

AGEING AND MENTAL HANDICAP

James Hogg,
Steve Moss and Diana Cooke

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Volume 24

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JAMES HOGG,
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 **Routledge**
Taylor & Francis Group
LONDON AND NEW YORK

First published in 1988 by Croom Helm Ltd

This edition first published in 2024

by Routledge

4 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge

605 Third Avenue, New York, NY 10158

Routledge is an imprint of the Taylor & Francis Group, an informa business

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British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN: 978-1-032-67433-9 (Set)

ISBN: 978-1-032-73161-2 (Volume 24) (hbk)

ISBN: 978-1-032-73176-6 (Volume 24) (pbk)

ISBN: 978-1-003-42708-7 (Volume 24) (ebk)

DOI: 10.4324/9781003427087

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Ageing and Mental Handicap

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London New York Sydney
CROOM HELM

First published in 1988 by Croom Helm Ltd
11 New Fetter Lane, London EC4P 4EE
Published in the USA by
Routledge Chapman and Hall Inc.
29 West 35th Street, New York NY 10001
Croom Helm Australia
44-50 Waterloo Road, North Ryde,
2113, New South Wales

© 1988 James Hogg, Steve Moss and Diana Cooke

Printed in Great Britain at
The University Press, Cambridge

ISBN 0 7099 5718 1

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publisher.

British Library Cataloguing in Publication Data

Hogg, James

Ageing and mental handicap.

1. Mentally handicapped old persons

I. Title II. Moss, S. (Steve) III. Cooke, Diana.

ISBN 0-7099-5718-1

Library of Congress Cataloging-in-Publication Data

Hogg, J. (James)

Ageing and mental handicap / James Hogg, Steve Moss, and Diana
Cooke.

p. cm.

Bibliography: p.

Includes index.

ISBN 0-7099-5718-1

1. Mentally handicapped aged. I. Moss, Steve. II Cooke, Diana.

III. Title.

[DNLM: 1. Mental Retardation—in old age. 2. Mental Retardation-
-rehabilitation. WM 300 H716a]

RC451.4.A5H64 1988

362.3'0880565—dc19

DNLM/DLC

88-14936

CIP

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ACKNOWLEDGEMENTS

The opportunity to undertake this extensive review was afforded in the first instance by a grant from the Joseph Rowntree Memorial Trust. Special thanks must therefore go to the Trust for this support, and to the Trust's Director, Robin Guthrie and to the Trust's Advisor at that time, Malcolm Johnson, for their encouragement and interest.

The opportunity to explore directly some of the issues affecting families with older sons and daughters with mental handicap came through a grant from the MENCAP City Foundation. This generous support is acknowledged and the outcome of the work is reflected in Chapter 8 of this volume.

In our efforts to familiarise ourselves with issues in this area we spent a considerable time in Oldham Metropolitan Borough meeting both service providers and their clients. We would like to thank all who gave their time to educating us. Much of what they provided appears in our illustrative study in Chapter 1. In that Chapter we mention several people by name and here will note only two people who played a special role in this venture. Sally Cheseldine, of the Community Mental Handicap Team, gave us our entrée into Oldham introducing us to the relevant service providers and clearing up many misconceptions that emerged in our first draft of Chapter 1. Dan Stansfield, Principal Officer responsible for mental handicap in Oldham Social Services Department, also gave us significant support and has continued to make additional work in Oldham possible.

Outside of Oldham we had also required assistance from Calderstones Hospital and here Tom McLean (Unit Director of Nursing Services) gave all the support we could wish for. Brian Shields (Charge Nurse) unstintingly gave us all statistical information we

Acknowledgements

requested. Our thanks to both of them.

Several dozen colleagues in the United States and Canada have provided detailed reports on the development of their own service plans. We have not been able to do justice to these contributions but trust that the citations that we do offer reflect our appreciation of their communications and go some way to ensuring our approach to the topic cannot be accused of insularity. We must acknowledge in particular Matthew P. Janicki, Director for Aging Services, State of New York Office of Mental Retardation and Developmental Disabilities, who has facilitated our contact with those workers in North America and the invaluable part played by the National Institute on Aging's Newsletter of which he is Editor.

Our own colleagues in the Hester Adrian Research Centre have also given their time to reading parts of this volume. Special thanks go to Hazel Qureshi and Margaret Flynn. Margaret Flynn, too, must be thanked for allowing us to use material that she herself is still in the course of publishing.

The complex operation of producing the camera-ready copy for this volume has been undertaken by Christine Houghton in collaboration with the second author. Special thanks are due to her for the high quality of her work and meticulous organisation throughout the production period in which the volume was written.

Finally, we gratefully acknowledge permission to use the following figures:

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Fig. 4.1: "Some alternative patterns of growth of mental age and associated changes in IQ";

Fig. 4.2: "Mean semi-longitudinal MA growth functions for the five levels of handicap. Numbers on the curves refer to numbers of subjects measured";

Fig. 4.3: "Age changes in IQ for the five levels of handicap computed semi-longitudinally", from M.A. Fisher and D. Zeaman (1970) "Growth and Decline of Retardate Intelligence", in N.R. Ellis (Ed.) International Review of Research in Mental Retardation, Volume 4. Copyright permission: Academic Press, Orlando, Florida.

Fig. 4.4: "Personal self-sufficiency. Mean factor scores for ten age groups. Each line represents a specific level of measured intelligence";

Fig. 4.5: "Community self-sufficiency. Mean factor scores for ten age groups. Each line represents a specific level of measured intelligence";

Fig. 4.6: "Personal-social responsibility. Mean factor scores for ten age groups. Each line represents a specific level of measured intelligence", from K. Nihira (1976) "Dimensions of Adaptive Behavior in Institutionalized Mentally Retarded Children and Adults: Developmental Perspective", American Journal of Mental Deficiency,

Acknowledgements

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Fig. 5.1: "Schematic model of the social support system of the elderly", from M. Cantor and V. Little (1985) "Aging and Social Care" in R.H. Binstock and E. Shanas (Eds.) "Handbook of Aging and the Social Services", 2nd Edition. Copyright permission: Van Nostrand Reinhold Company Inc., New York.

Fig. 7.1: "Characteristics of various residential settings as measured on six different scales by Baker *et al.* (1977)", from B.L. Baker, G.B. Seltzer and M. Mailick Seltzer (1977) "As Close as Possible: Community residences for Retarded Adults". Copyright permission: Little, Brown and Company, Boston.

