Older People with Learning Disabilities: A review of the literature on residential services and family caregiving

James Hogg & Loretto Lambe
White Top Research Unit
University of Dundee

1998
Acknowledgements

The authors wish to express special appreciation to Professor Gordon Grant (University of Sheffield) for his careful reading of Section 4 of this review and the detailed comments he provided. Professor Eric Emerson (University of Manchester) has responded to many requests for publications and original data which have proved invaluable. Unpublished data from the Leicestershire Learning Disability Register has been provided by Dr Cath McGrother, Director of the Learning Disability Register, in order to present more fully the data related to family caregiving in Leicestershire. The authors wish to express their gratitude to Dr McGrother for her rapid and full support for this work. The analyses of these data that are presented here complement those published by Dr McGrother and her colleagues. However, the extrapolations from these data go beyond the use to which they have put their findings and are entirely the responsibility of the present authors. We also wish to thank especially Mrs Lynne Keen for the detailed work entailed in bringing together the extensive bibliography that underpins this review.

This working paper prepared with a grant from the Foundation for People with Learning Disabilities to support the Growing Older with Learning Disabilities (GOLD) Programme

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation.

7th Floor, 83 Victoria Street
London SW1H 0HW
Tel: 020 7802 0300
Fax: 020 7802 0301
Website: www.learningdisabilities.org.uk
Email: fpld@fpld.org.uk
## Contents

1. SUMMARY 4

2. BACKGROUND 6

3. REVIEWING EXPECTATIONS AND OPPORTUNITIES 9
   - 3.1 Ageing and personal growth (development and opportunities) 11
   - 3.2 Physical and mental healthcare in the later years (including dementia care) 13
   - 3.3 Ageing and individuality 20
   - 3.4 Choosing a place to live: models and processes 22
   - 3.5 Friendships and relationships 33
   - 3.6 Participation and decision making (including advocacy) 34
   - 3.7 Implications for staff training 38
   - 3.8 Principal research findings and their implications for future service development 39

4. CAREGIVING IN THE FAMILY HOME 41
   - 4.1 Demographic aspects 41
   - 4.2 Motivation, satisfaction and consequences 43
   - 4.3 Reciprocity and perspectives on adults who lives at home 48
   - 4.4 Help and hindrance from service providers 52
   - 4.5 Training and informational implications 55
   - 4.6 Principal research findings on family carers and implications for future support 56

5. CONCLUDING COMMENT 60

6. REFERENCES 61

7. CONTACTS 71

APPENDIX 1 GENERAL TRENDS IN RESIDENTIAL PROVISION 72

APPENDIX 2 RESIDENTIAL PROVISONAL: CONTINUING CARE AND CONSTRAINTS 80
1. Summary

Research into the lives of older people with learning disabilities (60 years and over) and family caregivers (again 60 years and over) is reported within the framework of the Mental Health Foundation’s review *Building Expectations: Opportunities and services for people with a Learning Disability* (Mental Health Foundation 1996). The focus of the review is specifically the residential circumstances of older people whether provided in a service setting or by family carers. Demographic research shows that the increased life expectancy arising from improvements in health and social provision that have benefited the wider population have also led to increased longevity in people with learning disabilities. For half of this population life expectation will be as for the general population, though those with Down’s syndrome and with profound and multiple learning disabilities do have reduced longevity. With the exception of people with Down’s syndrome, those living into later life typically have good health, and as a result of differential mortality in the population of people with learning disabilities, they are on average more able than the general population of adults with learning disabilities. Although some decline in abilities may be manifest in their 60s, this does not become significant until they are in the 70s. However, people with Down’s syndrome show earlier decline, premature ageing, and are particularly susceptible to Alzheimer dementia and a range of chronic medical conditions.

Though the prevalence of people with learning disabilities is increasing, over the next 20 years this is a gradual process, and within any single local authority or health board region increase in prevalence will tend to be small. There is no ‘grey wave’ of older people with learning disabilities on the horizon who will imminently swamp service providers. In approximately 25 years there will be a more significant increase among the over 60s as the baby boom generation comes of age.

Within the population of older people with learning disabilities the issue of gender has typically been ignored. The special healthcare needs of women have not been addressed, and advice for family carers on their daughter’s healthcare needs is lacking. Within the populations considered the number of older individuals and family carers from ethnic minorities is relatively small. Again, these populations will continue to increase and fuller study of their needs and cultural values will enhance good practice in service provision.

With respect to some of the key themes of *Building Expectations*, it is important not to identify older people with learning disabilities as a distinct well-defined population uniquely different from the population of adults with learning disabilities or indeed the wider population of older people generally. Indeed, the intense interest in them over the past 10 years is as much a reflection of the fact that they remain in segregated services, though now typically in community settings, as the outcome of any particular set of characteristics they possess. Thus, the importance of acknowledging their individuality, of encouraging choice and autonomy, are no more or less important than to their under 60 years peers.

Similarly, there is no evidence to suggests that age presents a barrier to their living in the community in similar settings to other adults with learning disabilities. They enjoy the advantages and disadvantages of all the most prevalent models of community living, whether staffed group houses, supported living or adult placement. The review argues against the suggestion that we should be developing typologies of older people with learning disabilities and matching them to specific types of residential model. It is suggested that such a view is contrary to a needs-led approach and fails to acknowledge the continuity of the person’s life and aspirations as they get older. This last point is of
some significance given the enforced discontinuities in their residential histories. Where significant decline is evident, as in the case of the onset of dementia, then the development of appropriate support and design of living environments is called for rather than automatic transfer to congregate facilities. Indeed, there is no evidence to suggest that congregate care is of greater relevance to older people than it is to their younger peers, and the review supports the view that the move from institutional to community care is equally relevant to older people with learning disabilities as to younger. The on-going advocacy of village communities, which has included the view that they are particular relevant to older people, is therefore questioned. In the interests of comprehensiveness we also note the residential situation of people detained under the Mental Health Act in prison or secure settings, as well as evidence for some adults with learning disabilities being homeless.

It is suggested that any consideration of residential provision must view it as the basis of the person’s wider life in the community. The review noted that older people with learning disabilities, like their younger adult peers, have restricted informal networks of friends which rarely encompass people who are not family members, service staff or peers with learning disabilities. The central nature of input from family members even where the person is no longer living in the family home, is consistently reported. While living in small community settings is typically reported as enhancing domestic involvement and responsibility, access to the wider community tends to be restricted particular with respect to inclusive leisure opportunities. For the over 60s, employment opportunities are very poor, though variations between countries are reported. Integration into wider generic elderly services and the conditions surrounding this process are described with respect to both formal programmes and where this occurs as part of a ‘natural’ progression.

The importance of the above findings for staff training is considered and examples of staff training materials cited.

Non-normative family caregiving for adults with learning disabilities is described. Here family caregivers over 60 years of age make up over 40% of those caring for an adult with learning disabilities at home. During the past ten years there has been a growing emphasis in the research literature on the rewards and satisfactions of caregiving rather than an exclusive concern with stress and the burden of care. Influences on both satisfaction and stress have been studied in detail, with attention paid to the factors that influence maternal well-being and health. Reciprocity between caregiver and the adult with learning disabilities, as well as differences in their perspectives on the life of the latter, are considered. Central to any consideration of older caregivers is planning for the future or permanency planning. The general difficulty for caregivers to plan for a move from the family home is consistently reported. Factors influencing decision making are considered, and it is suggested that professional input should be based on a thorough understanding of the families’ aspirations and values. The point is made that any analogy between a transition from an institutional setting into the community and the transition form family home to independent living is totally spurious. With respect to the way in which service provision assists or detracts from family caregiving activities, the design of services from the perspective of caregivers is urged. Informational and training needs for both family caregivers and service staff are noted.

