workshops for parents on the basis of this work. Three further special schools have adopted Portage more recently, and their work is currently being monitored and evaluated." (p.43)

In Wessex too, there have been moves to translate Portage objectives into the school setting and to ensure that parents are not suddenly cut off from close involvement with their children's development when they start school. Pugh (1981) reports that in one school, where two parents were anxious to continue the project, a non teaching assistant (who was, however, by training a teacher) was employed to work with the families and the class teacher on devising curriculum objectives. The approach has now spread to other staff in the school. Meanwhile, researchers in Wessex too are planning to extend the home teaching service to other age groups. (Pugh, 1981).

Links between home and school may also be fostered by parent associations through which parents may be encouraged to participate in school activities - particularly extra-curricular ones - and to raise funds for special school equipment and amenities. (Hanvey, 1981). On a more modest scale, the provision of a diary for each pupil, which travels with the child to and from school each day and in which any problems, developments and programmes are entered by teachers or parents, may be an invaluable aid to mutual understanding and consistency of treatment. (Mittler, 1975). Such diaries are especially valuable where the child has communication difficulties, and where parents are geographically located some distance from the school, so that ready access is not easy.

Social workers, particularly school social workers where they exist, could also have a key role to play in promoting home-school links by liaising with families and encouraging the development of parent associations and groups (Hanvey, 1981; Mittler, 1975). Limited resources, however, will almost inevitably constrain social work activities to be crisis-oriented. The existence of both ongoing parent groups and workshops, and of a keyworker known to each family (probably at this stage of the child's life, a teacher) would ideally help to ensure that information, guidance and support was consistently and readily available to parents, preferably before such crisis points were reached.

5.2 Respite and relief

Short-term care schemes

Almost all parents will admit to a periodic need for time away from their children. Parents whose children are mentally handicapped are no exception. Indeed, given the greater demands made on parents by handicapped children as they grow older, heavier and, often, therefore, increasingly difficult to manage physically, the needs of such parents for periodic breaks from caring are arguably greater. Traditionally, however, such needs have largely gone unmet. On the one hand, offers of babysitting by friends and relatives may be less forthcoming where the child has a mental handicap; on the other, parents may both be reluctant to ask for help, and also feel protective towards children who have difficulty in making their needs known. Until recently, moreover, the chief source of relief care has been in hospitals or other institutions, which parents have generally viewed with understandable suspicion and distaste.

In the last few years, however, this situation has begun to change. Informal, locally-based schemes offering short-term relief for parents have developed in a number of areas. Pioneered by Leeds and Somerset Social Services Departments in the mid-1970s, and since developed in numerous other areas, such schemes have proved a resounding success with parents and children alike. The schemes operate by recruiting other local families to offer temporary, short-term, respite care for mentally handicapped children for variable amounts of time, from a few hours to perhaps a fortnight. The host family is paid for the service it gives (for example, on the basis of a weekly retainer, plus additional fees for care actually given, as in the Avon scheme - St.John Brooks, 1982). The service is usually free to the families of the mentally handicapped children concerned.

Most of the schemes rely on heavy social work involvement in the early stages - recruiting and training potential host families, carefully matching them to client families and gradually facilitating their introduction to one another. As families get to know each other, professional involvement tends to fade into the background. Families can make their own direct arrangements regarding the time and amount of care offered and required. Professional advice and help - via a social worker - is however always available should the need arise. A clear benefit of such schemes is that they not only provide respite for parents, but also give the children involved the positive experience of widening their horizons by getting to know another family. In many cases, friendships have developed between the families involved. Initial reluctance from parents to contemplate entrusting their handicapped children to other families has gradually evaporated. (St.John Brooks, 1982; Thomas, Smith & Smith, 1980). Indeed, parental support of such local respite schemes has now mushroomed to such a point that there is anxiety in some social service departments about what will ensue when parents no longer qualify for the service when their children leave school.

Details of how different short-term care schemes have been set up and run in various parts of the country, by social service departments, voluntary agencies and parents'groups are now available through a number of articles and publications. A particularly useful source of such information is the free factsheet produced by the Voluntary Council for Handicapped

Children "Short term respite care schemes for mentally and physically handicapped children" (VCHC, Factsheet 13, 1980). The factsheet gives a brief overview of fourteen different schemes in various parts of the UK with details of names, addresses and references for further reading, and includes accounts of the original schemes developed by Leeds and Somerset. More information on the Leeds scheme can also be found in Crosby, Runciman and Naylor (1978); on the Somerset scheme in Somerset County Council (1979) and Crine (1981). Crine reports that fifteen social service departments were operating schemes similar to the Somerset one by July 1981, some of which are described in the VCHC factsheet mentioned above. Fuller information on the "Give mum a break" scheme running in Bradford, can be found in Toward and Bower (1981). It includes a detailed account of the financial and administrative arrangements of the project (which is joint funded) and a description of the recruitment and training of substitute families and their matching and introduction to families with a handicapped child.

A vivid account of the scheme run by Avon Social Services Department, with a particular emphasis on the feelings and experiences of one pair of families involved, is given by St. John Brooks (1982). Parents' views on short-term care schemes are also described in Bromley and Lister (1980) and Thomas , Smith & Smith (1980). The former reports a survey designed to discover parents' views on the kind of respite care scheme preferred, so that services provided could be geared to parents' needs.

(A Somerset type scheme was favoured by parents). The latter reports an evaluation by both "natural" and "substitute" families involved in the Northumberland scheme, which found, amongst other things, a high degree of parental satisfaction. A number of reports mention the relatively low cost of family based respite schemes as an additional point in their favour in the current economic climate. (See, for example, Thomas, Smith & Smith, 1980; St.John Brooks, 1982. For more detailed information on costs and finances generally, see Toward & Bower, 1981).

Not all short-term care schemes have developed on the Somerset and Leeds model, however. Many are based on special short-stay facilities or hostels rather than on substitute family care. They are organised by a variety of agencies. Heathcroft, in Reading, is a purpose-built unit for children, run by the local social services department (Klein, 1979); the Gloucester Centre in Peterborough, also purpose-built, is run by the health service (North, 1979), as are community units, like Edge View in Kidderminster, which serve a variety of purposes in addition to providing short-term care for both children and adults (Hibberd & Simon, 1977. For further information on community units, see p. 91 below). Holy Child House in Hillingdon, is managed by a private hospital on behalf of the AHA and the Social Services Department, which share the running costs involved (Froud and Tidball, 1981). In Liverpool, short stay care is provided in a house set up by the Diocesan Catholic Social Services (Brandon, 1981); in Witney, in a house owned and managed by the Parents Association of a special school (Hunt, 1980). In Welwyn Garden City, Jubilee House came into being through the efforts of parents in the local NSMHC group, with the co-operation of the local housing department - which provided a pair of semi-detached houses - and the social services department - which will financially sponsor children needing short-term care there. (Guy, 1979). A number of other interesting schemes are also described in Maureen Oswin's pamphlet "Issues and principles in the development of short term residential care for mentally handicapped children." An appendix to the paper gives contact names and addresses for a variety of schemes throughout the country (Oswin, 1981 b). An extremely valuable summary of the advantages and disadvantages of different short term care schemes is given in the report of the Guy's Health District Development Group. (Guy's Health District, 1981).

Care attendant schemes

An alternative source of respite for parents is for care of their children to be provided by someone else, but within the family home. Ordinary sitting-in services of this kind have been discussed above (see p. 41). In a few areas, however, more regular help to parents is now available through organised care attendant schemes (often known as crossroads schemes). The fundamental philosophy behind such schemes is that parents are the experts in the day to day care of their own children. Paid care attendants going into the family home to give parents relief from constant caring will learn best from the parents (or the children themselves) how to give help in the way it is needed. The care attendants - often older married women - are given a little basic training on appointment, and then allowed time to become acquainted with the relevant routines, preferences and idiosyncracies of habit of the particular clients with whom they will work. Relief care is often given for only a few hours at a time, but that respite may provide the means whereby parents feel able to continue caring for their child at home rather than seeking alternative residential care.

Examples of the operation of different care attendant schemes are given in the Leonard Cheshire Foundation Handbook referred to above (p. 39) and in a free leaflet produced by the King's Fund Centre entitled "Stress and the caring relative. Crossroads schemes for mentally handicapped people." The latter gives a useful account of the development of such schemes, their cost and the training of care workers employed. It emphasises the need for such help to be offered when the mentally handicapped person is still young, so that mother and child do not become settled in their isolation and dependence only on each other. A particular value of such schemes, it is stressed, is the consistency of support offered, at a time when social work services generally are increasingly discretionary and crisis-oriented. (King's Fund Centre, 1980 a).

A third, and inspiring, account of this type of scheme is given in the pamphlet produced by the Birmingham Multi-Handicap Group on their parent relief service. Organised by parents of multiply handicapped children over ten - for whom provisions were felt to be particularly lacking - this scheme has now been funded with help from Birmingham's Inner City Partnership, to run for five years from April 1980. Parents pay a nominal one pound per sit payment to the care worker, which can be waived if necessary. Families and care workers are matched and linked by the project co-ordinator who is also responsible for recruiting and training staff. The value of the scheme and its flexibility in fitting the needs of the parents and their children are vividly illustrated by the case studies of families using the service in its first six months. (Birmingham Multi-Handicap Group, 1981).

5.3 Leisure, social and holiday activities

> "The idea of the total social desert that would face Kim as she grew older, began to haunt us ... There were no friends for her to play with and no invitations to tea or birthday parties - except from close friends. We had for some time been feeling rather like pariahs in the neighbourhood - for Kim, we began to realize, this could be the way she lived her whole life."
> (Collins, 1976, p.17)

Maurice and Doreen Collins' concern over the social isolation of their mentally handicapped daughter, Kim, will be shared by many other parents with mentally handicapped children, for whom social contact with peers - handicapped and non-handicapped alike - is desperately difficult to achieve. Out of the Collins' anxieties grew Kith and Kids, a self-help group of families with handicapped children, most of them living in North London. Kith and Kids - described more fully by the Collins in their book of the same name - began in the winter of 1970, with several families with handicapped children meeting once a fortnight on a Sunday to eat and relax together. The Sundays provided a chance for social contact for the whole family with other whole families - parents and children, handicapped and non-handicapped alike. For the handicapped youngsters there was the opportunity to shop, cook, set the table, eat and clear up after lunch and to enjoy a whole range of activities - art and crafts, singing, treasure hunts, cycling, football. The Sunday events were carefully planned beforehand by the parents at a weekday evening meeting so that there would be activities available for every person whether physically, mentally or non-handicapped. Over time, as Pugh (1981) observes in her review of the project, the parents in the group have built up a considerable body of experience. The weekday meeting can therefore provide an opportunity for discussing individual children and their problems. The Sunday gatherings are valuable for parents, in giving them support and the opportunity to share anxieties and experiences with other parents; for the handicapped children, who can relax and enjoy the social contact with other children and adults without the anxieties which often accompany excursions into the community, and for the 'normal' children, who can enjoy the social activities without self-consciousness about their handicapped siblings' behaviour, and perhaps derive some strength from the realisation that they are not alone in their situation (Pugh, 1981). (For some discussion of research into the effect on siblings of having a handicapped brother or sister, see Boyce (1977); National Children's Bureau (1981); Gath (1972, 1973), all of which list additional references for the interested reader. APMH (1980a) also discusses the needs of siblings and describes a group for siblings of Down's Syndrome Children run by a clinical psychologist. Pugh (1981) refers to the interviews with siblings of handicapped children carried out as part of the Family Involvement with Services in Haringey project, commonly known as FISH. Fuller details of this project from the Thomas Coram Research Unit, see p.133).

Pugh (1981) also gives an account of <u>Contact-a-family</u>, which like Kith and Kids, developed to overcome the problems of isolation for families with handicapped children. With the help of full-time workers, Contact-a-Family aims to bring together families with physically or mentally handicapped children in the same neighbourhood to form local self-help groups. In this way families can share experiences and problems, support and help each other and organise services and activities that are needed locally, for example, holiday playschemes, babysitting, help with transport, social clubs and so on. Local groups first started in Wandsworth and Ealing but have now spread elsewhere with the support of local social services, health and voluntary organisations. Different groups engage in a variety of activities, according to the interests, ideas and needs of local members. In addition to social activities like Saturday family clubs - where the whole family can pursue a variety of social and play activities with other families - some groups run visiting schemes like those mentioned on p.15 above. Here, parents in Contact-a-Family groups will visit newly born or assessed handicapped children and their families with a view to offering support, friendship and understanding in the difficult early weeks and thus helping to avoid feelings of isolation. For more details on Contact-a-Family and its activities, see Pugh (1981). A Contact-a-Family film shows how the original Wandsworth project got off the ground and how similar projects might be set up elsewhere. (See p.131).

Gateway and other clubs

Another important source of leisure activities for young mentally handicapped people are the five hundred or so Gateway clubs throughout the UK. Many Gateway clubs are for people over 16 but an increasing number include activities for younger people. The wide range of activities and sports encouraged by clubs is described in the Line 81 factsheet "Sport and Recreation." For more information, and details of local clubs, contact the National Federation of Gateway Clubs (see p.132). The factsheet also gives details of other sport and leisure organisations open to handicapped people. (Line 81, 1981). Further useful information on leisure opportunities for handicapped children is also available in the following free factsheets produced by the Voluntary Council for Handicapped Children: no.2 "Water sports for handicapped people" (VCHC, 1979); no.7 "Play and toys for handicapped children" (1980) and no.8 "Art, music, drama and the handicapped child" (1982).