FOREWORD TO THE 2024 EDITION

With the re-publication of this book after some 35 years, we were very pleased to be given the opportunity to write a foreword to the new edition. Much has changed in those years, and we would like to give readers some context within which to read the text. Many of the papers written on the topics since then would of course be discussed in a modern book. At the same time, some of the fundamental issues still remain. Many countries, the UK included, still have an increasingly ageing society, and life-expectancy of people with intellectual disability has continued to rise. Over those years there has been a growing understanding of the relationships between severity of intellectual disability (ID) and life expectancy. People with Mild LD, without an obvious syndrome, have a life expectancy similar to general population, (though an increased risk of dementia). However, they may not be known to services. This means that mainstream physical health and mental health services for the general older population need to be aware of assessing for ID, and to be aware that people with ID can have multiple morbidities such as Autism Spectrum difficulties and cardiovascular issues. We hope this book can offer some useful background on appropriate assessment and treatment, and on the issues of diagnostic overshadowing and knowledge of ageing.

One important thing to say is that some terms used throughout the book, in particular “mental handicap”, are now no longer used.

Much of the background to the book was dominated by moves towards deinstitutionalization of people with ID. Thankfully, in the US and most of Europe, these issues have largely been resolved. For countries who have not yet gone through these kinds of transitions, the detailed descriptions of facilities and movements of people from institution to community may prove very useful. Following these transitions, the US and UK showed some very promising developments and innovations in service provision, including residential options, employment and match-making. However, funding of such services continues to be somewhat unstable, often appearing an easy target for budgetary cuts. We must remain vigilant if such services are to be continued into the future.

In relation to the chapter on epidemiology, one thing that will certainly still apply is that the effect of differential survival means that older people with ID will tend to be more fit and able than younger cohorts. This, paradoxically, can lead to a lower pressure on services than for the younger cohorts. This should make it easier for services to embrace this group of individuals, rather than fearing they will be overwhelmed by their needs.

In relation to the chapter on health, one thing that has definitely changed is the increase in knowledge about mental health issues. At the time of writing, very few staff working in the field had knowledge of these issues. Now in many countries, it is a core part of the training curriculum. This includes huge improvements in both assessment and treatment. The former includes assessment systems and associated training, specifically designed for people with ID. The latter includes development and tailoring of existing models of therapeutic approaches for a range of mental health issues relevant to older people with ID. E.g. individual and family therapy, to help with bereavement after elderly parents die, preparing people for End-of-Life care, use of Life story books to help with identity, and therapeutic support following abuse.

Services have also developed in their acknowledgement of people with IDs' desire for romantic relationships and sometimes need for support in this area e.g. Developing dating services for people with LD. This is likely to have helped improve the mental health and quality of life of some people seeking relationships, rather than relying more on a medical model (e.g. medication to help with depression and loneliness).

The chapter on behavioural and adaptive functioning change is very much out of date, given the massive growth of knowledge about health in old age, dementia, its potential early diagnosis, and developing approaches to treatment. The point mentioned earlier, that healthier members of the population are more likely to live longer, is now constantly discussed in relation to lifestyle choices and approaches to health care provision for the whole population. Modern approaches to the health of older people with ID will be starting from a very different state of knowledge from when we wrote this book.

Chapter 5, Approaches to Intervention, was also written at a time when care provisions for people with ID were different from today. For the sections on behavioural interventions, it was only possible to base them on work that had been conducted in relation to people who were not considered "elderly". That was simply because there was virtually no specific literature on which to draw. Apart from that, the philosophy of care has also changed, moving away from behavioural targets to more socially based approaches.

The section on the importance of the ecology is still highly relevant. How do we help foster ecologies for older people that maintain the “core” of their lives, and offer continuing opportunities for enjoyment, mastery and fulfilment? This obviously applies to all older people, not just those with ID.

The discussions of work and retirement in Chapter 6 are as germane now as they were then. The crucial significance of work in our lives cannot be understated. Nowadays, many well-known high-profile people are working into their 80s and even beyond. At the time we wrote the book, most people with ID in the UK had only menial work. This compared markedly with the US, where one of the primary focuses of their ageing services was to help people into real-life jobs. As discussed at the time, there was a strong emphasis on the social development of people with ID in the UK rather than getting them into work. This will continue to be a topic for discussion.

Back in 1988, there was an ongoing debate as to whether it was appropriate to move older residents of institutions into community facilities. Our own research in Oldham, and reviews of the literature, made it very clear that the vast majority of people were much happier living in the community. For many countries, these residents have long ago moved out. There are, however, striking differences in the views taken by different countries about the appropriateness of smaller institutions or villages. The UK’s view is that nobody should live in an institution. Other countries are of the view that everybody should have a choice. Many people might prefer to live amongst a group of similar individuals, where they might at least have a chance of making some real friends. The question of cultural appropriateness of residence also needs careful consideration. These are difficult issues, and will no doubt continue to be debated.

The chapter on informal support is probably still a very useful discussion of the topics. In the UK, for instance, 2/3 of people with ID still live with older parents. For everyone, their ecosystem of informal support is one of the main factors that contributes to their sense of well-being and security. Elements of these ecosystems will include not just a family but also neighbours and friends. People with ID typically have relatively impoverished ecosystems, and anything that can enhance their level of support can only be a good thing. At the time we wrote the book, we heard many stories from parents of their experiences living alongside their son or daughter, who was now older. It continues to be vital for voluntary and statutory services to be aware of pressures under which parents may be living as a result of their lifelong caring role. Sensitively raising questions of future planning with people

and their elderly parents and families can help to avoid crisis decisions and unplanned moves at a time of bereavement.

In conclusion, while this book needs to be read with an awareness of the changes in the last 35 years, we are of the view that it is still relevant for current and future researchers, clinicians, and service providers. It gives the background history, and an older review of the literature, of many areas that are still pertinent to the lives of people with intellectual disability as they age.

Steve Moss, James Hogg and Diana Cooke, 2023

Chapter One

AGEING AND MENTAL HANDICAP - BACKGROUND AND AN ILLUSTRATIVE REPORT

1 INTRODUCTION

Since the turn of the century most industrial countries have seen a marked shift in the age structure of their populations. People are living longer and having fewer children, with the result that the proportion of older people has been steadily rising. This "greying" of society is predicted to continue well into the 21st century, with a consequent pressure on services to the elderly that is becoming of increasing concern to policy planners. In Britain, the numbers of those aged 75 or more will rise by 23 per cent between 1976 and 1996, while the proportion of very elderly people (aged 85 and over) will increase by 42 per cent in the same period (Walker, 1981). Similar trends for other countries are presented by Hendricks and Hendricks (1978) (see Figure 1.1) and Myers (1985).