For each of the two principal areas considered, i.e. residential provision and a life in the community, and family caregiving, detailed suggestions regarding possible initiatives are made, together with criteria for assessing them which emphasise needs-led, inclusive approaches, with suitable monitoring and evaluation.

Throughout the report we cite recent national and international initiatives in the field of ageing and learning disabilities that demonstrate clear developments and innovations in our approach to making high quality provision.
2. Background

Throughout both the developed and developing worlds, improved health and social care have led to dramatic increases in the life expectancy of both men and women. In some western countries life expectancy has doubled during the 20th Century while those surviving to 65 years do so in better health than in the past (Kinsella & Gist, 1995).

The social and medical factors leading to this improvement in longevity have also dramatically increased the life-span of people with learning disabilities in both the United Kingdom and the United States (Hogg, Moss & Cooke, 1988; Seltzer, 1992). Increased longevity among people with learning disabilities is reported in other European countries including the Austria, Germany and Switzerland (Wieland, 1987), Denmark (Dupont, Vaeth & Videbech, 1987), France (Reboul et al., Undated), Netherlands (Maaskant, 1993), and Ireland (Mulcahy & Reynolds, 1984). Though people with profound and multiple learning disabilities (Eyman, Call & White, 1989), and to a lesser extent those with Down’s syndrome (Eyman, Call & White, 1991), tend to have a lower than average life expectancy, a half of all of people with learning disabilities can now expect to live for as long as the wider population.

The impact of increased longevity on the prevalence of people with learning disabilities will clearly make itself felt in local administrative areas and regions, and it is this consequence that has led to a growth of interest in the subject of ageing and learning disability. It is important, however, to emphasise that with respect to local responses to the general demographic trend, in the next 20 years we are not dealing numerically with large increases in numbers. This may be illustrated with respect to a recent study on the epidemiology of learning disabilities in a single English city. Parrott et al. (1997) report on the increases in life expectancy of people with learning disabilities in the City of Sheffield. They note, for example increases in the number of people over 50 years of 12% and over 80 years of 58% between 1980-87 and 1988-94. It is important, however, to put such figures in perspective with respect to the number of individuals living into the later years. (Original data provide by Professor Emerson to the authors and re-analysed by them.) The above percentage for the over 50s represents the addition of 64 people over a 18 year period (1980-1998), approximately 3.5 people per annum being added to the population. The much higher percentage for the over 80s results in the addition of 10 people over the same period. In both examples, however, that actual increase in numbers will be offset by the death of some of those who are already over 50 or 60 years during this period. If for the purpose of the present report we reconsider these analyses for the over-60s in the city, then the absolute number has fallen from 300 to 288 between 1980 and 1998, and the percentage of the total population of people with learning disabilities from 12.89% to 11.52%. Their prevalence (number per 1000 base population) has also fallen from 2.69/1000 to 2.44/100. Inspection of other local surveys show that this situation is typical. Evans et al. (1994) present age data in 1986 and 1990 in four Welsh districts. Here people between 45 and pensionable age remained static between the two dates, the number dropped by one from pensionable age to 75 years and there was one person over 75 years at both times.

Parrott et al also note increased prevalence of people with learning disabilities in the 25-40 year group, the “baby boom” generation born between 1955-1970, indicating that there will be a relatively greater increase in prevalence in the over-60s in 20 years and thereafter, as they reach this age in 20 to 30 years time.

The proportion of people with learning disabilities over the age of 60 years from ethnic minority groups is lower than at earlier ages (Emerson & Hatton, 1998), and there is only a small minority of people from ethnic minorities in the general population over the age of 65 years, i.e. 3.2% of the over 65s are from such backgrounds (OPCS 1993). Emerson &
Hatton (1998) report that in residential settings in England, Scotland and Wales only 2% are from ethnic minorities, with the proportions of the various ethnic groups lower than would be predicted from general population figures. However, there will be a growing number of people reaching and exceeding this age in future years. Parrott et al draw attention, for example, to the increased prevalence of severe learning disabilities among UK Asian communities. Again, the impact of this situation on prevalence in the over-60s will in the next two decades be very gradual. Nevertheless, the issue of ethnicity as it affects both the professional provision of services and our understanding of family caregiving will be an emerging one in the coming years.

The purpose of presenting these figures, however, is not to dispute that increased longevity will lead to a progressive increase in the coming years in the number of people who have learning disabilities over 60 years, but to note that while such an increase is to be expected, within a single locality it is gradual and does not involve dramatic surges in numbers that are inherently problematical. Taken with the data we review below on the abilities and health of older people with learning disabilities, we are not confronting a significant “problem” over and above the wider need to make an increasing number of residential places available to adults with learning disabilities in the coming years as predicted by Emerson et al., (1996) and Parrott et al., (1997).

The extent to which the impact of the increasing prevalence of older people with learning disabilities has made itself felt in the literature on this topic may be illustrated by the following. The first comprehensive review of ageing and learning disability undertaken in the UK, supported by the Rowntree Foundation, could find only 13 publications in the UK related to ageing and learning disability (Hogg, Moss & Cooke, 1988). In the ten years since that review was published, the literature on this subject has burgeoned and nationally there are in excess of 200 papers and books bearing directly on this subject. They cover social provision, leisure, healthcare - physical and mental - and issues related to family needs. Internationally, there has been a proportionate growth particularly with respect to studies and documents emanating from North America and Australasia, as well as from Europe, in particular the Netherlands. Most recently, it has proved possible to bring together a comprehensive account of what is required to ensure a positive future for older people with learning disabilities as illustrated in Initiative 1.

It is important to acknowledge at the outset that this intensive focus is essentially the product of the social conditions that surround people with learning disabilities, not simply the outcome of improved health and social care. Two aspects of these conditions need to be emphasised. First, services for people with learning disabilities remain inherently specialised and/or segregated from mainstream services. Thus, as the person with learning disabilities gets older, she or he typically does not naturally gravitate to services for older people, but remains the focus of “special” concern. They are not older people first, as the rhetoric of some service providers would have us believe, but people with learning disabilities first, who happen to be getting older (Hogg, 1997). With the option of a life in an institution disappearing, their enhanced community presence challenges service providers with respect to their social, residential and health needs, and they appear as a relatively self-contained and identifiable group segregated from, but living in, the wider community (Hogg, 1997). The putatively “problematical” nature of this “group” is exacerbated by the general view of older people as part of “the problem of an ageing population”. Statistics on older people as an increasing proportion of the total population are invariably metaphorically described in negative terms: “the rising grey tide”, “an increasing burden on our health services” etc. The imagery of older people is also frequently denigrating (Rodwell et al., 1992; McHugh, 1993). Here then, from society’s point of view, we have a group of people - old and with learning disability - who are problematical from both standpoints and visible in respect to both their disability and their age.
Initiative 1: ARC's Preparing for a Positive Future: Meeting the Age Related Needs of Older People with Learning Disabilities

This important publication provides the single most comprehensive practical guide to service development for older people with learning disabilities. It was commissioned by the Department of Health and is available from the Association for Residential Care (ARC). The development project considered the pros and cons of three models of service provision:

- adapting learning disability services to the needs of older people with learning disabilities
- developing specialist or discrete services for them
- including older people with learning disabilities in generic or mainstream services for elderly people.