Holiday activities

> "It is not hard to see what a nightmare long school holidays are to most of the families and the extra strain they put on everyone in the house. Frequently school holidays are the final straw that make parents ask for residential care for their child..."
> (McCormack, 1978, p.54)

If parents are asked about the kind of provisions they would welcome for their mentally handicapped children, holiday activities feature high on the list (Shearer, 1978; Collins, 1976). The long summer holidays from school, when the child may be without occupation, stimulation or social contact with peers, can be a major problem for their families (NDG, no.2, 1977; Wyman & Russell, 1980/1). Mothers, in particular, suffer from round-the-clock care of the child, especially when s/he is severely or multiply handicapped or has behaviour problems which make even routine excursions like shopping a monumental feat of organisation to achieve. (Wilkin, 1979). Siblings too may suffer if parents are unable to participate in 'normal' holiday activities like trips and visits to parks, zoo, seaside or swimming pool because of the handicapped child. (McCormack, 1978). Anxiety about the effect on their 'normal' children of the handicapped sibling may therefore intensify during school holidays. Coupled with the burden of constant care, this may ensure that school 'holidays' are a period of unrelieved strain for parents. One solution to the problem recommended by the National Development Group is for schools to stay open for 48 - 50 weeks a year, with individual teachers taking staggered holidays. Another is for schools to operate a four term year, thus significantly shortening the breaks between each term (NDG, No.2, 1977). Where the long summer break continues, however, some schools have been prepared to lend their premises for holiday playschemes, organised largely by voluntary organisations of different kinds, often as a result of parental pressure. Below are brief accounts of some successful schemes which have proved popular with children and parents alike. Such schemes are, however, still woefully thin on the ground relative to the potential demand, and even where they do operate, shortage of funds usually means they can cater for only limited numbers of children and then only for odd days or short periods of the holiday break.

Kith and Kids Two-to-One Project

Two-to-One is a two week holiday playscheme which developed out of the Kith and Kids Sunday meetings (see p.53). Parents there felt that their handicapped children would benefit from a structured social training programme, and from some organised activity during the long summer holidays. With the aid of psychologists, a playleader, two volunteers per child and a lot of hard work, planning and fundraising, Two-to-One evolved to meet these needs. Full details of the development and operation of Two-to-One are given by Collins (1976), and by Pugh (1981); the following is a brief account of the scheme based on their reports.

Each year, before the scheme starts, parents complete the Gunzburg Social Assessment Charts to evaluate their child's skills in a variety of areas. The charts give the psychologists planning the project detailed information on each child. Parents also give their views on the areas where they feel their child would most benefit from help. On this basis, the psychologists plan a two weeks' programme for each child, which two volunteers will help to carry out. Many of the volunteers will not have had previous similar experience so their training in the basic premises of the behavioural approach is vital. The training is necessarily brief - a total of perhaps twelve hours, spanning a day and two evenings before the project starts, plus an introduction to their child and the family at one of the Sunday gatherings.

During the two weeks' project, the children's time is divided between intensive, individual work with their volunteers and group activities of different kinds, like singing, dancing and movement. The day ends on a quieter note - a book, a quiet game, perhaps a review of the day's events with a scrapbook and polaroid photos. Pugh (1981) notes in her comments on the project, that there has, as yet, not been the time or money to evaluate the project. No one can prove, therefore, that the children would not have made progress without it. It is, however, clear that new skills have been learned, and that the children do enjoy participating in the social activities taking place. Equally importantly, the project - though involving parents closely in working out their child's programme - also gives them a much needed break, so that they can 'take a deep breath and carry on afterwards with fresh enthusiasm'. (Quoted in Pugh, 1981).

Contact-a-Family

Contact-a-family also provide holiday activities for handicapped children and their families - at half-term and in the Easter, Christmas and Summer holidays. The activities include daytrips and visits, organised games, arts and crafts, use of inflatables and playbuses and visits by music and drama groups. The schemes are led where possible by parents, organised by a rota of parents and local volunteers, and grant aided by the local authority. (Pugh, 1981. More information from Contact-a-Family, see p. 131).

Barnardo's Chorley Project

Shearer (1978) describes the playscheme that evolved in Chorley in response to parents' requests for holiday activities for their mentally handicapped children. The scheme runs two days a week for a month, though with transport laid on for each child for only one of these days. Parents and children have responded to the scheme with enthusiasm - the most common criticism being that it does not run long enough. An appendix to Shearer's pamphlet contains useful notes on how to set up a playscheme, plus a sample information sheet to be filled in by parents, describing their child's abilities, feeding and medical requirements and so on.

Other holiday playschemes and activities

Another useful account of holiday playschemes run by local voluntary organisations is given by Bontwood (1981), who briefly describes four schemes which have evolved in different parts of West Surrey. The article highlights the variety of ways in which schemes may be set up and run according to local needs and resources. One scheme described, for example, ran successfully from 10 - 4, five days a week, for four weeks of the summer holidays, while another operated for only six days in a fortnight, from 10 to 3. Some of the schemes operated at Easter too. The article mentions not only the successes but also some of the problems confronting different schemes, which might be useful to others contemplating similar ventures.

Wyman and Russell (1980/1) refer briefly in their article to the holiday activities operated from the KIDS family support centre in Camden (see p.33 above). For details of the range of holiday programmes organised by the Royal Society for Mentally Handicapped Children and Adults, contact MENCAP (see p.132).

Holidays away from home

When it comes to holidays away from home, parents, as Mary McCormack succinctly puts it

> "have roughly four alternatives - take the child along; leave the child in residential care; take separate holidays, one parent staying home with the handicapped child; or forget the whole idea ..."
> (McCormack, 1978, p.64)

The alternative chosen will depend on a range of factors, particularly the child's age and severity of handicap or behaviour and communication problems. Some organisations run holidays for mentally handicapped children; there are also holiday facilities available which cater for families with a mentally handicapped child (see below). For many families, however, a summer holiday for the rest of the family will depend on the availability - and acceptability - of short term care provisions for their child (see p.46). In areas where satisfactory respite care schemes operate, where the child is happily familiar with another host family which is willing and able to have the child to stay for a week or two, then holidays away become a real possibility. In the absence of adequate short-term care facilities, the notion of a holiday may become meaningless to parents overwhelmed with anxiety and guilt over their child's well being. Separate holiday arrangements for mentally handicapped children must clearly be a positive experience for them, before holidays away can become a positive experience for the rest of the family also.

Information on organisations and publications dealing with holidays for handicapped children is available in the Line 81 publication "Holidays" (1981) and in the free factsheet "Holidays for handicapped children" produced by the Voluntary Council for Handicapped Children (Factsheet 3, nd). Some local information booklets or services for handicapped people, also include holiday facilities (see, for example, Bristol CMH, 1980). The MENCAP holiday accommodation guide for England, Scotland and Wales (there is a separate guide for Northern Ireland) lists accommodation where mentally/physically handicapped people can holiday, either unaccompanied, with their families or in groups. The guide is in five sections covering hotels and guest houses; self-catering facilities; holiday camps and centres; specialist accommodation and group booking facilities. MENCAP also runs a programme of special care, adventure and guest house holidays for unaccompanied mentally handicapped adults and children in the UK. (The guide is available, price £1.00 (50p for N.Ireland edition) from MENCAP Holiday Service Officer, see p.132).

Other services

For information on alternative residential provision in the community for mentally handicapped children who are not able to live in their family home, see Shearer (1981) and Dalgleish & Matthews (1981). Both of these include discussion of the health authority venture in Ashington, Northumberland - a home for four severely mentally handicapped children in an ordinary house in the community. More details about the Barnardo's cluster housing project for children in Skelmersdale, Lancashire, can be found in Wolfarth (1982). For more information about the local unit for children in Winchester, contact the Health Care Evaluation Research Team (see p.131).

CHAPTER 6 - THE SCHOOL LEAVER AND YOUNG ADULT

> "Provision for school-leavers and young people is now one of the most inadequate features of all our social, educational or health services for handicapped people." (Mittler, 1979, p.111)

The moment at which their mentally handicapped child will leave school is one dreaded by many parents. Bicknell (1981a) spells out the contrast for parents between support received by them in the past from school and child health staff, and the future adulthood of their son or daughter seen by them as

> "an empty void with the problems of unemployment, ill understood sexual drive, perhaps increasing behaviour disorder, and in relationship to their own increasing age and progressive weakness." (p.2)

The National Development Group's pamphlet "Helping mentally handicapped school leavers" also describes the difficulties that may arise at this time. Young people, at home without satisfying occupation or leisure opportunities, may present new problems of behaviour. There may also be a drop in the family standard of living if one parent is forced to give up work to look after the handicapped person in the absence of daytime facilities for them (NDG, 3, 1977). Under the pressure of these stresses, it is perhaps hardly surprising that this is the point at which many families will feel that they can no longer continue to cope with their child at home. Admission to a hospital may well be the only alternative. Hence, the dramatic peaking of hospital admission rates for the 16 - 20 age group: 25 long term admissions per 100,000 population, compared with 11 per 100,000 for all other ages. (NDG, 3, 1977).

In this section, we consider in turn three broad areas in which improved services are essential if mentally handicapped young people are to be enabled to go on living in the community after leaving school, as is their right: education and employment; family support; training for independent living and the provision of residential alternatives for those wanting to leave home.

6.1 Education and Employment

> "Any parent with a handicapped child has sooner or later to face the problem of what is open to the young adult when the present education system drops him or her. And unfortunately at the moment .... the answer still seems to be: not much." (Collins, 1976, p.136)

The needs of mentally handicapped school leavers, and some suggestions for meeting them, are usefully discussed in the Warnock Report, "Special Educational Needs" (1978) and, more briefly, by Mittler (1979). and by the National Development Group in their valuable guide "Helping mentally handicapped school leavers" (NDG, 3, 1977). All three publications stress the importance of careful assessment of every school child well before the point of school leaving is reached. Mittler (1979) emphasises that such assessment needs to embrace not only intelligence but many other characteristics, including social, self-care and language skills, competence in literacy and numeracy, and qualities of personality and temperament. Such an assessment should be followed by a decision on how these needs can best be met by the resources of the local community. It is, therefore, essential that those concerned with the assessment are aware of the whole range of resources available. Mittler, however, reports evidence of alarming ignorance amongst staff from a wide variety of agencies involved with handicapped people, of potential sources of outside help from other professionals, organisations or community resources.

The NDG pamphlet stresses that assessments should result in a recorded statement of the young person's future service needs, and how these will best be met. This statement should spell out the steps to be taken to ensure that the recommendations made are translated into action. The pamphlet suggests that the following professionals should, ideally, be involved in the assessment process: the head teacher or another member of staff from the school; the manager or staff member from the ATC: a social worker; a clinical or educational psychologist; a careers officer and the parents. Other workers - e.g. a nurse if the child is in hospital, a residential care worker if the child is in some other form of residential provision - should also be involved where appropriate, or consulted as necessary - as for example, a speech or physio-therapist. Examples of forms on which the results of the assessment and decisions made may be recorded are given in appendices 2 and 3 of the NDG pamphlet "Mentally handicapped children: a plan for action." The form should go with the young person to his or her next placement.

Sometimes, of course, the services recommended for a young person may not be available locally. In such cases, it is, however, still important for the assessment to be carried out and for decisions to be made about the services ideally required. It is also vital that planners and service providers be kept aware of facilities that are necessary but not available. At the NIMROD project in South Glamorgan, for example, required services are entered on the assessment form. Where the service needs cannot be met, the reasons are also entered (e.g. no ATC place available). In addition, the relevant authority is notified so that there is a steady flow of information and pressure to make provisions for unmet service needs.

The options that should ideally be available for mentally handicapped youngsters span the whole range of full-time, part-time and further education, work orientation courses and work experience schemes through to ATCs, sheltered, supported and open employment. The NDG pamphlet reviews the various options in turn, with examples of places where different schemes are operating. Mittler (1979) and the Warnock Report (1978) cover similar ground.

Collins (1976) discusses the service needs of the school leaver from the parental viewpoint in the chapter "After Sixteen - Employment or Dependence?" On the basis of discussions at Kith and Kids workshops on "After Sixteen - What?" they outline provisions currently available and contrast them with those they as parents feel to be necessary for their children. An important feature of their model service for the over-sixteens is the availability of continuing education in its widest sense - both education in social and other skills, which may best be provided in some further education institution or polytechnic, and continued education of the kind they have already been receiving at special school. Mittler (1981) makes the same point - that school should be seen almost as an interlude in the process of an education which should be life long. In practice, however, education for mentally handicapped young people in some areas comes to an abrupt halt at 16, despite widespread recognition of the benefits of full-time education beyond this age. The victory of parents in Oxfordshire in 1981 in their fight to win full-time education until age 19 for their mentally handicapped youngsters could be useful to other parents anxious to extend educational facilities for their children. A brief account of the Oxfordshire campaign and information on how to go about securing education provisions for youngsters beyond the age of 16, are given in the free leaflet "Education to 19 .... the right of ALL mentally handicapped people." (The Children's Legal Centre/MIND/ACE 1981). Collins (1976) describe their successful efforts to set up further education facilities for severely mentally handicapped people in their area; they also emphasise the general importance of flexibility in education and training provisions for mentally handicapped youngsters, given their enormous range of needs and abilities. A free list of independent voluntary establishments providing further education, social and vocational training and/or assessment and sheltered employment for handicapped school leavers is available from the Voluntary Council for Handicapped Children (VCHC, Factsheet 1, 1981). The Council also publish a useful guide to organisations and publications dealing with the sexual needs of handicapped young people - an important topic not otherwise considered in this review. (VCHC, Factsheet 6, 1979).