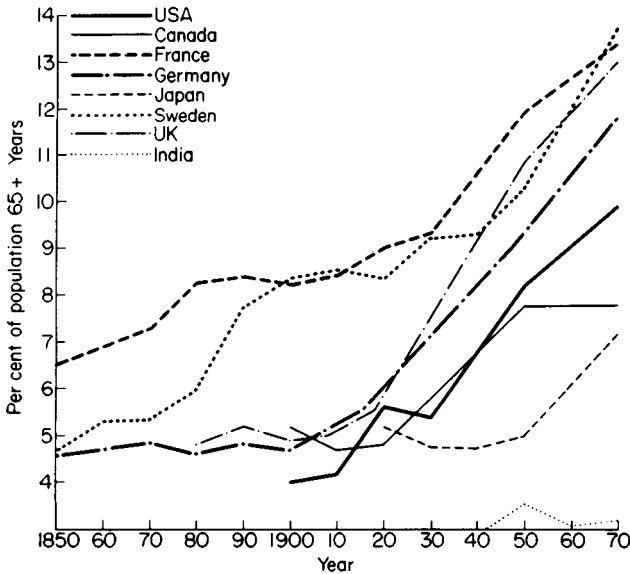
One of the fundamental determinants of increasing longevity has obviously been the improvement in quality of medical care. People are now much more likely to survive serious illness in old age than they were 50 years ago. For people with mental handicap, some of whom tend to be more susceptible to illness than their non-handicapped peers, these medical advances have had an even greater impact. Advances in perinatal care have resulted in a much greater proportion of impaired children surviving the first year of life, so that Fryers (1984) is able to report a current death rate of only 10 per cent among children with Down's syndrome, compared with 50 per cent in earlier studies (Carter, 1958; Hall, 1964; Oster, 1953; Record and Smith,

Background

1955). Mortality rates among adults similarly declined in the early part of this century

Figure 1.1:

Percentage of the population aged 65 and over for selected countries



Sources: United Nations, *The Aging of Populations and Its Economic and Social Implications*, Population Studies, no. 26 (New York: United Nations 1956); United Nations, *Demographic Yearbook*, 1973, 25th ed. (New York: United Nations 1974). (Adapted from numeric data.)

as former major causes of death were brought under control. Tuberculosis, pneumonia and influenza were responsible for 50 per cent to 60 per cent of deaths among people with severe mental handicap, a death rate which was around 13 times that of the non-handicapped population (Conley, 1973). Studies which are widely separated in time illustrate clearly this change in lifespan. Dayton *et al.* (1932) found 28 per cent of the people alive at 10 years to have survived to 60. Forty years later, Balakrishnan and Wolf (1976) reported a

corresponding survival rate of 46 per cent.

As a result of this dramatic increase in longevity, policy makers must now plan on the basis that approximately half of all people with mental handicap will reach the conventional age of retirement. Indeed, the concern with the topic of ageing, as measured by the number of published articles relating to older people with mental handicap, has burgeoned over the past ten years. However, the fact that the majority of the relevant literature dates from less than ten years ago, suggests it is not merely an increase in the numbers of older people with mental handicap that has stimulated the interest. Rather, there has been a growing awareness that the needs of this client group have been overlooked. They suffer the "double jeopardy" of belonging to two groups whose members are disadvantaged in Western Society, i.e. being both aged and having a mental handicap (Sweeney and Wilson, 1979). Ageing, even for non-handicapped people, usually brings the abrupt termination of "useful activity" at the age of retirement, while little value is attached to those positive features which senior citizens may possess to a greater degree than other members of society, e.g. wisdom and experience. An expectation of economic dependence is also the reality for many older people. Walker (1981) states that elderly people comprise the majority of those living in poverty in the UK, with around half of this group having incomes below the poverty line. In the USA, about 20 per cent of elderly people have incomes below the federal minimum (Hendricks and Hendricks, 1978).

Elderly people with mental handicap are liable to be even more disadvantaged than their non-handicapped peers. As Dickerson *et al.* (1979) point out "By middle age (40-55) persons experience loss of parents and some friends, loss of some of his sensory awareness (bifocals, hearing aids, etc.). We regard this as a normal loss pattern. However, for the retarded this loss pattern becomes a double or triple jeopardy. If he has lived at home with his parents, this loss may result in a change of home space. Thus, mentally retarded persons who become older may tend to become part of the life occupant category in long-term care institutions such as nursing homes. There the patients who are mentally

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retarded tend to be grouped with patients who are senile. (This seems to be another factor in how the mentally retarded elderly person becomes invisible. They get lumped together with these elderly senile persons and their behaviors are not differentiated.)" (p.12).

In the USA, the growing awareness of the need to plan services for, and research the needs of, older people with mental handicap has led to changes in Federal and State legislation. The Older Americans' Resources and Services (OARS) Act enshrines the rights of all senior citizens, including those who have a mental handicap. It is apparent, however, that most State and private agencies have no special plans or provisions for older people with mental handicap (Janicki, Ackerman and Jacobson, 1984; Sweeney and Wilson, 1979), although there are notable exceptions (e.g. Durow and Pierson, 1975). One result of these detailed investigations into State and private agency plans has been a heightened awareness of unmet needs and insufficient numbers of suitably trained staff. Social Services are increasingly being reviewed from the perspective of cost effectiveness and output, where this is defined as effect on the client. The question is no longer how many units of service were expended, but what happened to the client as a result of those services and how much did they cost (McAllister, 1975).

In the UK, the specific needs of older people with mental handicap have received little attention. In 1985 we were able to find only 13 references concerned with the needs of this older group of clients. There is an extensive literature on all aspects of ageing in non-handicapped people, but very little overlap between the two subject areas. Indeed, this lack of overlap is not peculiar to the UK. It is notable, for instance, that there is no reference to retardation or handicap in one of the most recent and major of the textbooks on ageing (Binstock and Shanas, 1985). However, this lack of overlap is probably not surprising when one considers the very different life histories and expectations of many people with mental handicap compared with those of non-handicapped individuals. Much of the literature on ageing in non-handicapped people is concerned with disengagement from the active roles of earlier adult life such as work and parenthood and with the consequent

changing roles in relation to family and friends. Thus, Fennel *et al.* (1983) state: "From quantitative data we know that among elderly people living in the community, proximity to and contact with children increases with age. We also know that in some cases parents and children have been involved in moves which bring them into greater proximity. At the same time, we know that reliance on the family for help increases in extreme old age."

In comparison, many older people with mental handicap have lived an institutional life for many years. Some of these people no longer have family or friends living in the community, or are no longer in touch with them. In these cases there is the danger that a move to the community will bring isolation, unless appropriate statutory networks of care and support are available. There is no doubt that these statutory provisions should exist, but it can be seen that sociological analyses of informal care networks relying on a lifelong history of family involvement may be of limited relevance.

It is to be hoped that eventually the majority of people with mental handicap will live their adult lives in the community, using generic services for elderly people in their later years when necessary. At present, however, there is an urgent need to examine policy issues and priorities for service provision to this client group. The current policy of community relocation is likely to have profound effects on the lives of many people who undergo this transition. We are therefore presented with two interacting considerations. On the one hand, people with mental handicap are living longer. At the same time they are also being asked to consider the possibility of making major moves towards independence, sometimes when they are already well beyond the conventional age of retirement.