All three models are judged to have their advantages and disadvantages (though Initiative 7 adopts a less positive view of the segregated/specialised options). However, it is argued, there is a need to set each model in the context of strategies to ensure an appropriate service. Good practice issues are considered in detail from the perspective of commissioner and purchasers of services on the one hand, and service providers on the other.

Among a number of individual case studies, two significant projects are reported:

- the work of a Joint Commissioning Team which led to the development of a range of options including expanded in-home support, inclusion in generic services for elderly people and funding of a community art programme
- the “Making Connections” Joint Training Project in the North East of England to increase the awareness of older people with learning disabilities, improve links to mainstream residential provision and to evaluate joint training between learning disability and elderly service sectors. Twenty seven organisations participated.

Section 4 of the report provides an extensive resource and information pack (pp. 105-210) which covers key pieces of the jigsaw that enables a positive lifestyle to be put together for older people with learning disabilities:

- what do I do during the day?
- getting older the impact of ageing
- death and dying
- where do I live? Enabling environments
- do people listen to me?
- who is supporting me? How do they support me?
- how do I feel? Health and well being
- remembering and relationships.

The report “Services for Older People with Learning Disabilities” Social Services Inspectorate, (1997) encapsulated the above arguments in two key paragraphs (p. 20, Paras. 4.5 & 4.6):

“Generalisations about ‘older people’ with learning disability may appear to contradict well established systems of service delivery which are based upon responses to individual need. For example, it might be argued that a well organised care management approach incorporating a systematic review procedure, will, inevitably, identify and address needs which are associated with age related changes in individual service users. The significance of the review is likely to increase as people with a learning disability become older. The
The introduction of a strategy which identifies ‘older people’ as a special group which has ‘typical’ needs, might undermine or distort the function of a needs-led service.

The way out of this dilemma is to recognise that, while individual differences and the provision of care to address individual needs is of utmost importance, the quality of service delivery can be enhanced by our understanding of the increasingly complex changes which occur as people grow older. The focus for strategic thinking should not be:

‘what are the services which will meet the needs of older people?’

but rather:

‘how are the needs of individuals likely to be affected by the physical, psychological and social changes which occur with increasing age?’

Their highly visible situation is accentuated by two further influences. First, only a minority will live in a way that is truly independent, i.e. requiring no support whatsoever to lead a life in the community. Second, many continue after the school years to live with families, an option that diminishes with the passing years. Linked to this point, we should note that broadly the same conditions apply to those leaving institutional or hostel settings, i.e. they rarely move back to their family home in the later years. If people with learning disabilities were fully included within society, neither the burgeoning literature referred to nor the emerging concerns noted would be such major issues. Both their special needs and their age-related needs would be met, or not, within the same framework in which we all get older.

In passing, one important point about the scope of this review needs to be made. From the point of view of the authors, arguments regarding the acceptability of large, congregate institutions should now be laid to rest. Emerson & Hatton (1994) and Emerson et al., (1996) extensive reviews of comparative studies of the quality of life of residents in long-stay hospitals and community settings, particularly staffed group houses, clearly signal the unacceptability of the former relative to the latter and we comment on these findings in considering staffed group houses below in Appendix 1.

The debate has now shifted, with no influential voices arguing for the traditional hospital model. Where congregate, isolated provision is advocated, it is village communities that are now being urged by relatives of hospital residents and some Health Board and Trust managers who see logistical and financial advantages to such a move. We also discuss philosophy and policies with respect to village communities in Appendix 1.

3. Reviewing expectations and opportunities

The present review takes as its starting point the Mental Health Foundations’ publication Building Expectations: Opportunities and services for people with a learning disability (Mental Health Foundation, 1996), approaching the subject of ageing and residential provision through this framework. In adopting this approach the intention is to acknowledge that where people live, and the conditions surrounding their lives, are crucial to a wide range of experiences and activities that affect their quality of life. To consider “residential settings” independently of, for example, opportunities for friendship or community participation would be to consider only part of the equation.

In undertaking such a review, however, there is a significant problem with respect to the scope of what should be included. It is questionable that there is any research that has been undertaken with adults with learning disabilities under 60 years that is totally irrelevant
to most of the over-60s, the lower age limit set for the present review. To cover in detail such relevant work would be beyond the scope of a review focusing on a particular age group, but it is important to bear this in mind. People with learning disabilities over the age of 60 years are as much a part of the adult population as their younger peers. Possibly as a consequence of this situation research which focuses on the impact of age within the wider adult framework remains relatively limited. When we consider residential issues specifically this is even more the case. Where age *per se* does have an inevitable impact on the living situation of the older person with learning disability, then clearer research questions have been formulated and more extensive work undertaken. The most notable example of this is the case of older caregivers (here taken as 60 years and over), usually parents, who continue looking after their daughter or son in the family home. This situation has generated a wide range of clearly defined questions and a substantial body of findings. The study of ageing with respect to a life in some form of residential provision is not, however, some kind of mirror image of family caregiving studies. It is not only that the questions to be asked in each domain differ in many ways, but that the relative conceptual coherence of the two areas is quite different. This is inevitably reflected in the way in which the present review is written and presented.

The relevance of the wider field of adult residential provision, as we have noted, is critical to older people with learning disabilities. However, this is presented in the review in Appendix 1 and can safely be ignored by those familiar with this area. No such separation is necessary for our consideration of older family caregivers. Here the non-normative, from a family development perspective, nature of their activities and the ways in which these activities have been studied permits a more fully integrated presentation.

The principal topics derived from “Building Expectations”, informed where relevant by key “overarching themes” from Chapter 9 of that report, appear in Figure 1 of this review. The information we present will be interpreted from the perspective of the aspirations set out in MHF’s report, i.e. how does available information help us to facilitate a fuller life for older people with learning disabilities which will increase opportunities for inclusion while at the same time ensuring their special needs are met. The topics noted have been reordered to permit essential background on ageing and learning disability to be considered prior to discussion of where and how people live. Sections 3.1 - 3.3 deal with the wider background to ageing as it bears on the question of residential provision, while 3.4 considers models of residential provision and their relevance to older people with learning disabilities. Sections 3.5 - 3.6 take two of the MHF topics, friendships and family, and participation and decision making, and consider them as integral aspects of the person’s life and inextricably bound up with where and she or he lives. We have considered the implications of our understanding of older people for staff training (Section 3.7). Conclusion regarding the review are summarised in Section 3.8, together with some indication of their implications for future service development. We have, however, not addressed technical issues related to finance and legal matters, dealt with in “Building Expectations”, which would require detailed treatment beyond the scope of this review if such consideration were to be helpful. In Section 4 caregiving by family members 60+ years is considered. In Section 5 we offer a brief perspective on the review.
Figure 1: “Building Expectations”: Principal areas of interest noted by the Mental Health Foundation (1996)

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<thead>
<tr>
<th>Principal topics in “Building Expectations”</th>
<th>Selected areas from “Building Expectations” Chapter 9 “overarching themes”</th>
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<tr>
<td>• Ageing and personal growth (Section 3.1)</td>
<td>Diversity and choice (opportunities and development)</td>
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<td>• Physical and mental healthcare in the later years (including dementia care) (Section 3.2)</td>
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<td>• Ageing and individuality (Section 3.3)</td>
<td>Staff training in learning disability and generic elderly services</td>
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<td>• Choosing a place to live: models and processes (Section 3.4)</td>
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<td>• Friendships and relationships (Section 3.5)</td>
<td>Ethnic minority dimensions</td>
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<td>• Participation and decision making: (including advocacy) (Section 3.6)</td>
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<td>• Financial and legal issue</td>
<td>Gender issues</td>
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<td>• Caregiving in the family (Section 4)</td>
<td>Family concerns</td>
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3.1 Ageing and personal growth (development and opportunities)

Two distinct trends need to be taken into account when we consider the development of older people with learning disabilities in later life. The first relates to the overall population of this group, relative to the population of people with learning disabilities earlier in their adult life. The second, is concerned with change within the surviving population of people in their later decades. However, superimposed on both these ways of viewing age-related change is the issue of whether the person has or does not have Down’s syndrome.