Adult Training Centres

ATCs constitute the main form of daytime service provision available for mentally handicapped school leavers, and indeed mentally handicapped adults in general. An overview of recent developments in ATCs, the kind of activities carried out there, the abilities of their students, and current proposals for change are given by Mittler (1979). Much of his information is drawn from the National Survey of ATCs carried out by Whelan and Speake (1977) and from the excellent pamphlet produced by the National Development Group "Day services for mentally handicapped adults" (NDG, 5, 1977). The pamphlet outlines the development and changing role of ATCs - signified by the proposed change of title to Social Education Centres. It gives detailed recommendations of how the shift of focus from traditional assembly work to social and further education of all kinds may be achieved, via chapters dealing in turn with the whole range of important issues - staffing, admission process, assessment, activities and programmes, record keeping, provision for the most severely handicapped people, preparation for work etc.

In practice, the reality of ATC provision lags some way behind this ideal. In the current economic climate, it is also clear that many ATCs are 'silting up'. Few trainees - or students - are likely to move on into sheltered or open employment. The majority will remain at the ATC for most of their adult lives. A lack of ATC provision for youngsters fresh out of school is becoming an increasing problem, given current financial constraints on social service expenditure. (Mittler, 1982).

Nonetheless, the literature does contain evidence of positive developments in ATC provision. In rural North Yorkshire, funds from the Rowntree Memorial Trust have financed a mobile ATC in the form of a converted double decker bus. The results of the evaluation of this project (the research is funded by the DHSS) may enable the development of similar services in other rural areas. (James and Hodgson, 1982). Chisholm (1979) reports on another rural ATC type venture - this time on a farm in Bletchley, Buckinghamshire - and Marsden (1981) describes the setting up of Dalewood House - a kind of voluntary ATC - by a local parents' group. Other examples of service provision by voluntary organisations are to be found in the Voluntary Council for Handicapped Children's free factsheet, mentioned on p.67. On the statutory side, the Evaluation Research Group report positive changes in staff attitudes and activities in ATCs in Sheffield between 1977 and 1979 (Armstrong, Heron & Todd, 1980). Fleming, Grove & Hope (1979) give an encouraging account of the development of an ATC in Bromsgrove, with welcome emphasis on interdisciplinary planning and monitoring and the encouragement via a social worker of strong links between home and ATC.

Employment

With widespread unemployment amongst the population at large in this country, the prospects of mentally handicapped people securing open employment would seem on the surface, to be bleak. There is some evidence, however, that local schemes aimed at promoting employment opportunities for mentally handicapped people may, nevertheless, succeed. White, for example, some years ago described an enclave scheme for mentally handicapped workers, established within a local packaging firm in Coventry. Of the original thirty trainees placed there at the time of the article, seventeen had progressed to ordinary paid employment. (White, 1975). More recently, Murray (1982) describes how in Newcastle 40 - 50 mentally handicapped people have gone into enclave schemes and open employment in the last two years. The Pathway Scheme - a training and placement scheme pioneered by MENCAP - has been a particularly successful means of placing mentally handicapped people in employment, in those parts of the country where it operates. Originally funded by MENCAP, Pathway Schemes in some areas are now local authority financed. Mittler (1982) observes that the scheme, with only limited resources and even with three million unemployed, has demonstrated the possibility of finding employment for some mentally handicapped people. He suggests that one of the best investments the Government could make would be to co-operate with MENCAP to appoint a team of Pathway Officers in each part of the country. For more information on the Pathway Scheme, see Klein (1980) or contact MENCAP (see page 132). Brief details and recommendations on sheltered employment, enclave sheltered work groups in open industry and employment rehabilitation centres are given in the NDG pamphlet "Helping mentally handicapped school leavers" (NDG, No.3, May 1977); see also the VCHC factsheet mentioned on page 67. For detailed information on ways of increasing the possibility of employment for mentally handicapped people, see Whelan & Speake (1981).

"Special Care" Provisions

For those young people who are profoundly or multiply handicapped, or who have severe "behaviour problems", opportunities for daytime occupation or training are much reduced. Recommendations for facilities appropriate to their needs in special care sections of ATCs are given in the NDG pamphlet "Day services for mentally handicapped adults" (NDG No.5, July 1977). Some of the problems associated with special care provision are helpfully discussed in the Guy's Health District report (1981).

Where special care provision at, for example, an ATC is not available, day care in a "local" hospital may be the only possibility. Malin et al (1980) point out that the standard of day care provided will vary enormously according to the resources of each particular hospital, but that little research exists on this subject. Some research has been carried out, however, on the day units attached to the new 96 bed hospitals in Sheffield, and is discussed by them. A particular problem in these units was their open plan design which created difficulties for staff and residents because of the associated noise, visual distraction and resident wandering. (Malin, Race & Jones, 1980).

In some areas, the absence of even hospital day care facilities (or their unacceptability to parents) may mean that families with very severely handicapped members may find at school leaving age that they are forced into round the clock care. In these circumstances, the availability of family support services will determine how long they are able to continue to cope.

6.2 Family Support Services

> "We believe there is a connection between this peaking of hospital admission rates (at 16 - 20) and the inadequacy of support services in the community."
>
> (NDG, 3, 1977, p.1)

The problem confronting parents of mentally handicapped young people may intensify at school leaving age for two reasons: a lack of day-time facilities (especially where the young person is very severely handicapped); and the sudden withdrawal of family support services previously available when the "child" suddenly becomes an "adult" and thus, in the eyes of service providers, ineligible for certain services. An example of the latter is the respite care schemes described above (page 47). In most of these schemes, eligibility ceases on leaving school, even though the need for such a service does not diminish at this point. The ideal solution of course, is to make available appropriate short-term care provisions throughout the mentally handicapped person's life, and it is likely that parents who have come to rely on respite care schemes during the mentally handicapped person's childhood, will put pressure on service providers to do this when they are confronted by the prospect of the scheme's withdrawal. For their part, service providers are keenly aware of the problem. (St. John Brooks, 1982). How local authorities running respite care schemes are to cope with the financial implications of extending services into adulthood remains, however, to be seen.

There is some evidence that other services for "children" may also cease to operate beyond school-leaving age. Shearer, for example, reports that parents of mentally handicapped children serviced by Barnardo's Chorley Project, were extremely anxious that the social work support on which they had come to rely, would cease once their children became adults. (Shearer, 1978).

Russell (1981), in a recent paper on the service needs of this age group, emphasises that practical help from professionals and others is still vital for mentally handicapped young people and their families. She quotes a survey of young mentally handicapped people in Ealing which discovered nine young people living at home who were not receiving the Non Contributory Invalidity Pension or Supplementary Benefit to which they were entitled. Over a quarter of parents expressed an urgent need for more financial help. Other surveys of mentally handicapped adults at, for example, ATCs have similarly found appreciable numbers not receiving the full benefits due. (Bennett and McGavin, 1980). The evidence of such surveys indicates that the need for routine social work, or other, support and advice on benefit entitlements and help available certainly continues beyond childhood.

Russell (1981) also stresses the need for domiciliary family support services, particularly for families with "special care" young people. Crossroads care attendant schemes family support services like the Birmingham parent relief service described above (p.52) have a crucial role to play here. Back up from a community mental handicap nurse - where such exist - is also important. Russell emphasises that it is vital that any family support services operate at weekends and unsocial hours, when families may be under most stress.

The continuing need for respite care provisions has already been noted. Russell points out that short term care in a local hostel - where such facilities are available - may be an attractive proposition for young adults, especially if it offers opportunities for leisure activities and socialising, which many mentally handicapped youngsters lack. (See p.79 below for further discussion of leisure activities for mentally handicapped adults). Hostels may however be unable to offer short term care for severely handicapped young people. This obviously poses problems for parents who have grown to rely on respite care schemes for their children (since foster families <u>are</u> able to cope with severe degrees of handicap) if they are then refused respite care facilities when their children are eighteen. (Crine, 1981).

Short stays in a hostel or with another family are important at this stage in the mentally handicapped person's life cycle, not just for the family which may need a break from caring - but for the young person him or herself. Dickerson (1981a) in a stimulating article on the challenges presented to parents as their handicapped children enter adolescence, points out:

> "So-called normal children prepare for separation from family and relocation from home of birth to home of selection or choice by many forays into brief time-limited experiences away from the family. Such experiences prepare the emerging adult for his eventual release from primary family relationships." (p.17)

Thus, as Russell (1981) comments, short term care away from home is a step in the direction of more independent living.

6.3 Training for independent living and leaving home

In the life cycle of a "normal" person, the late teens often mark the point of departure from the family home. The young person sets up home on his or her own. Normalisation means that the same possibility should exist for mentally handicapped youngsters too. In practice, this is rarely the case. Comparatively little residential provision exists for mentally handicapped people outside the family home or the mental handicap hospital. The absence of community support services and alternative residential options means that for many handicapped young people, any move from the family home may well be a move away from normal living - a move into a long stay institution.

In the last few years, however, the idea that mentally handicapped people should live in ordinary houses, just like non-handicapped people but with additional support as necessary, has rapidly gained acceptance. Some interesting projects and publications on the use of ordinary housing for mentally handicapped adults are reviewed later (see p. 83). For mentally handicapped youngsters the concept of ordinary housing provision is equally important. A crucial issue here is the need for young people to be adequately prepared for a move towards more independent living, by training in appropriate skills - e.g. the preparation of drinks, snacks and simple meals; shopping and the use of money; how to use public transport, telephones etc. This training should ideally, start at special schools and continue at the ATC or Social Education Centre. As Russell (1981) notes, however, such training becomes useless unless the skills are practised at home. She cites research carried out by Cheseldine and Jeffree at the Hester Adrian Research Centre (see p.132) which pin-pointed the lack of awareness and communication between home and school about what skill-training and risk-taking was taking place where, and how it was being carried out.
Wertheimer (1981 a) reports a similar lack of communication between ATC and home - with a resulting inconsistency in approach to social skill training for the individual involved - in her study of elder parents with a mentally handicapped person living at home. In the Cheseldine and Jeffree research, parent workshops had been held for parents of young people in the top classes at school. Parents and teachers worked with other professionals (e.g. physiotherapists and psychologists) using the Pathways to Independence checklist as a

basis for assessing each pupil's skills. Teachers and parents completed the list separately, then discussed any discrepancies and jointly worked out solutions and courses of action, so that training taking place at school could be practised and reinforced at home, and vice versa. Such workshops could also usefully be held for parents of students at Social Education Centres or ATCs. A similar model might be adapted, Russell suggests, to other community based services. A social worker or community nurse might co-operate with a family in completing such a checklist and working out priorities for skill training for the young person at home. (Russell, 1981). "Learning to cope" - a readable handbook for parents of mentally handicapped young people - is a useful guide for parents wanting to promote their child's independence in this way. (Whelan & Speake, 1979).

Some training for independent living is obviously helpful if the young person is to move away from the family home. Ideally, however, a range of residential alternatives should be available, so that mentally handicapped youngsters can live in a relatively well supported environment, away from home, even if they are not equipped to cope with totally independent living, much as their 'normal' peers may do in student hostels. Such units do not however need to be heavily "institutional". Camden's ten place residential unit for mentally handicapped young people, for example, is in fact a large house. It is clear from the description given by Shearer (1981) that, despite the level of handicap of the residents, the overriding atmosphere is that of ordinary domestic life.

Shearer also describes another project in Camden using ordinary housing to accommodate mentally handicapped young people not (yet) able to live without support. In an imaginative experiment three mentally handicapped young people are now living in a house rented on their behalf by the social services department. They share the house with a married couple who also have a mentally handicapped son. The couple are paid by the local authority for their support. When the young people come of age, they will become the legal tenants. It is their home until they choose to leave. Meanwhile, the couple are guaranteed rehousing by the local authority if ever they want to move. (Shearer, 1981).

The flexible approach adopted by Camden overcomes some of the problems that arise as services are withdrawn from "children" when they become "adults". In this case, the young people had previously been in a local authority children's home which they would soon have had to leave because of their age. The lack of good residential provision for handicapped children when they reach eighteen, in comparison with the often high quality of residential care available for them before then, is a common headache for service providers, both in the voluntary and statutory sector. Shearer (1981) for example, reports on the high quality of life offered by the Wessex units for children, but notes the large number of children that have gone into traditional hospital care at age sixteen, for lack of appropriate alternative. She also comments that planners in Northumberland originally assumed that the mentally handicapped children living in an ordinary house in Ashington would move out when they became adults, to make way for other children. Now, however, the house is seen as their home for life, until anything better turns up. Meanwhile a second home is planned to accommodate an older group of mentally handicapped adolescents, currently living in the local mental handicap hospital.

Further residential options for mentally handicapped young people are co-resident schemes like the one pioneered by Cardiff Universities Social Services, and now adopted elsewhere. In Cardiff "normal" university students live with mentally handicapped young people in a group situation, helping them to increase their cooking, shopping and other social skills in the course of everyday living. More intensive help may also be available to the mentally handicapped tenants via a CSV volunteer on a one-to-one basis, to improve their social skills. For a description of the Cardiff scheme see Drinkwater (1980), Pithouse (1978) and Mansell (1976, 1977). A video of life in the house is also available. (See p.131). Malin (1982) provides a more critical account of a similar scheme in Derbyshire, with comments on the kinds of problems encountered and suggestions for overcoming them. Other group homes have also operated successfully with a mixture of able and handicapped residents, but have drawn their able tenants from a variety of backgrounds, rather than from the student population exclusively. For an account of the setting up of two such homes by Camden Society for the Mentally Handicapped, see Heginbotham (1980).