2 DEFINING THE POPULATION OF OLDER CLIENTS

There has been much discussion in the literature of what definition we should use to characterise a person with mental handicap as "old" or "elderly". Many service providers consider that this line should be drawn lower

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than for the non-handicapped population (Hamilton and Segal, 1975). Thus, Daniels (1979) advocates an age criterion of 55+, while Janicki (1984) and Seltzer (1984) are in favour of including all people over 50 years of age. Some authors have suggested lowering the age criterion to 45 years (Thomae and Fryers, 1982), or even to 40 years (Fancolly and Clute, 1975; Kriger, 1975).

A number of authors advocate retaining the statutory age boundaries (i.e. 60-65) which apply to the non-handicapped population (Ballinger, 1978; Deshayes, 1979; Gress, 1979; Rowitz, 1979). It is noticeable, however, that the majority of these papers are written from a medical standpoint where statutory service eligibility may be an important consideration.

Evidence of premature ageing associated with Down's syndrome (see Chapters 2 and 3) does lend support to the view that, for some people with mental handicap, a lower age criterion is appropriate. It is important to bear in mind, however, that in the absence of a universally accepted index of ageing, any age criterion is essentially arbitrary. Thus, Sweeney and Wilson (1979) point out that many people with severe mental handicap are physiologically or neurologically impaired in their early lives. This makes it difficult to know whether a particular biological phenomenon is to be considered a symptom of "ageing" rather than environmentally induced disease, insult or trauma. Thomas *et al.* (1979) suggest that "It is not enough for a person to 'look old' and to be given a label of 'aging or aged'. In this day of consciousness-raising on every topic, professionals in both gerontology and developmental disabilities need to take a long look at their subjective, often presumptuous, expectations of client behavior" (p.46).

Within our study of service provision in Oldham Metropolitan Borough described below, it was necessary to employ an age criterion in order to give some context to the interviews with service providers. For this purpose we took 50 years as a lower age limit, although this did not preclude discussion of the needs of any younger clients who were thought to be suffering from premature ageing.

3 POLICY BACKGROUND

Approaches to the care of people with mental handicap have undergone major changes over the past decade. There has been a massive shift away from the notion of custodial maintenance in large isolated institutions to an acceptance of the fact that these people have a right to live a normal life in the community. As a result, patterns of service provision are showing an increasing emphasis on normal life styles and their integration as much as possible into community routines (Bruininks *et al.*, 1981).

The process of providing appropriate residential placements for mentally handicapped people encompasses three interrelated elements: 1) The prevention of admission by finding and developing alternative residential facilities in the community: 2) Deinstitutionalisation of existing clients, and: 3) The establishment of a responsive residential environment which protects human rights (Bruininks *et al.*, 1981).

In England and Wales, mental handicap policy has for over thirty years been directed to a shift towards community care. The report of the Royal Commission in 1957 strongly supported the community option, recommending a mandatory requirement on local authorities to provide appropriate services. The subsequent legislation, the Mental Health Act (1959) adopted most of the Commission's recommendations, but did not require local authorities to make community provision; it merely empowered them to do so. The White Paper "Better Services for the Mentally Handicapped" (DHSS and Welsh Office 1971) offered a statement of the principles that should guide community services and guidance to local authorities and health authorities on service development in line with Government objectives. Inadequacies in community and hospital services were identified and a 20 year programme of transfer of services from hospitals to the community set out. The recent report by the Audit Commission (1986) notes that this transfer implied a considerable expansion in social service provision since in August 1959 the Minister of Health had directed under the National Health Service Act (1959) that local authorities should buy residential and accommodation

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services for people with mental handicap.

Impetus has been given to the transfer and the nature of service provision more clearly defined through a variety of initiatives since publication of the White Paper, notably the establishment of the National Development Group for the Mentally Handicapped and the setting up of the Jay Committee (DHSS 1979). Further monitoring and advice has come from the National Development Team. It is of interest to note that thinking regarding the implementation of the community care policy has continued to evolve over this period and far more radical objectives have been set many local authorities than were ever envisaged in 1971. However, marked differences exist between different authorities in both the way in which the policy is being realised and the extent of commitment to the policy. DHSS publication "Care in Action" (DHSS, 1981) urged authorities to aim for smaller, more local units, and set as the main aim the development of each individual's capabilities at independent living. However, establishing homes in small group houses or in relatively independent residences such as housing association accommodation has become the required objective of some Regional Health Authorities and local authorities as we shall see later in this chapter. Variations in quality of provision are documented by the Audit Commission (1986), and problems in the realisation of the policy analysed here and in a variety of other studies (e.g. Donges 1982). A fuller comment on these difficulties which affect older people with mental handicap in significant ways will be made in Chapter 9 of this volume.

Legislation to enhance the quality of services received by people with mental handicap in the community has also been introduced in the wider context of provision for disabled people generally. The Disabled Persons (Services, Consultation and Representation) Act 1986 if fully implemented will lead to a more formal assessment of the needs of older adults with mental handicap with respect to help in the home, recreational facilities, assistance with transport, aids and adaptations, holidays, meals and access to a telephone. At the time of writing, this legislation, though on the statute book, has yet to be implemented. (For a valuable summary of this Act and its implication see Bingley and Mitchell

(1986)).

Although a major focus of these various policy statements has been closure of large mental handicap hospitals, it is important to remember that the resulting patterns of service provision are equally relevant to the lives of those clients who have never lived in an institution. Richardson (1981) estimates that, at age 22, 20 per cent of people with severe mental handicap were living at home with their parents. Some of these individuals may be sufficiently able to live a totally independent life when the time comes, but it seems likely that many of them will require some form of supportive residential alternative when their parents can no longer look after them. Nowadays it is to be hoped that, wherever possible, the chosen living situation is an appropriate community dwelling, although it is clear that this policy has not been adopted in the past. This fact is reflected in the figures for increasing institutionalisation as a function of increasing age.

Heron (1983) has pointed out that, because of the total independence of the Health and Local Authority administration, Britain provides a unique structural model of service delivery. As a result, the government policy directives on community care, coupled with the variable nature of priorities for expenditure at local level, have produced a number of different patterns of district service provision. Indeed, Heron (1983) suggests that there is an almost infinite variety of ways in which community service expansion and relocation of clients from the large hospitals could be handled. We will return later to some of these differing strategies.

The current situation, therefore, is of a general commitment to the run-down of large institutions and a concomitant expansion of community services. The way this policy is interpreted, however, depends on a complex interaction between the various interested parties, RHA, DHAs, LAs and voluntary bodies and on current spending priorities. Finance is, of course, one of the main determinants in the transfer of services and in this respect the local authorities are somewhat concerned. The role of finance and financial administration is analysed by the Audit Commission (1986).