What should our expectations be as people with learning disabilities get older? Are we to anticipate an increasingly deteriorating group of people from 60+ years? On the contrary, cross-sectional studies show a progressive improvement in the average level of ability as cohorts of increasing age are compared. This is the case whether we consider people still living in institutional settings e.g. Silverstein (1979) or in the community, Moss, (1991). However, this improvement is in part the outcome of differential mortality, i.e. the tendency for less able people, particularly those with profound and multiple disabilities, to die earlier. It is the more able healthier people with learning disabilities who survive into their sixties and beyond, at which stage their life expectancy will be very close to that of the wider population. While with increasing age these people will be vulnerable to the sensory and physical impairments that affect the wider population, from the viewpoint of residential
provision, and indeed wider services, we must question in what sense the places in which they live need to be any more “special” than those of their older peers without learning disabilities. Where significant difficulties do arise, whether mental or physical, then clear account must be taken of these with respect to all relevant aspects of the person’s environment, locational, its physical design, management and staffing.

Moss (1991) has drawn attention to the consequences of less able and more vulnerable people dying at a younger age. What effect does this have on the relative abilities of older people with learning disabilities when compared with their middle-aged and younger peers? He concludes: “Generally, it was found that differential mortality leads to an older population in good health and with a high level of functional skills.” (Moss, 1991)p. 430. One consequence is that for the population of older people with learning disabilities, self-care continues to improve right up to the age of 60 years with only modest decline thereafter. Although for technical reasons Nihira’s, (1976) earlier study is not directly comparable to that of Moss, he too found improvement into late middle age with only limited decrements thereafter. This finding applied to personal self-sufficiency (self-help activities), community self-sufficiency (shopping, independent travel etc.) and personal-social responsibility (use of leisure time, socialisation etc.). One consequence of this state of affairs that would be predicted is that younger people with learning disabilities will perform some skills less well than their older peers, a prediction confirmed in work by Maaskant et al., (1995).

Moss, too, shows a dramatic decline in challenging behaviour throughout the life course, dropping to almost zero during the eighth decade. A similar picture emerges for “offending” behaviour for people with severe learning disabilities, though more able people tend to show a peak of offending at 50, the behaviour declining thereafter.

Clearly, however, though this population is functioning at such a high level in the later decades, some decline in abilities is perceptible even from Moss’ and Nihira’s cross-sectional data. The nature of this decline can be better explored through longitudinal investigations of the sort recently reported by Maaskant et al., (1996). Here care dependence and activities of daily living were assessed over a three year period in seven cohorts of which the adult groups ranged from 20-29 years through to 70+ years. Though confirming the picture presented by the cross-sectional studies, it was only in the 70+ years group that significant decline in independence and skills was found over the three year period, though a much lesser decline was noted between 60-69 years. The principal problem areas related to difficulties with bodily care, toilet use and (un)dressing. Problems with eating did not increase. These authors comment on how rapidly this occurred, and argue for the person’s entitlement to engage in chosen activities rather than developmental programmes that may maintain skill and reduce dependency, an important issues that merits fuller discussion.

The implications of the ageing process for residential provision for older people with learning disabilities without Down’s syndrome is clear. They will typically be a group who are relatively able and, for their age, in good health. Though showing some decline in their 70s, there is nothing to indicate that as a group they require special consideration with respect to where they live. Clearly declining abilities, health related problems and choice will determine how and where their specific needs are met - as is indeed the case for the rest of the older population.
For some people with Down’s syndrome, however, a different picture of ageing emerges. A useful starting point is to consider this group in the framework of the paper by Maaskant et al., (1996) reviewed above. They noted longitudinal change over a three year period in ability and dependency was principally detectable in people without Down’s syndrome over the age of 70 years. Such decline was recorded in people with Down’s syndrome over 40 years of age, as well as decline in eating abilities. In addition, the changes were more clearly marked in people with Down’s syndrome. Das & Mishra (1995) provide confirmatory information on the relative decline of people with Down’s syndrome to other people with learning disabilities peers employing a variety of neuropsychological tests. In a further study which employed detailed cognitive tests with adults with and without Down’s syndrome, Devenny et al., (1996) make a further important point. On the basis of their data they suggest that decline in the performance of people with Down’s syndrome with age is not the result of pathology related to the development of dementia, but in fact represents precocious but ‘normal’ ageing. Nevertheless, as Prasher & Chung, (1996) show, dementia and medical illness do predict decline in adaptive behaviour among people with Down’s syndrome.

3.2 Physical and mental healthcare in the later years (including dementia care)

Good physical and mental health for people with learning disabilities are as crucial to their enjoyment of an acceptable quality of life as to the rest of the population. In focusing on residential provision, the health of the person both in her or his home and involvement in the wider community will be a critical factor in determining overall well-being. This is acknowledged by government which developed from its Department of Health, (1992) initiative its subsequent “A Strategy for People with Learning Disabilities” (Department of Health, 1995). The World Health Organisation is also at present focusing on issues of health and social policy in this area, described more fully in Initiative 2. For people with learning disabilities information regarding their own healthcare and their responsibility for it is an important prerequisite to their full enjoyment of life at home and in the community. That this responsibility will have to be shared with those who support them - professionals and family members - will clearly be the case for many individuals. It is not relevant to our present purpose to review in detail the wide ranging literature on the health status of adults with learning disabilities, or the consequences for health of getting older. These two topics have recently been reviewed by Turner & Moss, (1996) and Moss, Lambe & Hogg, (1998). In considering their reviews, it is important to differentiate the health status of people without and with Down’s syndrome.
The World Health Organisation (WHO) has invited the Ageing and Intellectual Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) to develop a summative paper on the health needs of people with intellectual disabilities, together with recommendations for effective intervention to improve the health status of such older adults. Dr M. Janicki (Director of Ageing & Special Populations for the New York State, Office of Mental Retardation & Developmental Disabilities) is the principal investigator, together with two co-principal investigators, Dr. P. Davidson (Director, Strong Centre for Developmental Disabilities, University of Rochester, New York) and Dr. H.M. Evenhuis (Hooge Burch, Zwammerda, Netherlands).

Four Working Groups have been established concerned with Social Health & Policy, Physical Health & Impairment, Biobehavioural Issues and Women's Health.

**Social & Health Policy** - This topic area concerns the health status and age in adults in both developing and developed nations, particularly with a focus on longevity of adults with disability into old age across nations. Specific reviews concern morbidity and mortality of adults with intellectual and developmental disabilities, and health and disability policy structures, as well as recommendations for the establishment and maintenance of structures for advocacy, social and health organisations, and primary health systems to sustain, increase, and promote longevity and healthy ageing. A central emphasis of the review is the issues of health and social policy related to older people with learning disabilities in the developing world.

The final report from this group will be made available at the 10th International Roundtable on Ageing and Intellectual Disabilities, Geneva, Switzerland, April 20-23 1999, an event conducted under the International Year of Older Persons: *Towards a Society for all Ages*.