A particular benefit of co-residence projects is that the mentally handicapped tenants have plentiful opportunities to mix socially with non-handicapped people, and to develop "ordinary" leisure-time activities, like an evening visit to the local pub. The subject of leisure activities for mentally handicapped adults is taken up in more detail in the section that follows.

CHAPTER 7 - ADULTHOOD

> "'How is it with us?' Virginia Meyers asked, a woman who, like her husband and millions of people like them, has pulled herself up by her own bootstraps to achieve her full humanity. 'It's no different than it is with anyone else, except that we're slower.'"
>
> (Meyers, 1979, p.206)

Adults with mental handicap have the same needs for a worthwhile and enjoyable life as other adults have: the possibility of meaningful occupation, training or employment; the opportunity to enjoy a variety of leisure and social activities; the chance of a home of their own; some say in the way their lives are to develop. In the preceding section we looked briefly at occupation and employment for mentally handicapped people (see p. 64). In this section we focus on their need for leisure opportunities, for residential provision in the community, and for participation in decision making about their own lives.

7.1 Leisure and social activities

A useful guide to promoting leisure activities for mentally handicapped people is Chris Gathercole's "Leisure, social integration and volunteers" - the fourth in a series of pamphlets by him on "Residential alternatives for adults who are mentally handicapped." (Gathercole, 1981). In his introduction to the pamphlet, Gathercole underlines the value of recreational activities to mentally handicapped people in giving them opportunities to learn new skills,to enjoy themselves and to let off steam and energy in acceptable ways. Recreation for the mentally handicapped person can also give a welcome break to the family, while giving the client the chance to make friends and participate in the life of the community.

People who are mentally handicapped, however, may find it difficult to initiate leisure activities. They may need much more prompting and supervision than other adults. If they live in lodgings (see p. 92), a family placement (see p. 93), or a group home (see p. 94), they may be specially vulnerable. Occasional scandals over mentally handicapped people wandering around the streets apparently aimlessly and with nothing to do have, as Gathercole points out, sometimes fuelled objections to mentally handicapped people living in the community. Hence, the particular responsibility on the professionals involved to ensure that their mentally handicapped clients have help to develop leisure pursuits. This is not a luxury, Gathercole stresses, but a fundamental part of resettlement and training for independent living.

The pamphlet reviews the various people who may usefully be involved in fostering the leisure activities of mentally handicapped people: for example, ATC staff, people involved in Gateway Clubs, parents and leisure volunteers - people specially recruited to befriend a mentally handicapped person and introduce him or her to appropriate social activities which they enjoy. The rest of the pamphlet is a helpful step-by-step guide on how to collect information on local recreation facilities; how to recruit and match leisure volunteers to clients and how best to supervise their activities. Appendix 1 contains a detailed "Leisure volunteer's guide" (obtainable separately from the pamphlet if required), with suggestions for the volunteer on how to find potential appropriate activities for the mentally handicapped person, both inside and outside the home and how to stimulate interest in them.

There appears, perhaps surprisingly, to be little else available which focusses on leisure opportunities for mentally handicapped people, with the exception of the work of Cheseldine and Jeffree at the Hester Adrian Research Centre on increasing the leisure skills of mentally handicapped young people (Cheseldine & Jeffree, 1981). Luckey and Shapiro, in their article "Recreation: an essential aspect of habilitative programming" drew attention to the relative neglect of this area some years ago, commenting that "much of the normalizing potential of recreation is yet to be realized", and outlining some of the early American ventures in this field. (Luckey & Shapiro, 1974). There is, however, little in this brief article of practical relevance to professionals interested in developing leisure pursuits for mentally handicapped people, though their account of the experience of ENCOR in Nebraska (a unique mental handicap agency discussed further on p.83 below) serves to illustrate that significant progress in this area is possible. When the Recreation Division of ENCOR started its operation, ENCOR staff did most of the recreational work themselves. Very soon, however, they developed a more consultative or advocacy role. By the first year, more than 300 volunteers and 40 different community agencies and organisations had become involved in the provision of recreational activities for mentally handicapped people. (Luckey & Shapiro, 1974).

Leisure opportunities for mentally handicapped people may, of course, take many forms. Traditionally, perhaps the most common provisions have been those specifically established for mentally handicapped people, like the Gateway Clubs described earlier (see p. 55). While the importance of such 'special' leisure provisions should not be underestimated for the pleasure and stimulation they afford to thousands of handicapped people, less segregated leisure facilities clearly have much to offer. As Wertheimer observes from her study of mentally handicapped people living at home with older parents:

> "If mentally handicapped people are to become more fully integrated into the life of the local community, they must have greater opportunities to mix and meet with non-handicapped people of their own age. For example, there should be less emphasis on the use of "special" leisure facilities such as clubs at training centres, and more encouragement to use ordinary leisure opportunities."
>
> (Wertheimer, 1981 a, p.36)

7.2 A home of one's own

> "The mentally retarded are human beings who are more like other people than they differ from them ... Their happiness - exactly as that of other people - depends greatly on the houses they live in."
>
> (N. E. Bank-Mikkelsen, quoted in Baker, Seltzer and Seltzer, 1977, p.3)

> "... the family should not continue to be regarded as the central agent in care and support until parents are old and infirm. We think that the community and the professional services must assume a far greater responsibility than at present ... accommodation varying from highly staffed homes to unstaffed houses and flats should be provided. This would allow the handicapped person to make a choice, jointly with his family, to move on and to establish a life independent of the parental home. This is the normal pattern within our society."
>
> (The Jay Report, p.45)

There is now a growing recognition - as the above quote from the Jay Report testifies - that adults with mental handicap should enjoy the same opportunity of living in ordinary homes in the community as any other adults. A residential service to meet their housing needs is thus an integral component of any system of community provisions for mentally handicapped people. Such a residential service needs to embrace housing in the community of all kinds - from highly staffed to unstaffed houses, flats and bedsits - appropriate to the needs and wishes of the individuals concerned. Such a service depends for success on two kinds of resources, as the King's Fund Project Paper "An Ordinary Life" makes clear. (King's Fund Centre, 1980). Firstly, material resources - the actual buildings where people live and the furniture and fittings necessary to make them comfortable and personal. Secondly, and more important, the people who staff the service - who employ home-making skills directly, on behalf of their clients, and indirectly, by helping clients to provide for themselves what they need to make a home and to become more independent in everyday living.

Most of our residential provision for mentally handicapped adults in the past, has been either at home with their families, or alternatively, in an institution - a long-stay hospital, or, less often perhaps a twenty-bedded hostel. Recently, however, there have been exciting developments in planning residential alternatives for adults with mental handicap. (See, for example, the Jay Report, pp.45-54). With these changes in ideas, have come the first innovative steps in practice.

"An Ordinary Life"

An invaluable tool in planning and developing residential alternatives for mentally handicapped adults is the King's Fund Project Paper "An Ordinary Life". Produced early in 1980, the paper was the product of a working group of professionals in the mental handicap field, several of whom had visited the service run by ENCOR in Nebraska - a comprehensive community based service for mentally handicapped people. The residential component of this service is made up entirely of ordinary houses in the community.

Mentally handicapped individuals live in ones, twos and threes in ordinary rented houses with the degree of staff support - resident or non-resident - appropriate to their needs. More able tenants may receive just a few hours a week of support, while a more severely disturbed individual might initially live alone with perhaps two staff members. The essential ingredient of the service is flexibility on the part of service planners and providers. As individuals change and develop, staff support is adjusted or withdrawn accordingly. The assumption is not that the client must move home as a result. More details of the ENCOR service are to be found in "Encor - a way ahead", a publication produced by the Campaign for Mentally Handicapped People (Thomas, Firth and Kendall, 1978). For more recent accounts of ENCOR, see Libby (1981) and Tyne (1982).

"An Ordinary Life" embraces a number of the features of the ENCOR model. It emphasises the need for residential (and other) services to be based very locally in each community, and to encompass a whole range of residential options, e.g. minimum support group homes, family placements, independent bedsits, group homes with resident staff support. This network of a variety of locally based residential alternatives has come to be known as the "core and cluster" model. One of the ordinary houses, perhaps slightly larger than the others, acts as a "core" house, providing support services and back up for the cluster of varied residential arrangements in the surrounding neighbourhood. (Tyne & Williams, 1979; Carle, 1981a). Sometimes, the core house may serve a training and assessment function. Small groups of individuals may live there, receiving training in social skills, while the appropriate level and nature of staff support required by them is assessed. In practice, it has gradually become apparent that some of the functions of the core house - providing a focal or referral point for other residential services in the community, a reservoir of relief staff, or basic training programmes for new clients and staff - may conflict with the desired ordinary domesticity of the home for its residents. The need to hive off the "office" functions of the core house - management, staff support etc. - has increasingly been recognised. The practice at ENCOR now is to locate these functions elsewhere, perhaps in a rented shop front office in the community. The Ordinary Life Working Group has now also abandoned the "core" concept in the light of evidence that it can be stretched - indeed abused - to embrace 20-bedded hostels, far removed from the ordinary housing originally envisaged. But the model of a network of different options for adults with a wide range of handicap, within their local community, is nonetheless valuable. The kinds of residential alternatives this may embrace are reviewed below.

At a local level, the first attempts are now being made to translate the ideas of "An Ordinary Life" into concrete and practical plans to meet the housing and other needs of mentally handicapped people in specific communities, as for example, in Southwark & Lewisham (Guy's Health District, 1981), and Bloomsbury (University College, Department of Community Medicine, 1981). At the same time, the first projects based on ordinary housing in the community are slowly getting off the ground - at NIMROD in South Glamorgan (see p.132), the Wells Road Project in Bristol (p.133) and elsewhere in the country (N.Western RHA, 1982).

Meanwhile, the King's Fund Centre (see p.132) are trying to compile an information bank of residential developments for mentally handicapped people based on ordinary housing throughout the country, to enable service planners and providers in different areas to make contact with each other and learn from each other's experiences.

Residential alternatives

i The family home

About 40% of severely mentally handicapped adults (and a far higher proportion of those with milder handicaps) currently live at home with their families. (DHSS, 1971). This statistic gives cause for concern on three counts.

Firstly, the principle of normalisation suggests that a more typical pattern would be for mentally handicapped individuals to have the same chance of setting up a home independently from their families in adulthood, as do most other people. (The Jay Report, 1979). Few mentally handicapped people - or their families - at present have this option.

Secondly, as parents grow older, the strain of coping with their mentally handicapped relatives must increase. Their quality of life - and that of the mentally handicapped person - is likely to deteriorate unless support services are maintained or indeed intensified. Regular respite care is essential, for the family - to give them a break from the non-stop routine of caring - and for the mentally handicapped person - to give different and varied experiences from home life. At present, short-term care for mentally handicapped adults is in short supply and is frequently hospital-based. Short-term care in a hostel or with another family in the community is clearly preferable. Another attractive possibility, however, would be the provision of a spare bed in each of the cluster of ordinary homes for mentally handicapped people in the community. In this way, adults with mental handicap, like any other adults, would be able to spend a weekend with friends as and when they wanted. Where an individual is profoundly handicapped or severely disturbed, respite for families via a care attendant scheme may be more appropriate (see p.51). Adequate employment or other daytime occupational facilities and real social and leisure opportunities are, as we have seen also essential: both for the family, to afford them respite from caring, and for the individual, whose life experiences may otherwise become increasingly impoverished as the social world contracts to that of his family.

Parent groups or workshops may be of great use, as Nick Keene (1980) reports, in encouraging parents to make use of short term care facilities, perhaps for the first time, and make plans, where possible, for their mentally handicapped relative's future. The courses described by Keene were run from an ATC and lasted from 7 - 10 weeks, each weekly session focussing on a different issue - DHSS benefits; short-term care; sitting-in service; behaviour problems, etc. The courses were well received by parents and led to some useful practical spin offs, e.g. the creation of a parents' newspaper, an increase in the take up of relief places in hostels, the correction of DHSS benefits received, and the publication of a sheet outlining hostel provision in Bristol. In addition, one group of parents organised letters to MPs and councillors urging the creation of more hostels and training centres, and several families enrolled in MENCAP's trusteeship scheme under which handicapped people are visited regularly by an appointed visitor after the deaths of their parents. (Contact MENCAP, p. 132).

The third, and most serious source of anxiety deriving from the large numbers of severely handicapped people living at home with their families, is the rising proportion whose parents are elderly: a phenomenon now well documented in a number of studies (Ineichen, 1980; Somerset County Council Social Services Department, 1976; Wertheimer, 1981). As John Chant has pointed out, providing residential alternatives in the community for these individuals when their parents die or finally become too frail to cope, poses as great a challenge for service planners and providers as the more traditional problem of those mentally handicapped adults already living in the hospital, who could and should be discharged back into the community (Chant, 1981). Meanwhile, the general absence of residential alternatives to hospital provision for adults with mental handicap causes them and their families alike to suffer enormous anxieties about their future. The existence of more community provisions would clearly do much to ease these fears. It would also do much to avoid the traumatic, but sadly commonplace,experience of sudden hospitalisation when parents die or finally become unable to cope - an experience vividly depicted in David Cook's novel "Walter". (Cook, 1980). Ideally, mentally handicapped adults would be able to move away from the family home before the point of crisis had been reached. The ready availability of training for independent living, from ATC staff or other (para) professionals in the community, and advice and counselling for parents is obviously essential for such a move to be a success.

ii Hostels

The main alternative to hospital provision for mentally handicapped adults who are no longer able to live at home with their families has traditionally been the hostel. Hostels have on the whole been established and run by local authority social services departments rather than health authorities, and have tended to cater for more able adults, drawn usually from the community, rather than the mental handicap hospital. A useful discussion of hostel provision can be found in Alan Tyne's report for the Campaign for Mentally Handicapped People - "Residential provision for adults who are mentally handicapped." (Tyne, 1977). The report covers the history and development of hostels; variations in provision between local authorities; their size, siting and planning; their relationship with residents' families and the local community; staffing patterns; short-term care provisions and their function, that is - whether they were providing transitional or permanent homes for their residents. In the former case, the hostel would be seen as a half-way house, providing training for residents to help them eventually to move on into a more normal home in the community; in the latter, the hostel would be seen as the residents' long term, if not permanent home, with much less emphasis placed on increasing their capacity for independent living. (For more discussion of this typology, arising out of a detailed study of twenty-five hostels, see Apte, 1968: "Halfway Houses").