With regard to the subject of this book, it should be noted that the policy of care in the community is as

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applicable to elderly people generally, as to people with mental handicap. Guidance has not, however, been as specific with regard to implementation of the policy for older people. In *Care in Action* (DHSS 1981), however, objectives are set emphasising the maintenance of the person in their home with adequate care services, active rehabilitation and treatment, and maintenance of acute and long-stay facilities where required.

The preceding brief discussion touches upon broad trends with respect to the life expectations of people with mental handicap, their present position within the framework of services and the fact they will be living their later life in a world in which the nature of that service provision is going to change in certain fundamental ways. In order to reflect the reality of this situation more fully, we will now describe the situation in one Borough and the main hospitals which will be discharging people with mental handicap into it.

4 AGEING IN OLDHAM

4.1 The Background

To make some of these issues concerned with ageing and elderly people with mental handicap more real, we would like to offer an informal account of the lives of such people in one area of the North West of England, Oldham Metropolitan Borough. To anyone unacquainted with the towns of this area, it is worth pointing out that Oldham is the real name of an actual town, despite the coincidence of name and the subject of this book. The choice of this Borough arose from the availability of co-operative colleagues, geographical accessibility, and good links with the large institutions that will be discharging Oldhamers to their home town.

There are many reasons why the choice was a happy one. We made contact with both service providers and clients during the summer of 1985. This was during a period of general reappraisal of services for people with mental handicap and a particular examination of the nature of provision for older people in this population. This was apparent at all levels of services and was leading to the development of specific

projects directed at aspects of ageing.

Having said this, however, two factors soon became apparent to us. First, the fact of attaining a particular birthday does not at any stage automatically lead to a person being classified as "aged, mentally handicapped" as distinct from "mentally handicapped". In terms of their characteristics, needs or the provision of services, we cannot consider a person with mental handicap who is over 50, 60, 70 or even 80 years of age as being in some distinctly different category from younger peers. For this reason our account has to focus on these individuals as part of a wider network of services provided for people with mental handicap in the Borough, and this will necessitate at the outset some general account of these services. Second, though we have described this study as informal, it emerged in a considerably more organised form than we had initially intended. We soon found that to organise our information we had to collect numbers in relation to both facilities and age bands. We had to be able in some measure to identify individuals so we could trace them across different aspects of the service network. In order to understand trends we had to relate these figures to projected changes in the Borough, including the reincorporation of Oldhamers from facilities outside the town. What emerges is not a fully fledged survey, though we do go some way beyond the impressionistic picture we originally intended.

At the time that these visits took place, Oldham was one of the ten Metropolitan Boroughs that made up Greater Manchester, the town itself being located North East of the City of Manchester itself. In 1981 the population was 220,1017 (OPCS 1984). With respect to the older population generally, the percentage of people of pensionable age (Age 60 for women and 65 for men) was close to both the Regional (North West) and National proportions, i.e. Oldham 17.2, North West 17.5, National 17.7 per cent. The picture was similar for the 75 and over population, the equivalent figures being 5.2, 5.6 and 5.7 per cent.

The White Paper "Better Services for the Mentally Handicapped" estimated that, for a population the size of Oldham, there would be 650-700 people with mental handicap, while estimates based on the Guys Health

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District Survey would lead to estimates of 200 children and 600 adults. The actual figure provided from the Oldham Register was 538, including some Oldhamers living outside the Borough. The shortfall between estimates and number on the Register is of special interest in this context, as it is likely that those not identified are people with mental handicap who are middle-aged and possibly living with ageing parents. Such families will not have received services for some years (Oldham Social Services Department 1984). Below we offer estimates of the number of people over 50 years of age who may be in this hidden group.

Before pursuing the question of numbers in more detail, it is useful to summarise the philosophy of the service providers as stated in both the Community Mental Handicap Team's own policy statement (Oldham Social Services Department 1984) and their "Parents' Handbook". This is in line with both national United Kingdom policy and enlightened practice elsewhere in the world. It is informed by the North West Regional Health Authority Model District Plan. Four basic views underlie developing practice:

1. Every person with mental handicap has the potential for development and has the right to live as ordinary a life as possible with the greatest degree of choice and independence that he or she can achieve.
2. Care for the person with mental handicap is a joint function of family and community. The Social Services Department itself is only one of several agencies that are seen as responsible for care. Hence, joint planning with the Departments of Health, Education and Housing is essential. To be effective the views of individuals with mental handicap and their families must be taken into account.
3. Services should be located in the community and be comprehensive, should lead to normalisation and should be individualised. Skilled personnel rather than specialised buildings are seen as the most appropriate way of achieving this end.

From the point of view of planning, this

philosophy necessitates the development of services that will prevent admission to long-stay hospitals and provision to relocate those already in hospital in Oldham itself.

This last point brings us to a central issue to which we alluded briefly above, i.e., the fact that some individuals on the Oldham Register are located outside the Borough, some in the long-stay hospitals. To these can be added those known Oldhamers who, though not on the Register, are also due to return to Oldham from such hospitals. At this point then, before proceeding with a more detailed account of what is happening in Oldham itself, we must take a broader look at the wider, Regional, context of hospital closure.

The North Western RHA's (1985) policy on hospital run-down recommends: "Accommodation should be in ordinary domestic housing dispersed throughout the community, with the degree of supervision appropriate to each person's needs, provided and organised in clusters based on neighbourhoods...A wide variety of ordinary housing is required, dispersed throughout the community, together with a wide range of support and supervision. The type of accommodation should be ordinary for its neighbourhood. It is not necessary to build houses specially for handicapped people although it may be necessary for some alterations to be made for people with physical handicaps" (NWRHA, 1985). No discrimination against older residents is intended in realisation of this plan which notes: "A number of residents in their 70s and 80s have been resettled very successfully already. It is inappropriate to argue that because services have deprived a person of ordinary home-living for a long time then they should continue to be deprived for the rest of their lives." (p.12.)

In passing, it is illuminating to contrast this approach with that developed in 1973 by the South East Thames RHA when the decision was made to close Darent Park Hospital. The Board's recommendations were that each area should have a residential centre of about 72 places, divided into houses or flats for 6-8 people, smaller, 24 place hostels in the community and group homes to make up the provision of each District to the level required by Better Service norms (Korman and Glennerster, 1984).

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Such contrast in provision will have implications for resources, the nature of the service and, through these factors, the lives of all groups of people with mental handicap, including the ageing and elderly. With respect to the philosophy and strategy stated by the Oldham Community Mental Handicap Team, there is close agreement with Regional philosophy, a state of affairs that should smooth the way to Regional Health Authority acceptance of plans for individual Oldhamers to return to the town. This is not necessarily the case elsewhere where plans at the local level are not consistent with those demanded by the RHA. For our present purposes, our interest in Oldhamers in long-stay hospitals has been limited to the two large institutions which can be regarded as the main, though not only, settings from which individuals will return.