Fuller details on the project are available on the web site at: [www.thirdageinc.com/sirgaid](http://www.thirdageinc.com/sirgaid)

People with learning disabilities obviously develop illnesses in all the principal areas of concern in *Health of the Nation*, i.e. with respect to cardiovascular disease and stroke, cancer, mental illness, sexually transmitted disease and through accidents. With increased longevity, people with learning disabilities are more vulnerable to cardiovascular disease and poor attention to health resulting in obesity or misuse of alcohol can through increasing cholesterol levels and hypertension lead to such disease. It has been suggested that lifestyle opportunities provided by community living may increase such risks and that prevalence of cancer among people with learning disabilities is on the increase. A similar situation has been suggested with respect to cancer and smoking, though the evidence on whether people with learning disabilities smoke more than their peers without learning disabilities is equivocal.

The third key area in *Health of the Nation* is mental illness. Turner & Moss (1996) report that the pattern of such illness among people with learning disabilities differs somewhat from the general population. In the latter, substance abuse disorders, neuroses and affective disorders including depression are relatively greater than in the population of adults with learning disabilities. Among those with learning disabilities, higher rates of psychosis, autism and behavioural disorders than in the general population have been reported. However, the higher prevalence of behavioural difficulties in people with learning disabilities is equivocal.
disabilities may inflate the figure for psychosis, and in reality this may be no higher than for the wider population.

A key area of concern with respect to ageing generally is the development of dementia, specifically Alzheimer dementia and vascular dementia. In people with learning disabilities without Down’s syndrome, dementia will typically occur in the later years of life with a similar prevalence to the wider population, i.e. 5% of those over 65 years and 20% of those over 80 years (HMSO, 1992). It is important to note that in any given population of older people with learning disabilities the majority with dementia will not have Down’s syndrome and will tend to be well advanced in years. The situation with respect to dementia in people with Down’s syndrome is radically different as we shall see below. Patel, Goldberg & Moss (1993) report that dementia sufferers with learning disabilities also have poorer physical health particularly with respect to their central nervous system and gastro-intestinal functioning. The development of dementia is also accompanied by a loss of self-help and community skills. They conclude: “...that the level of these people’s needs represent a major use of social services resources” (Turner & Moss, 1996) p.441.

Overall, with respect to mental health Turner & Moss see difficulties compounding already limited adaptive skills and being predictive of a move to some form of congregate residential care. With respect to the present report, it is clear that if older people with mental illness, including dementia, are to lead their lives in settings based on the same principle as the wider population, attention needs to be given to the kind of support offered in residential settings and the staff training required to achieve this. It is important to emphasise that in the wider fields of mental health and dementia there are now approaches which emphasise a positive and non-fatalistic attitude to such difficulties on which providers in learning disability services should draw e.g. Gruetzner, (1992).

With respect to services for people with learning disabilities and dementia, including residential provision, there is a marked absence of systematic information. From recent unpublished work undertaken in the east of Scotland by the authors it is clear that both family caregiving and maintaining the person in staffed group houses are vulnerable to break down when the person reaches an advanced stage of dementia. It is equally apparent that there is little systematic input from the major voluntary sector organisations concerned with dementia (though for an example of effective collaboration see Lambe & Hogg, (1995)), and there is also an absence of staff training. Transfer to a nursing home may be an outcome of this situation. Similarly, specific support to permit family carers to continue is typically absent, as is any attempt to consult the individual with dementia. This last short coming finds an important antidote in recent work reported in Initiative 3.
Initiative 3: The Voices and Choices of People with Dual Impairment

Dr Kirsten Stalker and Mr Paul Duckett of the Social Work Research Centre at Stirling University and Dr Murna Downs of the Centre for Social Research and Dementia (Stirling University) are at present completing the Voices and Choices of People with Dual Impairment project. The principal aims of the study have been to explore how far and in what ways people with learning disabilities and dementia are involved in making choices about their lives, and what limits or encourages their opportunity to make such choices. The work is funded by the Joseph Rowntree Foundation.

Interviews and guided conversation have been conducted with three principal groups of people:

- people undergoing assessment or already diagnosed as having dementia
- their family carers
- the professional most closely involved with the person.

The need to get to know thoroughly the person and to give them the fullest opportunity to express themselves is clearly reflected in the care with which interviews have been conducted, and the fact that each person has been visited between four and ten times.

The inclusion of people from a wide range of settings has been made possible by a consultant psychiatrist and a voluntary organisation facilitating access. With the appropriate permission, interviews have been tape recorded and transcribed, and provide a rich source of qualitative data for future analysis.

Particular care has been taken to obtain informed consent, and though it was not considered possible to involve the interviewees in designing the study, a reference group of older people with learning disabilities have commented on specific aspects of the design from their own perspective.

The study has shown it is feasible to include in research many people with learning disabilities who are thought to have, or have been diagnosed as having, dementia. The importance of taking this insight into services for people with learning disabilities and dementia cannot be over emphasised.

Analysis is now taking place and several products are anticipated:

- a report on the work
- a booklet dealing with subject of dementia for people with learning disabilities
- a checklist to guide good practice
- papers for both professional and academic journals

The fourth area of concern in Health of the Nation is sexual health, and specifically the reduction of the prevalence of HIV. In reviewing the very limited literature Turner and Moss report an absence of information on prevalence of sexually transmitted diseases in people with learning disabilities, but evidence that practices related to safe sex are typically not being adopted by them, as well as their vulnerability to sexual abuse. Again, changing lifestyles - including where a person lives, have important implications for sexual lifestyle, sexual health and concurrent risks (Cambridge, 1994) and in considering older people, these issues remain as pertinent to those who give them support. It is important not to assume that people with learning disabilities over the age of 60 are in some way “past sex”. Their sexuality and its implications should be fully acknowledged.
The issue of accidents, too, figures among Health of the Nations five priorities. Turner & Moss report that a variety of factors place people with learning disabilities more at risk for accidents than the wider population. Department of Health (1995) noted the need for carers and service providers to address safety issues. Since some of the areas leading to vulnerability noted by Turner & Moss are specifically associated with ageing, e.g. dementia, sensory decline and movement disorders, this is an issue of added importance that should guide the way in which residential provision for people with learning disabilities over the age of 60 is designed. In assessing a person’s needs, it is clear that the issue of risk and how the actions of staff as well as environmental design may reduce the probability of accidents must be addressed explicitly.

Though we have addressed the issue of health needs in people with learning disabilities without Down’s syndrome from the perspective of Health of the Nation there is a wide range of conditions prevalent in the older population that have an important bearing on both the health services they require and the wider social support that is entailed. Brock, Guralnik & Brody (1990) cite the National Centre for Health Statistics noting the ten most prevalent conditions, which include hypertension and heart disease noted above. The other eight are arthritis, orthopaedic impairment, hearing impairment, tinnitus, visual impairment, cataracts, chronic sinusitis and diabetes. In some conditions prevalence is higher in the older population of people with learning disabilities than the general population, notably visual impairment (Evenhuis, 1995a), though this is the case to a lesser extent for hearing impairment (Evenhuis, 1995b).