Tyne's second report "Looking at life - in a hospital, hostel, home or unit" (Tyne, 1978), gives a more qualitative, descriptive account of life in a hostel. It also attempts to measure the 'quality of life' offered to residents on the basis of the degree to which the hostels (and other units) studied were able to meet a range of residents' day to day needs. (The 25 item check list used as an index of the "quality of life" offered, is reproduced in the Appendix to Tyne's report). More detailed information on all aspects of hostel provision is to be found in Denise McKnight's thorough review of published literature on the viability of small residential units for mentally handicapped people. (McKnight, 1980). The review includes research on hostel provision and looks at research findings on the design of residential units (size, location, whether purpose-built or adapted, their physical environment); staffing; community attitudes; types of residents; and parents' needs and views. A much briefer look at hostels is given in Malin, Race & Jones', 'Services for the mentally handicapped in Britain' (1980), which describes their history and some research findings on the effects of different staffing patterns on life for the residents. There is also a brief overview of the Wessex hostels for severely handicapped people. (For a summary of the findings of the Wessex research into the effects on costs, staff, clients and their families, of providing accommodation for severely mentally handicapped people in relatively small - 20-25 bedded - locally based hospital units, rather than in the traditional, large mental handicap hospitals, see Felce, Smith & Kushlick (1981). Detailed reports on different aspects of the Wessex research are available from the Health Care Evaluation Research Team, see p.131).

A vivid critique of the institutional, rather than homelike features, often characteristic of hostel provision is provided in Ann Shearer's "No place like home? Hostels and homes for mentally handicapped adults." (Shearer, 1975). A fundamental criticism of hostels generally,of course, is that a "home" for twenty or more people can hardly be classed as "ordinary life".

iii Community units

A similar criticism has also been made of the newer community units now to be found in some parts of the country. These units tend to vary in size from 12 to 30 beds though Gerry Simon in "Local services for mentally handicapped people" comments that 24 beds has been found to be the most convenient and economical

> "8 catering for long term residents, 8 providing residential care with training for up to a two-year period, and 8 being retained to meet the demand for short-term, on-demand services."
>
> (Simon, 1981, p.24)

The units combine long and short term residential provision with daycare, and maybe space for the local community mental handicap team, a toy library and a meeting place for parent and other groups and workshops. (Simon, 1981).

In his article "Home is where the heart is", Chris Gathercole (1979) observes that each of the functions of community units - as set out in the first report of the Development Team for the Mentally Handicapped (DHSS, 1978) - is indeed a necessary part of any comprehensive locally based service for mentally handicapped people. It is not, however, clear that all of them need to be provided within the same unit. He argues that there is much to be said for separating the residential functions of the unit from the rest, since it is difficult to provide a proper "home" where there are offices too. He goes on to suggest more appropriate locations for each of the services in question, observing that although 24 bed hostels are better than hospitals, units of less than 6 people are the most homely. The article concludes with the verdict that the "community unit is an extension of hospital thinking into the community." (Gathercole, 1979).

iv Lodgings

The use of ordinary lodgings for mentally handicapped adults has proved mixed and sometimes controversial. In their introductory chapter to "The Cherries Group Home", the Races (1979) quote Kathleen Jones' findings that

> "Except in certain outstanding cases, accommodation in lodgings was very often unimpressive and sometimes of a very poor quality."
> (Jones et al, 1975, p.184)

The Races comment that the pattern of life in lodgings is heavily determined by the individual landlord or landlady. Uncaring profiteers have to be contrasted with genuinely concerned individuals, but some successes have been achieved. A rather grim portrait of life in lodgings is also given by Tyne in his "Looking at life" report (Tyne, 1978).

The plight of over 30,000 mentally disordered, elderly and disabled people living in private boarding houses is documented in a report from the National Institute for Social Work "At Home in a Boarding House" (1981). The report notes that many of the residents of these erstwhile holiday boarding houses require some degree of nursing or social support, but few proprietors have the training or expertise to provide for these needs. The report includes recommendations for ways of improving the service offered to residents of such homes. A more positive viewpoint is to be found in "Room to let" - a report by MIND (1977) on nine social services lodgings schemes. (Again, not all of them catered for mentally handicapped people). On the whole, however, it seems that the more supportive and supervised environment of a family placement, group home or hostel is likely to provide a more satisfactory quality of life for adults who are mentally handicapped, than is to be found in ordinary lodgings.

v Family placements

A potential source of accommodation for some mentally handicapped adults may be long-term foster care or a "family placement" - that is for them to live as part of another family in the community. The host family will have a responsibility to provide not only for the individual's physical well-being (by supplying board and lodgings) but, to some extent, for their emotional well-being also. They will also be expected to help the mentally handicapped adult develop towards greater independence.

A useful guide to setting up and running family placement schemes is Chris Gathercole's "Family placements". (Gathercole, 1981). It covers issues like recruitment and payment of host families and matching of clients with carers, and includes as helpful appendices for people interested in setting up such schemes - notes for carers and sample application forms. Much of the pamphlet is based on the experiences of North Yorkshire Social Services Department, where a pilot family placement scheme - for physically handicapped, mentally ill and elderly as well as mentally handicapped individuals, recently operated. A full history and analysis of the project, and some lessons for those wishing to set up similar schemes can be found in Maureen Penfold's final report of the experiment "Family homes for the handicapped." (Penfold, 1980). It is worth noting here that of the four different client groups which the scheme was designed to serve, adults with mental handicap proved to be the easiest to place.

For family placements to be optimally successful, it is clear from these reports that other support services should also be available: daytime employment or occupation, and the provision of training and leisure facilities for the handicapped adult; social work or other support if and as necessary, and the availability of short term respite care at regular intervals, for the host family.

With the exception of Maureen Penfold's work, family placement schemes have not been widely documented or researched. Denise McKnight in her discussion of adult fostering (within her larger literature review of residential care for mentally handicapped people generally) notes that the little research evidence that exists shows mixed findings on the success of such schemes. She reports, for instance, several American research studies showing high levels of placement breakdown. She also reviews the evidence on characteristics related to a placement's success - again the findings are mixed and even conflicting. She concludes that alongside the encouraging descriptive accounts which now exist to demonstrate the potential for developing foster care as part of a system of alternative residential placements, more firm research evidence as to the value of fostering is required. (McKnight, 1980).

vi Group homes - and beyond

Over the last decade, a small but steady trickle of adults with mental handicap have been given some systematic training in the skills needed for independent living, and have then gone on to successfully set up home (usually with three or four other adults) in a house or flat in the community.

There are now a number of publications available to help those wishing to establish group housing schemes of this kind, largely based on the author's own experiences. Chris Gathercole's pamphlet "Group homes - staffed & unstaffed" (1981) provides a guide to the whole process of acquiring property, sorting out finances, training clients, making links with the local neighbourhood and giving appropriate support and supervision to the individuals concerned. Another pamphlet by the same author, "The Resettlement Team" (1981) covers the important ground of the overall planning of community-based residential schemes: who should sit on the resettlement team; how to ensure good public relations with the community; identifying potential residents; adaptation of homes and fire precautions; organising the scheme overall.

Christopher Heginbotham has also furnished a number of useful publications based on his professional experiences in a London Housing Association and Borough Housing Department, and as chairman of a local society for mentally handicapped people. His most recent publication "Housing projects for mentally handicapped adults" (1981 a) reviews a range of housing developments for mentally handicapped adults and includes helpful tips, born of past experience, for those embarking on such schemes. His "Housing for mentally handicapped people" (1980) also gives valuable information for local societies on how to go about obtaining property and then managing a group home, with some description of the first housing ventures undertaken by the Camden Society.
Another useful source of some detailed information on setting up and running housing projects for mentally handicapped people is the report of a seminar on that theme organised by the Centre on Environment for the Handicapped. (CEH, 1981). A number of other publications give some account of the operation of group homes in practice. The Races' description of the early history of 'The Cherries' group home in Slough furnishes some detailed and vivid insights into an early experiment in group living. (Race, 1979). Another publication from the Centre on Environment for the Handicapped (CEH) - gives a brief outline of some

other early ventures in this field. (Franklin, 1973). In their "Services for the Mentally Handicapped in Britain", Malin, Race and Jones (1980) comment that there has, however, been little evaluation of group homes generally - most of the literature being of a descriptive nature. Nigel Malin, himself, has in fact, been responsible for one thorough study of six group homes in Sheffield (Malin, 1980). The findings and implications of his research (as summarised in Section C of his report, pp.104-118) should prove of interest and value to those running, or preparing to run, group homes. Alan Tyne's research for the CMH publication "Looking at life" (1978) also provides some descriptive material on life in a group home as compared with other kinds of residential provision for mentally handicapped adults.

Support

Most group homes to date have been termed "minimum support" group homes - that is, they have catered for more able adults who can cope successfully with an independent life in the community with a minimum amount of outside support. The nature of this support has varied. Inevitably, more support has been necessary at the establishment of groups than later on when they become more settled in the community, though, as the Races' account of life at "The Cherries" makes clear, the need for support may intensify periodically as individual or group crises occur. (Race, 1979).

Support has been provided in a number of different ways in different schemes and areas. In Somerset, home helps have been used very successfully. (Chant, 1978). In the group homes studied by Malin in Sheffield, both home helps and social workers were involved. Some problems over their respective functions at times are reported (Malin, 1980).

In Camden, it is hoped to employ a peripatetic social skills worker to support handicapped people in the community, giving assistance with budgeting and other skills needed for independent living. The need for such a social skills worker, the financial and organisational implications and the wider care aspects of the proposal are explored in an unpublished paper by Heginbotham (1981 a). In Waltham Forest, where a parents' group has been highly successful in establishing group homes in the community with local authority support, particular local residents who have taken on a befriending role with a specific home, have proved an important resource for the residents. Additional support in one of the Waltham Forest developments, has been provided in the shape of a resident care worker living in a self-contained maisonette on the same premises, providing twenty hours a week support, advice and training to those living in the group home, as they require it. A fascinating account of the Waltham Forest housing initiatives is included in the very useful report of the seminar on "Housing Projects for Mentally Handicapped People" held by the Centre on Environment for the Handicapped in November 1981 (CEH, 1981). In co-resident schemes like those existing in Cardiff, Derbyshire and in Camden (see p.77 above), non-handicapped tenants may also be a source of support and help for those with mental handicap. A similar principle also operates in the l'Arche communities, where volunteers and people with handicaps live together with little differentiation. (For more details of l'Arche, see Shearer 1975, 1976. For information on this and other village communities, see VCHC Factsheet No.4 "Village and community residential homes for the adult mentally handicapped").

Perhaps the most exciting- certainly the most challenging - aspect of the Ordinary Life concept is that ordinary housing should be available for any mentally handicapped adult. The opportunity of life in an ordinary house in an ordinary community should be denied to no one on the grounds that they are too profoundly handicapped or behaviourally disturbed. Instead, the amount of staff support available must be increased sufficiently to enable them to cope. In ENCOR, this means that houses have a wide range of staff support - both resident and non-resident. In Britain, the idea that severely handicapped adults might be helped to live elsewhere in the community than the parental home is still novel. As yet, there are no examples of such a comprehensive service in full operation. At NIMROD in S.Glamorgan, however, the first staffed homes for severely handicapped adults are now open; a similar house is soon to be opened in Bristol. (For a brief outline of the NIMROD service, see Mathieson & Blunden, 1980; more information on the NIMROD and Bristol developments is available from the addresses on pp.132-133 below). The social services department of the London borough of Greenwich meanwhile have recently advertised for two people to live in rent free with a young profoundly handicapped woman in exchange for some care at evenings and weekends (The Guardian, 6.1.82). With their aid and that of two full time community service volunteers, this woman will be able to continue life in her own home. (For details of the Community Service Volunteers' one-to-one programme which places volunteers with individual people with disabilities in this way, see Shearer, 1982).

The need for flexibility

An important ingredient of all these developments is flexibility. Services must adapt to their clients' needs, rather than the reverse, and be sensitive to changes in their needs as they occur. Thus, one resident in a group home may increasingly feel attracted to a less gregarious, more private existence in a bedsit or flat for one. This has been an unanticipated experience within the Waltham Forest housing scheme, which seems likely to recur elsewhere. Other residents may form close attachments and want to marry or live together in their own independent - council or privately rented - home. Just as "normal" adults have different housing needs at particular stages of their lives and according to their own individual personalities, so too do adults with mental handicap. The challenge for service planners and providers is to ensure that mentally handicapped adults are able to move into different kinds of accommodation as the need arises, and to avoid the trap of assuming that group homes - however appropriate for some - are the universal ideal for all.