4.2 An Estimate of Numbers

Let us now return to the question of numbers of people and specifically to the proportion of individuals who are over 50 years of age. In order to see these people in a wider historical context, it is worth noting that at the time of our visits those who were 50 to 59 years of age were born between 1926-1935, those from 60 to 69 years, between 1916 and 1925, and those over 70 years, before 1915. Using the Oldham Register of June 1985 and complementary information collected by us in the Authority the breakdown in Table 1.1 can be given. This gives a grand total of 75 people over the age of 50 years living in the Borough itself. The figures for the "Identified at home group" are based on information on place of residence supplied by the two ATCs/SECs. The estimate is based on the assumption that there are 160 adults not on the register. We have taken the proportion of people in each age band that would be expected on the basis of Midwinter's (1972) figures on people with mental handicap living in the community and extrapolated from these.

4.3 Service Provision for Older People in Oldham

As we stated above, to consider the position of older people with mental handicap in Oldham, it is necessary

Table 1.1:

People over 50 years of Age Living in Oldham Metropolitan Borough

<u>AGE:</u>	50+	60+	70+	80+
<u>LOCATION:</u>				
Hostels	19	18	1	0
Home Making Scheme	5	1	0	0
At home (identified)	9	5	0	0
At home (estimated)	6	3	1	0
Independent	4	3	0	0
<u>TOTAL:</u>	43	30	2	0

to take a broader look at the general service context. This we will do, and will then "place" the over-50s within this framework.

Community services are provided by specialist teams. They operate in three Core Teams, 1 to 3, working from the Community Mental Handicap Team base, Woodfield Centre. Core Team One is concerned with children, and therefore our own interest focussed on Teams Two and Three. Team Two is concerned with adults living in the community, including some with parents well into their 80s. Team Three concentrates on rehabilitation and maintenance, serving adults who are resident in the area. This team aims to give clients a more independent life in the community. Team members work with staff in residential settings to assess residents' capacity for independent living, prepare them to move out and support them in their own homes. Input to the Core Teams comes from Social Workers, Psychologists and Community Nurses, and we will consider their interacting roles in relation to the ageing population of

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people with mental handicap in Oldham.

4.3.1 Social Work Input.

Overall responsibility for social services for people with mental handicap rests with Dan Stansfield, Principal Officer Social Services Department. The leader of all three Social Work components of the Core Teams is Richard Woolrych. Brenda Lees (together with Maureen Martin) is the Social Worker primarily concerned with the Social Work aspect of Core Team Two. Discussion with her about older clients with mental handicap revealed concern regarding individuals living at home with their parents or other relatives. Essentially we are considering the 24 "at home" people identified and estimated above. As we shall see, such people, paradoxically, face potentially greater problems than those who are in hostels or are being prepared for leaving hospital. According to Brenda Lees, these problems stem from two sources. First, people with mental handicap who have lived with their parents all their lives have not, generally speaking, gained experience in self-care skills. As a result, the death of a parent or disablement through illness can cause a crisis in the life of the person with mental handicap, due to his or her inability to cope. Obviously, if the person is already known to the Social Service Department (SSD), this event can be planned for, (assuming the cooperation of the parent). Sometimes, however, people do not come to the attention of Social Services until a relatively late stage. In extreme cases this will be on the death of a caregiver, but sometimes it is a third party, neighbour or friend, who alerts the Department to a potential problem. Wendy's mother, for example, was in her 90s when she died. Social Services were not informed of the death; it was only when Brenda Lees read of it in the local paper that the situation came to the attention of social services.

Expectation regarding future care can also be unrealistic. In one instance, according to the mother, it had been agreed that a daughter would look after her brother who was mentally handicapped after the mother's death. However, when both the parents died within a few weeks of each other, the sister said that she was unable to cope, having a family of her own. The

parents willed the house to their daughter, along with a request to allow the son to continue living in it. Clearly society here confronts a dilemma. Should the sister and her family be expected to provide support for the brother for what may be both their lifetimes, or renounce any right to the property?

Over the years, too, the relationship between carer and cared-for tends to become symbiotic, or even reversed. Brenda Lees mentioned several cases where the mother had become so disabled herself that it was she who actually relied on her son or daughter with mental handicap for her day-to-day care. Mark, who lived with his aged mother, came to the attention of the Social Service Department when he stopped attending the Adult Training Centre/Social Education Centre. It turned out that he was having to do literally all the physical tasks necessary to keep her and the house going. Up to the time she became ill, the mother always got up to get her son off to work. With the onset of her chest complaint she was then taking at least one hour to recover after getting up, so she was attempting to cope by rising at 6.00 am. Eventually this became impossible. The mother refused any help. She pointed to the tidy house as evidence of her continuing capability, but it emerged that it was her daughter who was coming in to tidy up.

The second problem is the attitude of older parents. They were brought up in a time when views of mental handicap and social welfare were very different. Social welfare was seen, at best, as charity, the acceptance of which indicated failure and a sense of shame. At worst, it was something imposed on people, irrespective of their wishes. For many of these older parents the name of their "local" long-stay hospital, "Calderstones", is still inextricably linked to stories of children being taken away and locked up. As a result, visits from social workers and offers of help tend to be looked on with deep suspicion by older families. They see it as the thin end of the wedge, the ultimate aim being to get their son or daughter into an institution.

In one instance attempts had been made to visit the home of an older woman with mental handicap. Interviews were sometimes conducted through a crack in the door. The client lived with her brother as well as

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mother, the brother being particularly uncooperative, refusing to join in discussions at all. The Social Worker assumed that it was he who took over the job of dressing his sister after mother had become too feeble, and she pointed out the unacceptability of this arrangement. Though subsequently aware of the death of the mother, the social worker has no information on the present whereabouts of her client, although she assumes that a sister has taken her, rather than the brother whom she knew to be unwilling. Difficulties present themselves in knowing how to proceed. Should the social worker attempt to make contact when not requested to do so? Would the client be functioning at too high a level to fit in with the clients usually found in local authority old-peoples' Part Three accommodation if this option were considered?

A more explicit instance of suspicion regarding threatened institutionalisation can also be cited. The manager of the ATC attended by one 58 year old man with mental handicap received a message that the man had been seen walking in front of buses. Up to that time he had been quite able to deal with public transport, but as a result of these incidents it was decided that he should start using the Local Authority transport. His mother, who had actually asked for such transport over two years before, was very suspicious, seeing this as a ploy to get her son into a hostel by showing that he was incompetent. The main problem in engaging in effective social work is the very independence of this older group of people. Brenda Lees encourages younger parents to contact and meet the older ones. She feels that an introduction to modern attitudes to service provision comes better from other parents than from herself.