In many respects the picture of the person with learning disabilities who is 60 plus years is one of ageing in much the same way as the rest of the population, though this does not hold for people with Down’s syndrome. We have already reported the work of Maaskant et al., (1996) with respect to the very early decline in their abilities in the 40s relative to their peers without the syndrome. We have also noted the view that the ageing process is essentially normal but occurs very prematurely. Certain linkages between Down's syndrome and disease are now well established, notably congenital heart problems, death from leukaemia, visual and hearing problems, and deterioration of hearing at an earlier age than in both the general population and among people with learning disabilities. Hypothyroidism and hyperthyroidism occur with greater prevalence than in the general population. Perhaps attracting most attention has been the link between pre-senile dementia and Down’s syndrome. The neuropathological evidence of dementia is probably present in all people with Down’s syndrome from 30 years onwards, though it is important to emphasise that not all will go on acquire the disease clinically and behaviourally. As noted above, figures on prevalence vary across studies (Zigman et al., 1995) though Turner & Moss, (1996) suggest a working figure of 40% of people with Down’s syndrome having the condition in their 50s. Epilepsy, already higher among people with Down’s syndrome than the general population, will also increase in incidence.

It is important to emphasise that on the whole the people with whom we are concerned who do not have Down’s syndrome represent a relatively healthy population, subject broadly to similar health problems in later life as the rest of us. Clearly health-related problems related to premature ageing present themselves in a different way with respect to people with Down’s syndrome who from middle age onwards represent a medically very vulnerable group. Within the framework of residential services or supporting a person in her or his own home, carers will wish to ensure that appropriate healthcare is offered in response to illness by the GP and Primary Healthcare Team, as well as generic specialist services. In some situations specialist input by Community Learning Disability Teams may be called for. In addition, the opportunity should be offered to improve self-care through education, though in line with the entitlement to personal choice, wrong decisions regarding smoking, alcohol, diet and sexuality will be made. The issue of monitoring the health of a person with learning disabilities must also be viewed in the same framework, i.e. as a matter of choice where this
is possible and with minimal intrusiveness where this is not the case but is viewed as being in the person’s best interest.

Significant decline in health, particularly mental health, can lead to congregate residential provision. It is important that the general philosophy to be discussed below of ensuring that needs determine the appropriate provision should inform residential decisions just as they do for the healthier individual.

Moss & Patel (1997) investigated the impact of dementia on people with learning disabilities over 50 years old. They found that a diagnosis of dementia was related to increased disability and health problems, reduced enjoyment of life, increased irritability and proneness to violence. With respect to service provision they note two alternative approaches, first, relocation of the person to a specialist dementia facility, second, retention in a learning disability setting. Their own results indicate that the pattern of cognitive and non-cognitive change is similar to that in the general population of people with dementia: a potential argument for them being served by mainline dementia services. However, Moss and Patel suggest that since their needs are no more complex than other people who will be accessing learning disability services, continuity of service and maintaining contact with friends could be overriding factors.

While this view merits consideration, an essential adjunct to it should be that learning disability staff should be trained in approaches from the wider field of dementia care in how to support the person with dementia. The care management approach to dementia has been urged and described by Janicki et al., (1995) in international guidelines of which all service providers should be aware.

Detailed consideration regarding the design of residential services for people with learning disabilities and dementia has been provided by Koenig, (1995b) with respect to physical, emotional, motivational, leisure and organisational aspects. (See Initiative 4.) He also considers a wide range of approaches and alternative therapies to assist dementia sufferers including reality orientation, validation therapy, resolution therapy, reminiscence, touch therapies and music. It should be added that while Koenig draws on best practice in the field of dementia, research into the effectiveness of both service design and interventions for people with learning disabilities with dementia is generally lacking.
**Initiative 4: Minda Incorporated and dementia care**

One of the most extensive programmes of dementia care for people with learning disabilities has been documented by Minda Incorporated in Brighton South Australia. Here, against a thorough background of a literature review on ageing and a survey of carers (Koenig 1995a), best practice is documented in Koenig (1995b) and approaches to assessment are dealt with in Koenig (1995c).

Best practice is described and is dealt with in relation to:

- health aspects (self-care, continence, physical problems and medication)
- physical decline (early dementia, advanced dementia, movement and sensory loss, awareness)
- behavioural change (mood swings and depression, confusion, aggression, wandering, sleep)
- social aspects (self esteem, choice, self confidence, dignity, communication, relationships, identity)
- communication (receptive, expressive, interdependence, touch)
- environment (physical, emotional, motivational, recreation and routine)
- counselling strategies (reality orientation, validation, therapy, resolution therapy, reminiscence, music)

The authors note that there is no one approach to dementia care, but emphasise the following principles:

- a clear statement of the **rationale** of the care program
- **documentation** of care practices
- findings of any **formal evaluations** that have been undertaken
- **peer recognition** in the field
- care giving **expertise** in care and training
- delivery of **cost effective care**
- **achievement of relevant service standards** (Koenig 1995b, p. 4)

Central to the Minda documents is the issue of on-going assessment by practitioners and carers (Koenig 1995c). While the role of medical diagnosis is seen as crucial, the part that can be played by those in immediate contact with the person with learning disability is seen of great importance. The **Broad Screen Checklist of Observed Changes for Adults with an Intellectual Disability** was developed and designed to indicate a decline in a broad range of observable behavioural signs within specified time frames and which may be indicative of the onset of dementia. The development of the checklist bears on the important issue of placing those in closest contact with the person with learning disability in a position both to observe and act upon on-going assessment, seeking advice where necessary.

“Building Expectations” rightly signals gender and ageing as an overarching issue with respect to the lives of older women with learning disabilities. With respect to healthcare this is a major concern to mothers for their daughters. Knowledge of gender and should also inform professional practice. It is, however, a neglected issue that has only recently begun to receive attention in the general field of learning disability, let alone with regard to the subject of ageing. For this reason the World Health Organisation has commissioned the **International Special Interest Group on Ageing and Intellectual Disability** to undertake a review of the issues involved and to develop guidelines with respect to policy. This information is due for presentation to WHO in April 1999 and can be made available to the
Foundation for People with Learning Disabilities together with the findings of three other working groups concerned with other aspects of ageing and learning disability (See Initiative 5).

**Initiative 5: Women’s Health: A World Perspective**

The World Health Organisation (WHO) has invited the Ageing and Intellectual Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) to develop a summative paper on the health needs of people with intellectual disabilities, together with recommendations for effective intervention to improve the health status of such older adults. Dr M. Janicki (Director of Ageing & Special Populations for the New York State, Office of Mental Retardation & Developmental Disabilities) is the principal investigator, together with two co-principal investigators, Dr. P. Davidson (Director, Strong Centre for Developmental Disabilities, University of Rochester, New York) and Dr. H.M. Evenhuis (Hooge Burch, Zwammerda, Netherlands).

Four Working Groups have been established concerned with Women’s Health, Social Health & Policy, and Physical Health & Impairment, Biobehavioural Issues.

**Women’s Health:**

The proposed paper will deal with the global perspective on women’s health, and cover issues related to treatment, training of professionals, health promotion, and personal and practical support. Literature reviews on physical health and ageing including menstruation, sexual health, vulnerability and protection, fertility and contraception, therapeutic amenorrhea, menopause, osteoporosis, breast and cervical cancer, heart disease, and dementia are all considered. Policy and service recommendations, together with research issues are dealt with.