7.3 Participation and self-advocacy

> "Mentally handicapped people and their families should participate in the planning and running of services on which they may be dependent. Services which are not firmly based on the views and experience of mentally handicapped people and their families are unlikely to meet their needs."
> (Independent Development Council, July 1981)

> "It is striking how often planning teams are not even aware of deficiencies which are all too obvious to the consumer."
> (Development Team for the Mentally Handicapped, 1980, p.9)

An important trend in recent thinking about services for mentally handicapped people has been the gradual recognition of the need to involve them in decision making about their own lives. Traditionally - as the quote above from the Development Team's second report indicates - little thought has been given to asking mentally handicapped people, and their families, the kinds of services they want and need, or enabling them to make their views known to those planning and providing services. One interesting exception here is the survey reported in "Project 74" in which all the mentally handicapped adults living in one borough's hostels or attending ATCs talked about their lives and work and their wishes for the future. (London Borough of Wandsworth Social Services Department, 1976).

A brief, but extremely useful overview of the relatively new ideas of participation and self-advocacy by mentally handicapped people in the UK is given by Williams in the <u>Key Concepts</u> series published by the Campaign for Mentally Handicapped People (Williams, 1982). The article discusses the first conferences of mentally handicapped people in Britain in the early 1970s, which led on later to "participation" events where handicapped and non-handicapped people got together to share discussions, activities and daily living. (For details of these see CMHs "Participation papers" - a collection of reports of these early events). In many ways, as Williams observes, these early participation events were the forerunners of the more recent self-advocacy movement which aims to enable handicapped people to take their own decisions and exercise control over their own affairs. In the UK, self-advocacy groups have, on the whole, been based in ATCs where students or trainees have come together in committees to discuss issues mainly to do with the running of their centres. In a few centres, however, as at the Avro Centre in Southend, committees have now moved beyond this primary concern with day to day life at their particular centre, to pursue much wider and more political issues. In Camden, meanwhile, an independent self-advocacy group made up of people from local group homes, hostels and ATCs - rather than just from one ATC - has recently come together to discuss issues of concern to mentally handicapped people in the area. (For information on ATC committees, contact Bronach Crawley at the Hester Adrian Research Centre - see p.132 - who has carried out a postal survey of ATCs in the course of researching this subject;

for details of the Camden group, contact Camden Society for the Mentally Handicapped, p.131).

The most comprehensive account of the development of the self-advocacy - or People First - movement is the recent publication "We can speak for ourselves". (Williams & Shoultz, 1982). The book describes the history of the movement in the USA and in this country, and gives much detailed information on how to make self-advocacy work in practice: an invaluable asset for people wanting to set up or support self-advocacy groups in their locality or place of work.

CHAPTER 8 - THE ELDERLY PERSON

> "We hope that more and more elderly people who are mentally handicapped will have recourse to normal provisions and services."
> (The Jay Report, 1979, p.52)

The amount of research and literature available to guide planners and practitioners on appropriate community services for elderly mentally handicapped people is pitifully small. Yet as more mentally handicapped people are able to live out their adult years in the community (rather than in a hospital) and as more survive into old age, the need for information in this area becomes more acute. To date, the literature has largely focussed on elderly people in mental handicap hospitals (e.g. Ballinger, 1978; Spencer, 1978), or has reported American research (e.g. Mueller and Porter, 1969; Snyder and Woolner, 1974; DiGiovanni, 1978; Cotten Sison & Starr, 1981). There has been little on the needs of elderly mentally handicapped people living in the community in this country. Two recent exceptions are the APMH paper "Mental Handicap: the elderly mentally handicapped person" which reports the proceedings of a day conference held on this subject in September 1981, and includes a reading list on the topic, (APMH, 1982a) and a short article by Alison Wertheimer, arising out of the same conference. (Wertheimer, 1981b).

The questions confronting service planners and providers regarding policies for elderly mentally handicapped people are - or should be - inseparable from those for elderly people in general. Thus, normalisation principles would suggest that elderly mentally handicapped people should be able to retire from their previous employment or occupation at 60 or 65 as the non-handicapped do. All elderly people will want meaningful occupation in their retirement - those who are mentally handicapped are no exception. They may, however, need special help and training to assist them to find it. ATCs could have an important role to play here, as Wertheimer suggests in her excellent article "When retirement means more care" - helping people move away from mental handicap services to day centres, lunch clubs and other services provided in the community for elderly people generally. In this respect, old age could indeed be a positive time for mentally handicapped people, giving some of them maybe their first chance of meeting and mixing with their "normal" peers.

On the other hand, old age may bring sorrow and crises to mentally handicapped people as it does to others. DiGiovanni (1978), for example, points out that mentally handicapped people living in the community who become widowed are likely to be especially vulnerable with the loss of their partner. (For a detailed and sensitive exploration of the whole issue of bereavement and mentally handicapped people, see Oswin, 1981 a).

Similarly, elderly mentally handicapped people who have lived with their families in the community all their lives will suffer - as their non-handicapped peers do - at the trauma of leaving their home when they, or their relatives,become too frail to continue coping alone, and will need proper support and attention throughout this difficult time. The APMH paper describes how in West Wiltshire, reviews are now held on the situation of each mentally handicapped person once he or she reaches the age of fifty, in an attempt to plan ahead for their future residential and other needs and thus avoid the shock of sudden change. Plans made at the review can be carefully monitored and changes in living or day care situations brought about gradually. Individuals can be helped to become familiar with new settings and build up relationships of trust with new people on a planned and phased basis so that, for example, holiday periods can be spent in the place where a handicapped person will go if a sudden breakdown in the home situation occurs. Similarly, people currently in a hostel, but perhaps finding the presence of younger residents there an increasing strain, can have a gradual and increasing contact with an elderly people's home, making the transition from one to the other easy and free from fear. A range of residential alternatives is also being opened up for those not requiring the degree of care given in an elderly person's home or hospital - small group houses (staffed and unstaffed), sheltered housing and supported lodgings. Local Councils of Voluntary Service are also involved, helping those living in houses in the community to make use of local facilities for the elderly and thus become integrated into local neighbourhood life. (APMH, 1982 a).

For some elderly mentally handicapped people admission into an ordinary old people's home may be a possibility. The APMH paper suggests that 'normal' people in old people's homes may resent the introduction of mentally handicapped people (though the evidence for this comment is not given in the paper) and that preparation is needed on both sides (APMH, 1982 a).Research from America reports on the contrary that elderly mentally handicapped people have been found to blend and mix well with other residents in a nursing home situation. (Mueller & Porter, 1969; DiGiovanni, 1978).

These studies also report that mentally handicapped residents proved less of a "problem" to staff than other residents did - largely, it seems, because many of them were already accustomed to institutional life, to being infantilised by staff and to living without a significant degree of personal autonomy. Life in an old people's home was less of a shock to them than to other residents and they were less likely to exhibit "difficult" behaviour. Mueller and Porter (1969) report that the nursing homes they surveyed did not have special staff training for the care of the handicapped residents. DiGiovanni (1978) in his review of the literature on elderly mentally handicapped people, quotes this as indicating that special staff training was not in fact needed. The validity of this interpretation is, however, dubious since evidence on the integration of mentally handicapped residents into the homes was collected only from staff and not from residents themselves or by direct observation of everyday life there. Nonetheless the integration of mentally handicapped old people into existing nursing and old people's homes within the community, as at ENCOR, is clearly more desirable than their segregation into units purpose built for their "special" needs.

In a society where elderly people tend to be devalued and services for them are often dehumanising and inadequate, there is, of course, a danger that 'normalisation' will be invoked as a rationalisation for unsatisfactory provisions for elderly mentally handicapped people, like their non-handicapped peers. Though integration not segregation must, of course, be the goal for mentally handicapped people in old age just as at other stages of their lives, it must be integration into an improved service for all elderly people, handicapped and non-handicapped alike.

In the meantime, it is vital, as Joan Bicknell argues, that those providing services for the elderly do not refuse those elderly people who have mental handicaps, and heartening to learn that, in her view, positive changes have been taking place in this area - that

> "the services available to us all when older are beginning to accept the elderly mentally handicapped person as well."
> (Bicknell, 1981 b, p.8)

Meanwhile, as the brevity of this section illustrates, much work remains to be done in exploring how best we can meet the needs of people with mental handicap as they move into old age.

CHAPTER 9 - EMERGING PATTERNS

> "The basic principles on which we should work are clear - in brief, that of recognising the rightful place of mentally handicapped people in our communities and of making services available accordingly. Given that framework, the detailed provision of services within the statutory and voluntary resources available should be for the local community and its authorities to decide. In doing so, they will need to study carefully lessons learnt elsewhere, and the ideas of those with special experience in this field ..."
> (Patrick Jenkin, Foreword to "Mental Handicap: Progress, problems and priorities" - DHSS, 1980)

The preceding pages have documented the growth of a rich variety of schemes designed to give mentally handicapped people of all ages the help and support they need to live as full and as "normal" a life in the community as possible. In this section, the emphasis shifts away from a detailed review of recent developments, to a consideration of their implications for the professionals and others involved, both for their training and their ways of working. What patterns can be identified in the wide range of ventures described? What tentative conclusions can be drawn about the development of services for mentally handicapped people in the future?

9.1 The implications for the professionals - and others - involved

A wide range of professionals are involved in the provision of community-based services for mentally handicapped people in this country. The social worker, community nurse, health visitor, psychologist, speech, occupational and physio-therapist, teacher, G.P., psychiatrist and others - all have roles to play. The exact nature of their individual contribution cannot be explored exhaustively here, neither can the hugh variations which occur in practice from area to area, and from project to project. Nonetheless, some indication of their potential (or actual) role in promoting and delivering services to people with mental handicap and to their families is sketched out below, together with references to where more detailed information can be obtained.

The health visitor

The non specialist health visitor is a key source of advice and support for many mothers of "normal", non-handicapped babies and young children. Following the principle of normalisation it would seem that the health visitor may therefore be the most appropriate person to fulfil this role where the child is handicapped. There is some support for this view in the Warnock Report (1978), and the APMH project paper "Mental handicap: the first twelve months". (APMH, 1981a). Daniel (1981) gives some insight into the nature of the contribution the health visitor can usefully make to help the mentally handicapped child and the family, and the kind of service she may provide. At a practical level, however, as Malin, Race & Jones (1980) observe, there are a number of obstacles hindering the wide spread involvement of health visitors in this way: they are in short supply, they generally lack specialist training in the field of mental handicap and they are likely to encounter relatively small numbers of mentally handicapped children in their day to day experience. Together these factors may well conspire to render the health visitor of limited help to the mother of a child with mental handicap (Sinson, 1978; Hewett, 1975). To overcome this problem, some degree of specialist training in handicap is being provided for health visitors in some areas (Williams, 1979; see also p.22 above) and, as in Leicester, specialist health visitors are being employed to deal with handicapped children and their families. (Baker, Grace, Janes and Lindley, 1980). A detailed discussion of the whole question of using generic or specialist health visitors for handicapped babies and children can be found in a very thorough report on the subject from the Disabled Living Foundation. The report is based on material drawn from questionnaires completed by local health authorities, social services and education departments, from visits to places where different health visiting schemes operated, and from a survey of the opinions of parents with handicapped children. (Southwood, nd).

Clearly there are wide variations in health visiting practice with regard to handicapped children throughout the country. Even where specialist health visitors are employed, there is debate over whether their role is as a support or a resource for the non-specialist health visitor with handicapped children on her case-load, or whether they should provide a direct service to the children and families themselves. (Health Visitor, July 1979, Editorial). Meanwhile, the case for using the health visitor as the "keyworker" for the family of the pre-school mentally handicapped child seems strong (p.15) and their employment as home teachers in early intervention schemes like Portage seems,on the evidence available, to be effective, viable and to make economic sense (pp.18-24).

The social worker

A brief outline of the role of the social worker in the provision of services for mentally handicapped people and their families is given by Malin, Race & Jones (1980). They identify her primary function as assessing needs, and then arranging so far as possible for the provision of appropriate services to meet those needs. They also comment on the overlap of function between health visitors and social workers, in some areas, as the health visitor role has developed an increasing social work rather than simply medical or nursing bias. Potentially, Malin et al point out, social workers have much to offer parents of mentally handicapped children - particularly, their knowledge of local facilities and services, and their ability to negotiate access to resources. In practice, however, the contribution that social workers are actually able to make in supporting and advising parents on a long-term basis is frequently less than the ideal. (McCormack, 1978; Fox, 1974). Social workers usually receive little specific training in handicap, and have little contact with, and therefore, experience in dealing with mentally handicapped people and their problems, in their day-to-day work. The situation is made worse by a high turnover of relatively inexperienced social workers, limited resources, and the greater priority which social workers have in general to give to other client groups.

In the last few years, there have been a number of moves to confront these problems. Two documents from the Central Council for Education and Training in Social Work have discussed the issue of more specialised training for social workers involved with handicapped clients. (CCETSW, 1974; 1979). In some areas, there has been a shift towards a greater degree of specialisation within social services departments and social work teams, enabling some social workers to focus particularly on (mentally) handicapped clients and their problems. (DHSS, 1978; Stevenson, 1981). The scope for social work involvement with mentally handicapped people and their families is wide, as Hanvey's thorough exploration of the subject makes clear. (Hanvey, 1981). For another detailed overview of the scope of social work practice with mentally handicapped people - though this time from an American perspective - see Dickerson, 1981 b. Simon (1981) also reviews the contribution of the social worker in this field, with a detailed account of the specific tasks in which she might usefully be involved.

A number of valuable roles for the social worker can also be identified from the literature reviewed earlier: in particular, the social worker may play an important part in helping parents in the initial stages of coming to terms with their child's handicap, providing ongoing advice, support and information, facilitating the formation of self-help groups, acting as keyworker in short-term respite care or family support schemes, negotiating access to local facilities of different kinds, offering advice on welfare benefits, and support to adults living in group homes. (See Howell, 1979, for an account of the work of a specialist social worker in Avon, employed to develop group homes.)