Family members often make assumptions about other relatives taking over responsibility on the death of the parents. This is frequently not justified and needs forward planning to avoid a crisis developing.

Social work intervention can only move at the pace the family is prepared to accept. Since older mothers tend to be very resistant to offers of help, this can be very slow indeed. Core Team Two tries to get the family to look realistically at their situation and to plan for changes, or a move to a new residential situation.

It is important to appreciate how different was the social and service milieu in the past with regard to mental handicap when considering these families. As noted above, fear of institutionalisation was very real, and often distorted patterns of life were established. Brenda Lees describes one mother of 75 with a son of 55. On the birth of her son the mother had advice from a relative that he should never see his reflection, never be around machinery, and never use a razor. As a result, she has spent the last 50 years with no vacuum cleaner or washing machine, and her son waxes his beard to remove it. Attempts to alter this way of life have been totally unsuccessful.

These difficulties are compounded by a range of deficiencies in community services to which our attention was drawn. First, the needs of people with mental handicap are not responded to by the Housing Department since the factor of stress or problems arising from the mental handicaps do not contribute to the points system on which allotment of accommodation is based. Active collaboration with the Housing Department to alleviate this situation is on-going at both the level of Social Workers and Rehabilitation Officer and between the Principal Officer responsible for mental handicap and the Director of Housing. Second, medical services are seen as inadequate relative to those provided for children. Indeed, there is a feeling that there is actual discrimination against older people with mental handicap, the long waiting list for orthopaedic services being cited. Further, monitoring of the appropriateness of prescriptions is considered inadequate. One notable exception to this state of affairs that was commented on in many discussions was that of psychiatric care where services for older people with mental handicap in the District Hospital were highly praised. Third, problems with allowances were also commented on, particularly the mobility allowance with its criterion of physical disability. Less problematical, though not invariably so, is that of attendance allowance, received by some families dealing with parents and relatives in the family home. In general, allowances related to the fact of increasing age were regarded as satisfactory.

The account we have given emphasises the specific problems of ageing people with mental handicap and

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their families. Clearly families do cope and provide a good family life through much of adulthood. Equally, however, problems do exist, in some cases in extreme and even tragic form. Only detailed and formal analysis of the balance of problems and their relation to ageing would permit a definitive statement on needs and resources.

One of the resources that contributes to dealing with the problems of the individual with mental handicap whose families encounter difficulties is the *Olive Claydon Assessment Centre*. The focus of this centre, which was set up seven years ago, is to assess individuals with mental handicap with respect to suitability for various types of placement and to provide initial training in implementing the intended plan. Assessment is extended over a six to 18 month period for up to 25 non-residential clients, generally in the younger age range. The centre has also been involved in assessment of clients in the *Home Making Scheme* which we describe below.

When older families cannot cope with their son or daughter with mental handicap, assessment of the individual and the resources required to maintain them is undertaken. Doris, a woman in her earlier fifties, could not be maintained in the home by her father when her mother became hospitalised. Following assessment at the Centre, she moved to a hostel for preparation for a return to her father with adequate input from a community nurse. In this and in other instances the emphasis is on assessment of both the older individual and the resources required to maintain the person in the most independent and ordinary life possible. For this reason staff of the Centre work closely with Social Work, Psychological and Nursing staff from Core Team Two. Within this arrangement the main input comes from the psychologists while Brenda Lees (Social Worker) liaises between the assessment centre and those involved in the next environment to which the person moves.

Core Team Three deals with adults with mental handicap living independently or in hostels. Their clients live predominantly in the Borough, though some live elsewhere, while some of these are in long stay hospitals. The Social Work component of this team consists of Martin Haigh (Social Worker) and Sue Griffiths

(Rehabilitation Officer). The Social Work component of Core Team Three does not deal with residents of Calderstones Hospital who are the responsibility of the *Home Making Team*.

Discussions regarding placement in the community follow yearly meetings of the multidisciplinary Core team arranged by the Hostel or ATC. These can involve Social Workers, Psychologists, Nurses and peripatetic home-helpers. At such meetings a decision is taken regarding eventual community placement, dependent upon the client's own willingness and how realistic such placement is. Sue Griffiths and community nurses subsequently work with the selected client in his/her hostel until the necessary skills have been acquired. The hope that her support after the move could be reduced has not proved the case, sustained involvement being required to avoid the client getting into difficulties with everyday living. It was felt that there was a lack of adequate community support staff and that this led to the requirement that those living independently needed a high level of living skills. Transfer to the community would be facilitated if more staff were available.

In the judgement of this team, age is not seen as a potential barrier to community resettlement. They had been associated with relocation of at least four clients around pensionable age, 57, 64, 64 and 66 years. All moved to warden-controlled accommodation of the kind used by frail but not mentally handicapped elderly people. Two other individuals had followed this route prior to Sue Griffith's appointment. For younger people, it was a problem to become involved in the community given lack of employment opportunities and the often inappropriate nature of Adult Training Centre activities. More involvement in Further Education Colleges and other forms of education were deemed desirable. In some instances voluntary work was suggested, e.g. as in the case of a client who works in a children's nursery. In contrast, the feeling was that it was easier for older people to live a constructive life through retirement activities. It should be added, however, that others in Oldham with whom we discussed this possibility felt that lack of money severely curtailed such opportunities during retirement.

The picture presented by the social workers in

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Core Team Three is markedly different from that of Team Two. No specific problems related to ageing were commented on and the process of relocation out of hostels was influenced primarily by competence not age. There is, then, a paradox. The more apparently normalised life of older people with mental handicap, often maintained by their families in the community without services, presents a greater problem to social services when age-related factors come into play, than is the case for those in the non-normalised environment of the hostels. This picture is confirmed if we consider staff views in the three Oldham hostels to which we turn in section 4.4.

4.3.2 Psychological Input.

The psychological service consists of three full time clinical psychologists under the immediate direction of Maggie Gibb. Their broad aim is, of course, consistent with the wider CMHT aims, and the NWRHA Model District plan, i.e. to promote independent living in the community and prevent institutionalisation. At a more detailed level support is given to families, and both support and training to direct care staff and other professionals. The psychologists, too, contribute to the planning and development of services and the creation of appropriate environments for people with mental handicap.

With respect to adult services, each of the two core teams described above has a psychologist working alongside Social Workers and Community Nurses. At weekly meetings of the Teams, the psychologist takes on the role of key worker for some individual clients and becomes jointly involved with other key workers when this is requested. The psychologist acts as adviser in programme planning and in the development of services when these are found to be deficient.