The final report from this group will be made available at the 10th International Roundtable on Ageing and Intellectual Disabilities, Geneva, Switzerland, April 20-23 1999, an event conducted under the International Year of Older Persons: Towards a Society for all Ages. Fuller Details on the project are available on the web site at: [www.thirdageinc.com/sirgaids](http://www.thirdageinc.com/sirgaids)

3.3 Ageing and individuality

We argued at the outset that in focusing our attention on “older people with learning disabilities” we were in danger of developing yet another category of people with special needs for whom special provision was judged to be required. Whatever the historical conditions that led to this state of affairs (i.e. continued segregation of adults with learning disabilities from the mainstreams of community life, later life being generally viewed as a “problem” for society), there will be few people working in the field of learning disability who do not, at worst, pay lip service to treating individuals as such and respecting the choices that arise from this individuality. Though the present review is defined in terms of the lower chronological age of older people with learning disabilities (60 years), and the studies noted above consider chronological ageing, in the wider field of ageing studies there has been a growing acknowledgement that getting older in the sense of increasing years is not the only way in which ageing can be viewed. Such chronological ageing may be distinguished from biological ageing and social ageing. Biological ageing describes the inevitable physiological changes that occur with the passing years in all living organisms, the mechanisms underlying which are now the subject of intensive investigation. The rate and progression of such ageing, however, varies from individual to individual, with both genetic and environmental influences determining its course. Social ageing may also be viewed as the
outcome of physiological change and environmental influences, but reflects particularly the ever changing ways in which society views getting older. Blaikie (1992) nicely captures this point in the following comment:

“The ‘chronological bonds’ which once bound people to age-appropriate behaviours are being loosened. In modern times, older citizens are encouraged not just to dress young, but to exercise, have sex and socialise in ways often indistinguishable from their children’s generation.’ (Blaikie 1992) (p.3).

While the impetus to a special concern with people with learning disabilities has undoubtedly come from the obvious evidence of increased *chronological age* in this population, underpinned by the evident improvement in biological ageing on which this is dependent, it is questionable whether those of us working in this field have adequately reflected on the idea of the loosening of ‘chronological bonds’. There is a sense in which a pervasive image of older people a quarter or more of a century earlier informs our view of older age in the population of people with learning disabilities. At the present time even 60 years of age is now well before the end of the active life of a person living in the late 1990s. Those working in the field of learning disability, often with little or no contact with services for older people generally, do not appear to have reflected on a contemporary view of ageing that has become widely accepted in society, a view which affirms that personal development does continue well into later life.

In Laslett's, (1989) important book “A Fresh Map of Life”, he proposes four *Ages*: the First Age of dependency in which socialisation and education are predominant experiences; the Second Age of maturity, independence, familial and social responsibility; the Third Age of personal achievement; and the Fourth Age of decline leading eventually to death. Laslett emphasises that this progression is not uniquely linked to chronological, biological or social age. While Third Age opportunities may become available when a person retires, retirement may come as early as 50, 55 or 60 years of age, or economic inactivity may occur earlier through redundancy or long-term unemployment. Similarly, a person retiring at the conventional age of 65 years may fail to engage in Third Age opportunities, and may through choice or otherwise not take advantage of opportunities that may lead to increased self-fulfilment.

That Third Age opportunities exist in later life for people with learning disabilities cannot be disputed e.g. Atkinson & Williams, (1990). However, while the First Age is clearly defined for them through infancy and schooling, the Second Age as described above, is not typically available to most people with learning disabilities. Employment opportunities remain poor, and marriage, children and all that goes with a family are also rarely enjoyed. While people with learning disabilities, their families and those who provide services will continue to aspire to as ordinary a life as possible, attention has increasingly been directed to encouraging personal growth and self-realisation in the post-school years and in middle age in a way which is directly compatible with Laslett’s view of Third Age development. That this should continue post-60 years is not in dispute, and the role this view will play in shaping where a person lives and the nature of their accommodation - psychologically, socially and materially - requires special attention.

These opportunities point towards making available a residential context, the ethos of which is based around personal choices made by the individual her or himself. Such choice will initially be exercised in relation to that context, i.e. the neighbourhood where the person’s home is, its physical characteristics, with whom she or he shares that home - if anyone - and the activities enjoyed both at home and in the wider community. Whatever the administrative and financial constraints that at present exist with respect to such decision making, it is the expression of a person’s individuality through such choice that is widely agreed to be the basis of the development of residential provision.
3.4 Choosing a place to live: models and processes

3.4.1 Choice and consultation

Throughout community care plans and evolving models of service delivery, personal choice and consultation with individuals are invoked as central to planning and providing. The immediate practicalities of changing and/or improving the residential situation of people with learning disabilities can be at odds with these aspirations. Though there is now little doubt regarding the improved quality of life and well-being of people who have moved from institutional settings to the community (see Appendix 1), questions still exist as to how far personal choice guides providers with respect to the type of accommodation, its location and those with whom the person lives. Though most resettlement plans emphasise consultation with residents, experience of such programmes typically shows that they are in varying degrees driven by what potential providers offer, resource availability, hospital closure time-tables, and optimising resources through grouping of residents. Where family care ends abruptly, similar constraints may operate even where there is proper consultation with the individual. Typically when community residential services have been put in place, investment in housing stock imposes constraints on flexible moves by the individual.

It should be added in passing that, particularly in later life, similar constraints exist for the wider population of older people where their personal financial situation precludes purchasing exactly what they wish, or where their physical and mental abilities are insufficient for them to live with the degree of independence to which they have aspired.

The limitations on individual choice in moving home are starkly captured in the words of the opening sentence on residential transitions for older people with learning disabilities by the Social Services Inspectorate, (1997), p. 33 Para 5.39:

“Inevitably, there will be occasions when it is necessary to move people from one form of accommodation to another.”

Here the essential passivity of “being moved” is clearly signalled, and inevitably conditions the ensuing process of implementing the move that the report goes on to outline:

- clear information on why the mooted move might be appropriate;
- full participation of the person and their advocates in decision making;
- defining a range of options with the person and her/his advocate;
- exploration of options with short stays/visits;
- ensuring maintenance of existing activities and networks following the move.

While it might be unfair to suggest that these perfectly reasonable tactics involve bolting the stable door after the horse as gone, the issue that has been evaded is who makes the decision to move and under what conditions.

This extremely difficult situation of aspiring to choice for the person with learning disabilities and the traditional processes through which services are determined by professionals or family is a reflection of several factors. These include: the difficulty of determining the views of some people with learning disabilities with respect to complex decisions; the financial constraints that dictate that some preferences cannot be met within available resources; the inherent processes by which decisions are made, including the quite objective responsibilities that service providers have for the person for whom they provide; and finally, the nature of the service and type of model about which deliberations are to be made.
3.4.2 Choice constrained

For some individuals policy and professional judgement will lead to continuing NHS provision. In addition, despite Moss’, (1991) findings described above (Section 3.1) that challenging and criminal behaviour decline with age, we would still anticipate a few individuals over 60 years being in contact with the criminal justice system or a danger to themselves or others. In the interest of comprehensiveness the residential consequences of this situation merit consideration. These are dealt with in Appendix 2.

3.4.3 Research into residential provision for older people with learning disabilities

3.4.3.1 Change and stability in the lives of people with learning disabilities

The situation of older people with learning disabilities is paradoxically characterised by both extreme stability and instability, often within the lifetime of a single person, and typically influenced by policy decisions far beyond their control. Many people with learning disabilities will have lived in a single residential setting for many years, and it is far from unknown for them to have spent 50 years or more with their family or in a long-stay institution. This stability, however, has been seriously disturbed by two trends, i.e. the decline in the availability of family care with increasing age, on the one hand, and the progressive reduction of places in long-stay institutions. Hogg & Moss (1993) reported that during the previous five years 37% of their population of over 50s with learning disabilities had moved home at least once. Similarly, May & Hogg, (1997) report that 86% of their community population had moved during the past 10 years and 75% during the past five years. Of those who had moved to a community residence in the past 10 years, the largest category of such moves was within the community to residences offering increased independence (41%), followed by moves from the family home (30%) and from a long stay hospital (17%).