Clearly, where social workers have adequate time and resources at their disposal, they are able to offer mentally handicapped people and their families a much needed and warmly appreciated service. (Shearer, 1978; Tebbett, 1980). In the current economic climate, however, with resources in ever shorter supply, a major increase in their direct involvement with handicapped people seems unlikely. More probable is a trend towards a social work contribution which encourages and supports self-help groups, and promotes what is loosely called "community care", through the harnessing of volunteers and informal social networks of different kinds. Whether such a role is feasible, or, ultimately desirable, time, with perhaps the help of the Barclay Report (National Institute for Social Work, 1982) will tell.

The community nurse

The broad function and role of community mental handicap nurses is well outlined by Simon (1981). He documents their purpose, the growth in their numbers, their line of responsibility and their functions, and observes that it is regrettably still the case that many are appointed without specific training or an adequate induction to community based work of this kind. He also reviews various long and short term training courses which are available and relevant to their needs.

Since community mental handicap nurses are a much more recent development than their psychiatric counterparts, the literature available on their role is relatively small. A detailed literature review by Griffith and Mangen (1980) on community psychiatric nursing, for example, contains only three references in its section on community mental handicap nursing services. A brief but useful overview of the emergence and development of the community mental handicap nursing team is given by Carr, Butterworth and Hodges in one chapter of their book on "Community Psychiatric Nursing" (1980). By far the biggest contribution to knowledge about community mental handicap nurses and their work to date, however, is the research conducted by Hall and Russell, which monitored the establishment and early operation of community mental handicap nursing teams in Avon (Hall, 1979) and complemented this local study with a national survey of such teams. (Hall & Russell, 1980 a). The same authors have also produced reports on the response of consultant psychiatrists to the development of community mental handicap nursing services (Hall & Russell, 1980 b); on the response of families receiving such services (Hall, 1981); on how nurses in one team managed new referrals to the service (Hall, 1980); and on the similarities and differences between the work of community psychiatric nurses and their mental handicap counterparts (Hall & Russell, 1982). In addition to these few evaluative studies, the literature also contains a small but growing number of interesting, descriptive accounts of the successful use of community mental handicap nurses in various parts of the country. (See, for example, Bicknell and Morley, 1979; Davies, 1977; Thomson, 1980; Williams, 1980).

A commonly voiced anxiety concerning the employment of mental handicap nurses in the community has been the potential overlap of role with that of the local authority social worker. This issue is addressed by Simon (1981) who suggests that where both are working as members of a community mental handicap team (see p.123 below) some merging of roles and 'grey areas' are inevitable. It is nonetheless valuable, he concludes, to attempt to identify specific individual tasks while appreciating that some flexibility is vital, some overlap is unavoidable and that the roles of different staff members will vary in different localities and with different clients and their families. Simon does in fact list the different areas in which the community nurse and social worker might operate respectively. (Simon, 1981). The possible overlap between the two professionals is also discussed very usefully by Tebbett (1978) and by the Development Team for the Mentally Handicapped in their first report (1978). Their conclusion, based on the experiences of teams where the different workers have been able to establish very satisfactory working relationships based on mutual respect for each others' skills, is that the potential overlap of role need not necessarily be a problem; team members should be able to share the responsibility for providing a reliable and flexible service to families and to ensure, by the way they work together, that the service does not become fragmented. Hall (1981), in her study of families receiving help from the community nursing service, found that clients had only a vague conception of the functions of a community nurse, even when they had extensive contact with the service. However, the majority did note some distinction between the roles of community nurse and social worker. The nurse was distinguished in the eyes of the clients by a greater understanding of the problems facing them and by providing a more useful source of advice on behaviour management. Both sets of professionals were welcomed equally as potential avenues to short term and long term care.

It is clear then from the literature that is available, that community nurses, where they exist, can provide a valuable service to mentally handicapped people and their families. The likely trend, therefore, seems to be for the numbers of such nurses to increase, as the emphasis on community rather than hospital based care for mentally handicapped people continues, given the constraints on social work expansion discussed above. The main tasks then, as now, will be to ensure that such nurses receive adequate induction, support and opportunities for career advancement in their new role and, most importantly, the appropriate training for the job. (For a discussion of possible training options, see Report of a Working Party set up by North West and Mersey Regional Community Mental Handicap Nurses' Group, 1981; also Elliott-Cannon and Charles, 1981, on the same report).

Other specialists

The contribution of other professionals to community-based services for mentally handicapped people and their families is no less important than that of the three groups reviewed in some detail above, but, since their roles are generally more clearcut and less prone to potential overlap with one another, they are discussed only briefly here.

The work of the clinical psychologist in mental handicap is usefully out-lined by Hogg (1981). He describes the variety of ways in which the psychologist may intervene to help handicapped people and their families and emphasises the complexity of knowing how to offer appropriate assistance in ways that are acceptable, sensitive and useful to the families concerned. From the literature reviewed earlier, it is clear that the psychologist has a vital role to play both in directly intervening to help the mentally handicapped person, and also in training others - parents and professionals - to do likewise, via parent groups and workshops, home visiting schemes and other similar projects. A major problem, of course, is that clinical psychologists specialising in mental handicap are in short supply, hence the move to offer posts split between mental handicap and other specialities. For an often critical discussion of the role of the clinical psychologist in mental handicap, and some suggestions for improvement, see Dickens (1978); Bailey (1978); Gardner and Painter (1980); McHatton (1980). Westmacott, Cameron & Wallis (1981), report on an interesting attempt to co-ordinate the input of educational, clinical and other applied psychologists in the field of mental handicap in Hampshire. A useful discussion of the respective roles of the clinical psychologist, psychiatrist and nurse in mental handicap services can be found in the paper produced by Lancashire CC and AHA (1981).

Speech therapists, who also have a specialised and vital contribution to make in promoting the development of mentally handicapped people in the community are likewise in greater demand nationally than supply. Again, as with clinical psychologists, one attempt to meet this problem is by offering posts split between mental handicap and other specialities in order to attract more recruits into the field. In addition, there would seem to be economic and other, benefits to be gained from pursuing the possibility of increased skill-sharing by speech therapists, along the lines regularly adopted by clinical psychologists - that is, teaching parents and other professionals certain basic skills which they can practise on a more intensive and ongoing basis with the client than is feasible for the speech therapist herself. There are now a number of accounts in the literature of successful skill-sharing ventures of this kind - using parents (McConkey, Jeffree & Hewson, 1979; Hogg, 1981); a houseparent (Belt, 1979); and a hospital nurse (Greene, 1977). (See also, Walker, 1976, for an early progress report on a Makaton Workshop for a mixed professional group). There is also an extremely interesting report in the literature of a skill-sharing exercise within the physiotherapy service in Southampton. Here parents, teachers, care assistants and volunteers have all been given instruction in physiotherapy techniques for helping handicapped children and adults, with a view to ensuring that despite the relatively small number of therapists available, skilled help can still be given to those who need it. (Compton, 1978). Physiotherapists have also been involved in the home visiting schemes in South Glamorgan and Exeter (see pp.18-22) and in the opportunity playgroup at Yeovil (p.32). Occupational therapists have similarly been involved in home intervention schemes of different kinds (see, for example, Bidder and James, 1981), as have peripatetic or home teachers. In some areas, advisory teachers for young handicapped children also exist, organising parent groups, workshops and home visiting schemes and liaising with playgroups, nursery classes, opportunity groups and special schools. (Butler, 1980; Miller, 1980). The message from these developments seems to be that a variety of professionals - psychologist, health visitor, speech, occupational, physio-therapist, social worker, nurse, teacher and so on - while each having their own unique set of skills to offer in their particular professional role, may also serve equally well as home advisers or supports for self-help groups, according to local circumstances - providing appropriate training and multi-disciplinary team back up is available as necessary.

The medical profession

The paediatrician is likely to be the first member of the medical profession the parent of a handicapped child will encounter. He or she may well be involved in breaking the news of the child's handicap, and in providing subsequent consultations regarding the child's development. A brief account of the role of the paediatrician in this respect is given by Jolly (1981). Brimblecombe (1976b)- again briefly - discusses ways in which the relationship between parents and paediatrician may be improved, in the light of his experiences at the Honeylands Family Support Unit in Exeter. Otherwise, there appears to be little literature available on the role of the paediatrician in this field - in particular, on the developmental paediatrician who may play an extremely important role in the care of the mentally handicapped child.

The family's contact with their general practitioner is likely to be longer lasting than their contact with the paediatrician. From the literature available, however, it seems that many GPs have little knowledge or experience of mental handicap or information about local facilities, and that the advice and help they are able to offer the family is thus limited. (Lloyd-Bostock, 1976; Shearer, 1978 b; Ineichen & Russell, 1980). Nonetheless, some families do say that their GP is helpful (Bayley, 1973; Ineichen, 1980). Hewett's research (1970) suggests that doctors described in this way are those who listen to parents. In her study, the parents concerned had a realistic idea of the extent of the doctor's expertise on their child's condition, but were grateful to those doctors who took their worries seriously. Fox's fascinating study based on interviews with parents of handicapped children similarly concludes that a major problem in the doctor/patient relationship was that doctors had problems in listening to and sympathising with their clients. (Fox, 1974. Interestingly, Fox himself was a doctor, though the parents interviewed were not aware of this.)

One way of improving the service offered by GPs to mentally handicapped people and their families might be to offer more training in mental handicap. Ineichen and Russell (1980) report, however, that although few of the doctors in their sample had received any training in mental handicap, there was a generally negative response to this proposal. The authors suggest as an alternative way of increasing GPs' effectiveness in this area, that appropriate information on handicap and the local facilities available, should be channelled in their direction. Bain (1976) reports an interesting development in West Lothian, where local GPs have specialised in different areas. The GP specialising in paediatrics holds 5 sessions per week in paediatrics, a major component of which concerns the continuing care and assessment of handicapped children. This system of specialisation in the primary health care team has greatly reduced the number of attendances the children have to make at hospital departments. The team has also benefitted from the attachment of a full-time clinical psychologist who has also helped parents of handicapped children individually and through a series of parent workshops, and formed valuable links between services and schools in the area.

The role of the consultant <u>psychiatrist</u> in the field of mental handicap has been much debated in recent years. The debate has largely hinged on the extent to which mental handicap in general should be seen <u>primarily</u> as a specialist medical problem (in which the psychiatrist has the most important contribution to make) as it has traditionally been in the past. An alternative viewpoint which has gained increasing acceptance in recent years, has been that the psychiatrist's contribution to the wellbeing of people with mental handicap is but one specialist contribution among many others from different professions, and may be most appropriately focussed on those mentally handicapped people who have psychiatric problems. (For a succinct exposition of this latter view, see Bicknell, 1981 b; for an insight into the recurring debate over the consultant psychiatrist's role in mental handicap, see Godber, 1973; Shapiro, 1974, 1975; Pilkington, 1975; Kushlick & Blunden, 1975; Forrest, 1975; Spencer, 1975; Royal College of Psychiatrists, 1974). A more detailed exploration of the role of the "medical specialist in mental handicap" is given in the CMH Enquiry Paper "Who's consulted". (Tyne, nd). For an analysis of the respective roles of the psychiatrist, clinical psychologist and nurse in relation to mentally handicapped people, see the interesting paper produced by the Advisory Panel on Services for Mentally Handicapped People in Lancashire, now accepted there as county council and health authority policy on the issue. (Lancashire CC and AHA, 1981). For a recent discussion of training schemes for the psychiatrist specialising in work with people with mental handicap and some suggestions for increasing recruitment to the field (e.g. by offering posts split between mental handicap and child psychiatry), see Day (1981).

Para- and non-professionals

The distinction between the professionals and others involved in providing services for mentally handicapped people is not an easy one to draw. Home helps, care assistants, therapist aides, domiciliary or peripatetic care workers, home visitors, care attendants, foster or substitute parents, volunteers, advocates, neighbours, friends, relatives and, most importantly, the family - have, as we have seen, an enormous and vital contribution to make. Without them, the professionals' task would be impossible. The challenge for the professionals is to see that adequate, and appropriate, training, support, information and resources are available, as and when they are required, to the families and paraprofessionals concerned. An increased emphasis on skill-sharing, on working with groups rather than individuals, on recruiting and supporting volunteers to become involved with people with mental handicap can all help ensure that, despite shortages of skilled manpower in many areas, services appropriate to the needs of mentally handicapped people and their families are still effectively and sensitively provided.

9.2 Ways of working

The involvement of an increasingly wide variety of professionals, paraprofessionals and non-professional people in the provision of services for people with mental handicap must inevitably entail new ways of working. A clear theme from the literature reviewed earlier is the need for partnership and team work, both among and between professionals, paraprofessionals, parents, volunteers and mentally handicapped people themselves. Perhaps the most important message here is the need for the different individuals concerned to recognise and respect the contribution of others as being of equal importance with their own. Beyond that, the practical organisation of teams locally, both the district handicap teams proposed in the Court Report (Report of the Committee on Child Health Services, 1976) and the community mental handicap teams recommended by the National Development Group (Pamphlet No.2, 1977) and the Development Team for the Mentally Handicapped (1978), demands careful attention. (For more detailed consideration of this subject, see Plank's research, 1982; also APMH, 1977, 1980 b, 1981 b; Simon, 1981; Marshall, Preston-Shoot and Wincott,1979). In addition, the question of an appropriate base for professionals in the team has to be considered. As the desired focus of service provision increasingly shifts away from the mental handicap hospital to the community at large, bases in that community which are easily accessible to mentally handicapped people and their families must be found, in community units (Simon, 1981), health centres or clinics - as in the Wells Road Project in Bristol (see p.133), local social services offices, as in Poole ('Action for Mental Handicap', November 1980), or in specially rented shopfront offices or resource centres, as at ENCOR and NIMROD. In rural and remote communities, the base may even need to be mobile - for example, some kind of mobile resource unit, like that suggested by Philip Seed, on the basis of his research in the Highlands and Western Isles of Scotland. Ways of working for professionals and paraprofessionals - like the community care workers he proposes in his book - will also need to be tailored to the particular nature of demands for, and possibilities of, service provision in such remote areas. (Seed, 1980).