With respect to the facilities in Oldham described later in this chapter, the psychologists have a number of functions. With respect to Adult Training Centres, they act as key workers for some individuals and advise staff on the development of suitable programmes. They also arrange informal discussion groups with ATC staff on general issues such as leisure, self-advocacy and

normalisation. In addition specific training courses may be put on in ATCs as well as other centres, e.g. the Olive Claydon Assessment Centre. Similar input to the three hostels in Oldham is provided by the psychologists, as well as to the *Home Making Scheme*. (This input is described when we consider that scheme.)

The roles and activities described above are concerned with all adults in the Borough, of course. With respect to ageing and elderly people with mental handicap, the psychologists' role is again to facilitate independent living, but also to enable such people to cope with important transitions in their life. Special interest has been shown in evolving a pre-retirement course, "The Step Forward Group", which we describe more fully below (4.5). Similarly, the issue of bereavement becomes a key issue as the parents and relatives of the person with mental handicap themselves age and die. Together with a nurse or social worker, the psychologist will give support in the home of both a practical and emotional kind.

4.3.3 Community Mental Handicap Nursing Input.

Community Mental Handicap Nurses are part of the Core Teams. Three are attached to each of the three Core Teams, and three more are responsible for resettlement of those returning from long-stay hospitals. Overall responsibility for this group rests with the Director of Community Nursing, Dorothy Simpson, while David Brunskill is Senior Clinical Nurse. Each team of three nurses deals with approximately 25 clients. As described by David Brunskill and Claire Gormanly (of Core Team Three), the role of the Community Nurse can be partially distinguished from that of the social worker by the intensive focus on the client rather than the wider pattern of relations between client, family, friends and services. The nurse spends more time living and working along side the clients in their homes, hostels or ATC/SECs. At a more specific level, behavioural assessments of strengths and weaknesses are made and goal plans developed. Where appropriate, these are directed to facilitating independent living with the CMHN progressively reducing his or her support.

With respect to community nursing, there has been

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a growing awareness of the needs of elderly clients. In particular, specialisation has developed in relation to the needs of elderly parents of adults with mental handicap. It was emphasised that there is a need to "get the ball rolling" long before the parents can no longer cope. Here again, joint input by community nurse and social worker is called for with the former giving the intensive programmed input. Issues of bereavement and separation can also demand the professional attention of the nurses in the home.

Where a community nurse encounters problems of dementia in older clients, the preferred treatment will be through the GP and local psychiatric services. David Brunskill emphasised the need for changes in local services to cope with these problems where experience with this client group may be lacking. Failure here can still lead back to referrals to long stay hospitals. One important development in this respect is the formation of a forum between psychiatric staff and nurses under the auspices of the Mental Illness Joint Care Planning Team which should have special relevance to older people with mental handicap.

In many respects this role is seen not as a *nursing* role. Specific medical problems of clients living with their families will be dealt with by the Health Visitor who works along side the three Teams or the District Nurse, and ultimately through the General Practitioner and other generic medical services. Therefore, the CMHNs work in close collaboration with Shirley King (Liaison Health Visitor) who, though based in Core Team 1, also works with adults. Her role is essentially to identify resources in the community for other members of Core Team Three, notably with respect to dentistry, chiropody, dietary expertise, medical services, and for younger people, family planning. Her involvement with clients is less than for the CMHT members though this becomes more intense when elderly people are considered. She has been involved in the pre-retirement groups noted above and described in 4.5 below.

Collaboration is, of course, essential with respect to other Core Team members. It is felt that there are strong similarities between the Nurse's role and that of the Social Worker, despite the somewhat differing focus noted above. With respect to their role in assessment,

the psychologist, Sally Cheseldine, is involved from the outset. Joint visits are made by two people, who may be nurses, psychologists or social workers.

4.4 Older People in Hostels

There are at present three hostels in Oldham, with the following distribution of people over 50 years of age:

Table 1.2:

<u>AGE BAND:</u>	50-59	60-69	70+
<u>LOCATION:</u>			
Wellington Lodge	5	10	1
Nuffield House	6	3	0
Willow House	8	5	0

From the point of view of our own exercise, Wellington Lodge is of special interest. This is a large Victorian house still bearing many of the features of its earlier life as a private home. As the Officer-in-Charge, Jill Milne, told us, until five years ago it provided for ambulant elderly people, into which group, three, new, older residents (ages 59, 63 and 70) with mental handicap were introduced. For these people the effect of integration was not beneficial. They began to display the withdrawn behaviour of the existing residents. A decision was taken to move the original residents to a new home and to make Wellington Lodge a home exclusively for older people with mental handicap. This transition took place in 1981, the original three responding positively to the introduction of their mentally handicapped peers with great pride in their own ability to "know the ropes". These transfers came from the other two hostels in Oldham, from the District Hospital and from a hospital for people with epilepsy in Lancashire (now closed).

Referrals come through the CMHT as well as from hostels and hospitals throughout the Borough. The

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Officer-in-Charge invites prospective residents to visit the Lodge and have tea or to stay for a week or weekend. Ample time is given to discuss whether they wish to come on a permanent basis. The residents' ages are 40+ (1), 50+ (5), 60+ (10) and 70+ (1). The nature of the house is such that it is not possible to deal with people with severe physical handicaps and potential residents with such problems would be located elsewhere.

The backgrounds and personalities of these residents were diverse. Arnie, aged 57, has spent 24 years living in a locked ward at Oldham and District Hospital. On arrival at Wellington Lodge he had 'borrowed' clothes from the other residents' lockers, so used was he to communal clothing. Bedrooms remained 'wards' for some time. However, despite a past history of violence he had settled well into the Lodge. Terry (aged 62) came from Willow House. Until Christmas 1984 he had worked in a local mill as a labourer, then having to take voluntary redundancy. Ernest (aged 62) had lived with his sister who died in an accident and had moved via another hostel to Wellington Lodge. Henry (aged 58) had not been to the SSD when he lived in the community with his sister and brother-in-law prior to moving to Wellington Lodge 12 months ago. These individuals reflect the diversity of backgrounds of residents, none of which have presented any long term bar to assimilation in the Lodge. Though some residents have come from their families and the families of many of the others live in the area, contact is slight. In all instances residents' parents are dead, and in all only four receive visits from their relatives.

Residents share eight bedrooms, one of which is single, four doubles and one with three-person occupancy. The sex of a new admission is therefore taken into account, though opposite sex sharing is a possibility (of which no residents are availing themselves at present). Two residents (ages 67 and 65) at present wish to marry. Counselling is being undertaken, but Jill Milne is emphatic that should the couple marry it will not be publicised as some out-of-the-way event.

Assessment of adaptive behaviour is undertaken employing the standard assessment procedures used in other hostels. This permits continuity of assessment when transfers are made. Areas of special concern are