9.3 Monitoring and evaluation

A further issue for staff as new forms of service provision develop, is the need for regular monitoring and evaluation both of their own performance and of the overall service which they are involved in providing. A good introduction to both these processes is given in 'An Ordinary Life" (King's Fund Centre, 1980, pp.36-37). A useful guide to monitoring staff and providing them with positive feedback on their performance is Houts and Scott's "How to catch your staff doing something right" (1975 b).

In order to evaluate a service or scheme, it is necessary first to have clear ideas of the principles on which it is based, and the specific goals which it is intended to meet. Carle (1981/2) provides a brief but extremely useful discussion of elements and approaches in the evaluation process. There are now a number of publications available offering a variety of means for evaluating the quality of provision. On the residential side, see for example, Personal Social Services Council (1977); NSMHCA, SE Region (1980); and NSMHCA (1979). For a detailed approach to the evaluation of all types of service provision, see the National Development Group's "Improving the quality of services for mentally handicapped people - a checklist of standards" (NDG, 1980); and, Wolfensberger and Glenn (1975) "PASS 3. Program Analysis of Service Systems - a method for the quantitative evaluation of human services."

For details of PASS workshops in this country, contact CMHERA (see p. 131.)

9.4 Training

As thinking about services for mentally handicapped people has changed over the last decade, and community-based initiatives have mushroomed, the question of appropriate training for the professionals involved has loomed large. A central debate has focussed on the possible creation of a new profession of care staff, complete with a new training programme, which would cut across the present skills and job content of existing nurses and social services staff in this field. This debate was sparked off initially by the discussion in the Briggs Report (Report of the Committee on Nursing, 1972) of the possibility of a new kind of care staff for mentally handicapped people, and fuelled by the controversial recommendations of the Jay Report (Report of the Committee of Enquiry into Mental Handicap Nursing and Care, 1979) on the subject, in particular, on the centrality of social work skills to care staff training. The issue has recently been explored further by the joint working group on training for staff working with mentally handicapped people (GNCs/CCETSW, 1982), and resolved with a recommendation that although there should be some joint training between the two groups, the two professions, and their qualifications, should remain separate.

For the other professionals involved in services for mentally handicapped people, a common theme from this review would seem to be the need for general introductory courses on mental handicap initially, followed later by short in-service training courses and workshops on specific topics, skills and techniques as required -

for example, on Portage,behaviour modification, skill-sharing, normalisation, goal-planning, monitoring and evaluation, or individual programme plans. (For information on individual programme plans, see Carle, 1981 b; Blunden, 1980; Houts and Scott, 1975 a). The British Institute for Mental Handicap, CMHERA, (Community and Mental Handicap Educational and Research Association), and the Association of Professions for the Mentally Handicapped (see p. 131) all offer a variety of courses, workshops and experience on in-service training of this kind. The need for professionals and their managers locally, of course, is to encourage and facilitate attendance of staff at such courses, and their subsequent dissemination of knowledge and expertise gained to colleagues in the field. (See Mittler, 1978, for a useful discussion of these and other important issues in staff training; GNCs/CCETSW, forthcoming, on in-service training for staff working with mentally handicapped people; Firth and Barrow, 1981, on training for hostel staff in Rotherham; Mittler, 1981 a, on the training needs of teachers working with mentally handicapped children, adolescents and adults in the community; APMH, 1982 b, for a report of a conference on "Mental Handicap - interdisciplinary training").

9.5 Where do we go from here?

One encouraging lesson to be learnt from the huge variety of projects outlined in this review is that, despite the formidable obstacles of restricted resources and a heritage of institution-based care for mentally handicapped people, some exciting developments in community-based services are nonetheless taking place. As these developments spread, certain aspects of service provision will demand closer attention than ever before: the need for careful and continual monitoring and evaluation to ensure that the services delivered fulfil the goals initially set for them; the need for constant and sensitive support systems for staff, particuarly residential staff, who are living and working with mentally handicapped people in new and untried ways in ordinary housing in the community; the need for positive encouragement by service managers for their staff's involvement and participation in plans for change. (Towell, 1982). Equally, there will need to be an increased commitment to the participation of handicapped people themselves in the services that affect their lives - through self-advocacy groups or the involvement of families or volunteer advocates speaking on their behalf. (Information on advocacy from The Advocacy Alliance, p. 131). Most importantly, perhaps, there will be the need to recognise that community care cannot necessarily mean cheaper care since that has too often in the past been obtained at the expense of intolerable burdens on the families concerned, and in particular on the women members of those families. (Wilkin, 1979; Equal Opportunities Commission, 1982).

Clearly, the way forward is not easy, but the emphatic message of these pages is that commitment to change can and often will bring eventual success. For those keen to bring about local changes, some useful ideas on how to proceed are to be found in the final section of 'An Ordinary Life' (King's Fund Centre, 1980). Though the focus there is on creating better residential services, the hints and strategies are equally applicable to the development of any locally-based project: How should we go about generating wider interest and support for this new pattern of services? How do we gain the commitment of staff? How can we persuade the main local decision-makers that this new kind of service is possible? - and so on. The advice given is, like the rest of the paper, helpful and to the point. The concluding comments on establishing a local residential service for mentally handicapped people apply equally appropriately to the whole range of other community-based services described in this review:

> "... in the end, a comprehensive locally-based residential service for mentally handicapped people will grow from the enthusiasm, initiatives and sheer doggedness of local people. That is the challenge to everyone who reads this paper. We believe that mentally handicapped people have the right to expect that it will be taken up."
> (King's Fund Centre, 1980, p.42)

APPENDIX 1 - COMPILING THIS REVIEW: USEFUL SOURCES OF INFORMATION

The material on which this review is based was drawn from a wide variety of sources - journal articles, research reports, conference papers, biographies and books of different kinds. About a thousand such references were used in putting the review together, though only a fraction of this number - those judged to be most useful - appear in the final text. Since the focus of the review was recent developments in community-based services, a particular emphasis was laid on publications appearing since 1975. Some earlier references were, however, also included where these were found still to be of value and interest. Setting out on the compilation of such a review is a daunting process. The following sources which proved helpful in this task, will, it is hoped, prove equally useful to others embarking on similar ventures.

1. Bibliographical services

"Current Awareness Service"

- lists recent publications (including journal articles) in the mental handicap field, grouped by subjects.

Monthly, from BIMH (see p.131).

"Mind Information Bulletin"

- annotated list of recent publications (including journal articles) in broad mental health field.

Monthly, from MIND (see p.132).

(Publication currently lapsed. A new bulletin is planned shortly).

"Care of the mentally disordered"

- annotated list of recent publications (including journal articles) in broad mental health field, grouped by subjects.

Monthly from:- Humberside Area Health Authority

Information and Reference Service
Springfield House
Springfield Way
Anlaby
Hull

2. Mental handicap journals and newsletters

"Apex" (now "Mental Handicap") - quarterly from BIMH

"Mind Out" - quarterly from MIND (ceased publication, February 1982)

"Parents' Voice - quarterly from MENCAP

"APMH Newsletter" - quarterly from APMH

"CMH Newsletter" - quarterly from CMH

3. Publications from organisations concerned with mental handicap

Association of Professions for the Mentally Handicapped

British Institute of Mental Handicap

Campaign for Mentally Handicapped People

Independent Development Council for People with Mental Handicap

King's Fund Centre

MENCAP (Royal Society for Mentally Handicapped Children and Adults)

National Development Group for the Mentally Handicapped

Voluntary Council for Handicapped Children

(For details of how to contact all these organisations, see APPENDIX 2)

APPENDIX 2 - WHERE TO FIND ORGANISATIONS MENTIONED IN THE REVIEW

THE ADVOCACY ALLIANCE
115 Golden Lane
London EC1 OTJ

Tel: 01-253 2056

ASSOCIATION OF PROFESSIONS FOR THE MENTALLY HANDICAPPED (APMH)
126 Albert Street
London NW1 7NF

Tel: 01-267 6111

BRITISH AGENCIES FOR ADOPTION & FOSTERING RESOURCE EXCHANGE
11 Southwark Street
London SE1

Tel: 01-407 8800

BRITISH INSTITUTE OF MENTAL HANDICAP (BIMH)
Wolverhampton Road
Kidderminster
Worcs. DY10 3PP

Tel: 0562 850251

CAMDEN SOCIETY FOR THE MENTALLY HANDICAPPED
245 Royal College Street
London NW1

Tel: 01-485 8177

CAMPAIGN FOR MENTALLY HANDICAPPED PEOPLE (CMH)
16 Fitzroy Square
London W1P 5HQ

Tel: 01-387 9571

CARDIFF UNIVERSITIES SOCIAL SERVICES (CUSS)
Joint Students Union
Park Place
Cardiff CF1 3QN

Tel: 0222 43474

(For information - including video - on CUSS group home)

CENTRAL COUNCIL FOR EDUCATION AND TRAINING IN SOCIAL WORK (CCETSW)
Derbyshire House
St. Chad's Street
London WC1H 8AD

Tel: 01-278 2455

CENTRE ON ENVIRONMENT FOR THE HANDICAPPED (CEH)
126 Albert Street
London NW1 7NF

Tel: 01-267 6111 ext.264/5

COMMUNITY AND MENTAL HANDICAP EDUCATIONAL AND RESEARCH ASSOCIATION (CMHERA)
16 Fitzroy Square
London W1P 5HQ

Tel: 01-387 9571

CONTACT-A-FAMILY
16 Strutton Ground
London SW1

Tel: 01-222 2695

(Contact-a-Family film from:-
Concord Film Council
201 Felixstowe Road
Ipswich)

THE DISABILITY ALLIANCE
21 Star Street
London W2 1QB

Tel: 01-402 7026

HEALTH CARE EVALUATION RESEARCH TEAM
Dawn House
Sleepers Hill
Winchester SO22 4NG

Tel: 0962 68455

(For information on research on locally based hospital units in Wessex)

HESTER ADRIAN RESEARCH CENTRE
The University
Manchester M13 9PL

Tel: 061-273 3333

INDEPENDENT DEVELOPMENT COUNCIL FOR PEOPLE WITH MENTAL HANDICAP (IDC)
126 Albert Street
London NW1 7NF

Tel: 01-267 6111

KING'S FUND CENTRE
126 Albert Street
London NW1 7NF

Tel: 01-267 6111

KITH & KIDS
Carol Schaffer
27 Old Park Ridings
Winchmore Hill
London N21

LINE 81
(Information Service)
Room 17
252 Western Avenue
London W3 6XJ

Tel: 01-992 5522

MENCAP HOLIDAY SERVICE OFFICER
119 Drake Street
Rochdale
Lancs OL16 1PZ

Tel: 0706 54111

MENCAP NATIONAL CENTRE (Royal Society for Mentally Handicapped Children & Adults)
117-123 Golden Lane
London EC1 ORF

Tel: 01-253 9433

MENTAL HANDICAP IN WALES - APPLIED RESEARCH UNIT
~~The White Houses~~ ST. DAVID'S HOSPITAL
~~40/2 Cowbridge Road East~~ CARDIFF
Cardiff CF1 ~~9DU~~ 9TZ

Tel: 0222 226188

MENTAL HANDICAP INFORMATION SERVICE
Avon Social Services Department
Upper Belgrave Road
Blackboy Hill
Bristol BS8 2XR

Tel: 0272 731127

MIND (National Association for Mental Health)
22 Harley Street
London W1N 2ED

Tel: 01-637 0741

NATIONAL CHILDREN'S BUREAU
8 Wakley Street
Islington
London EC1V 7QE

Tel: 01-278 9441

NATIONAL DEVELOPMENT GROUP FOR THE MENTALLY HANDICAPPED (NDG)
NDG pamphlets available,free,from
DHSS Store
Health Publications
Site 2
Manchester Road
Heywood
Lancashire OL10 2PZ

NATIONAL FEDERATION OF GATEWAY CLUBS
117 Golden Lane
London EC1Y ORT

Tel: 01-253 9433

NIMROD
The White Houses
40/2 Cowbridge Road East
Cardiff CF1 9DU

Tel: 0222 373002

PARENTS FOR CHILDREN
222 Camden High Street
London NW1

Tel: 01-485 7548

PRE-SCHOOL PLAYGROUPS ASSOCIATION (PPA)
Alford House
Aveline Street
London SE11 5DH

Tel: 01-582 8871

THOMAS CORAM RESEARCH UNIT
41 Brunswick Square
London WC1

Tel: 01-278 2424

TOY LIBRARIES ASSOCIATION
Seabrook House
Wyllyotts Manor
Darkes Lane
Potters Bar
Herts EN6 2HL

Tel: 0707 44571

VOLUNTARY COUNCIL FOR HANDICAPPED CHILDREN (VCHC)
8 Wakley Street
Islington
London EC1V 7QE

Tel: 01-278 9441

WELLS ROAD PROJECT
Knowle Clinic
Broadfield Road
Bristol BS4 2UH

Tel: 0272 776292

APPENDIX 3 - BIBLIOGRAPHY

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