May & Hogg (1997) note, and the same point may be applied to Hogg & Moss’ data, that this residential instability reflects “...a response to a particular, and largely time-specific, set of circumstances that is unlikely to be repeated, and as such offers little guide to future developments.” (p.58) Though this is undoubtedly the case, the degree of disruption experienced does hold lessons for future planning. The majority of these transitions have been initiated either by service providers in response to policy objectives or as a result of family caregiving no longer being tenable. Though consultation with individuals may have taken place and change been in the best interest of the person, the overall picture is not one of people with learning disabilities being empowered to make personal choices regarding where they live in future. This aspect of choice must be born in mind when we consider issues to do with individuality, choice and decision making discussed below (Section 3.6).

The changing situation with respect to where people live may be illustrated by two studies that have explored the residential situation of older people with learning disabilities. May & Hogg (1997) found in a longitudinal study of adults with learning disabilities, the percentage of those living at home declined from 60% in their early 20s, to 37% in their forties. In the same study a comparison was made between three cross-sectional cohorts in the age ranges: 18-23 years; 38-43 years; and 58-63 years. Overall, of 38% (67/178) of individuals who lived at home with their families, all but three lived with one or both parents. As would be expected, there was a decline in the numbers living at home: 66% at 18-23 years; 31% at 38-43 years and only 6% at 58-63 years. Of the total of 67, 54 (81%) had lived with their family all their lives, the proportion in each age band declining as would be expected: 54%, 25% and 3% respectively. By far the best predictor of whether a person remains at home is
the presence of both parents, though the survival of one parent, usually the mother, is almost as good a predictor. We will return to this point in our discussion of family care, below.

In a population of 2117 adults with learning disabilities (20-70+ years), McGrother et al., (1996) report 43.5% living at home with family carers. The percentage and number of adults cared for declined across the age range from 50% of all adults living at home with carers in the 20-29 year band, to 1.2% at 60-69 years, and 0.6% 70+ years. When viewed as a percentage of all adults with learning disabilities in the region, a somewhat different picture emerges: in the 20-29 year band 71.4% lived with a family carer, 8.8% at 60-69 years, and 7.5% at 70+ years. The decline is expectedly great, and only 18 adults over the age of 60 years were still living at home with a family carer, i.e. 0.85% of the total population of adults with learning disabilities.

The concomitant of these figures is, of course, that with increasing age the number of people moving into residential provision accelerates. Indeed the majority of transitions from the family home will have taken place before the person with learning disabilities reaches 60 years.

There is a further aspect to the issue of stability that also has an important bearing on how we view the life of the person with learning disabilities as she or he gets older. The lives of the majority of people in society are characterised by periods of stability punctuated by highly significant transitions. While the advent of education for people with learning disabilities in the UK during the 1970s means that school leaving is now as much a part of their lives as other young people, the hoped for progression into employment, career development and retirement, is lacking from the lives of all but a few people with learning disabilities. Similarly, relationships leading to marriage or a long term partnership, having children and their growth to adulthood and their own careers and families, is typically very restricted (Seltzer, 1992).

3.4.3.2 Residential models and older people with learning disabilities

Two distinct categories of research question with respect to residential provision for older people with learning disabilities can be formulated. The first category is concerned with where people live and the relation between age, the characteristics of individuals, and different types of residential model. There is a sense in which such a consideration is value-free and describes the situation at a particular point in time. In contrast to such descriptive work, the second category of questions is far more complex and indeed contentious. Here subgroups of older people with learning disabilities are defined and the effectiveness of different types of residential model with respect to these subgroups are then investigated. Seltzer & Krauss (1987), p. 169, have clearly articulated such an agenda suggesting: “The person-environment fit concept...is particularly important in light of the heterogeneity of the population of elders with mental retardation. Comparative studies of the effects of the various program types on specific subgroups of elderly mentally retarded persons are needed. This information will further our understanding of the best methods of meeting the different service needs of this heterogeneous and vulnerable population.”

With respect to available research studies it is evident that the first of these categories has received considerably more attention than the latter and we will shortly review these. With respect to the latter, however, there is an absence of information and indeed good reasons why the pursuit of matching subgroups of people to types of residential service is quite inappropriate. The first reason is essentially philosophical as such an approach cannot be regarded as individualised and needs led. The second has an empirical basis in that research has now shown that it is not the category of residential provision that determines the quality of the provision, but a wide range of variables related to management and
operational policies. In the present review, therefore, we will consider studies identifying where older people with learning disabilities live, and whether there is any intrinsic evidence to suggest that particular models are inherently unsuitable for them as they get older. We will then comment further on the research agenda proposed by Seltzer & Krauss, (1987) in order to elaborate on the inappropriateness of such a pursuit.

The first major study on the distribution of residential provision with respect to the age of people with learning disabilities was Seltzer & Krauss’ national (USA) survey of programmes for this population. The typology developed for this work identified: foster homes (adult placement); group homes; group homes with nurses; intermediate care facilities; apartment programmes and mixed residential programmes. We will not here define these categories (for this see Seltzer & Krauss, (1987), pp. 59-70, except to note that apartment programmes are also referred to as semi-independent living programmes and do not have 24-hour staffing, while mixed residential programmes also serve generic elderly people and people with other forms of difficulty than learning disability. Differences in the distribution of older people in these settings were reported, with the highest percentage in mixed programmes and the lowest in apartment houses. The latter also had the most able people in contrast to the intermediate care facilities where people with the greatest intellectual disabilities were found.

Distinct differences in programmatic aspects and correlates of contrasted types of residential provision were also reported. Thus, the mixed residential programmes approximated least to conventional learning disability services as they had the highest percentage of residents at home during the day without formal programmes. In contrast, intermediate care facilities offered structured programmatic activities supporting residents including those with highly significant needs. Group houses, both with and without nursing staff occupied an intermediate position with respect to structured programmes. Apartment programmes which approximate most closely to supported living models enabled greater access to generic elderly services, supported individuals with milder intellectual disabilities, and adopted a supportive rather than programme orientated model of provision.

There is no comparable national UK survey of community residential provision for older people with learning disabilities. Moss, Hogg & Horne (1989) and Hogg & Moss, (1993), however, provide a detailed picture of one metropolitan borough in which special care was taken to identify all residents with learning disabilities 50 years and over, even those not known to learning disability services. In this population, 14% lived at home with families while 24% remained in long stay hospitals. Of the remainder living in the community, 21% lived in group houses or others forms of supported accommodation and 35% in hostels. 6% were in some form of sheltered accommodation. In the decade since this study was undertaken, it may be anticipated that the balance of institutional: community provision will have moved decisively in favour of the latter, as will the proportion of people in hostels relative to small community accommodation. As in the Seltzer & Krauss study, intellectual differences were noted with respect to residents, with those in group houses and independent settings, and those in sheltered accommodation, most able. Adaptive behaviour assessment of community competence showed a similar pattern, though with respect to personal competence (e.g. self-help abilities) hostel and family residents were the most able.

McGrother et al. (1996) provide a somewhat different typology classifying residences as: 1) NHS; 2) local Authority; 3) private; 4) voluntary; 5) other residential; 6) family home; 7) at home without family. Reanalyses of McGrother et al’s original data by the present authors enables some points of comparison to Moss et al’s findings. In the 50 years plus group McGrother’s data indicates that 12.6% of individuals in lived in the family home compared with that of Moss et al’s 14%, a remarkably similar figure. The former has, however, dropped to 8.3% for the present review’s population of people with learning disabilities over
60 years. McGrother’s figure for NHS provision of 31.5% for the 50 plus group is slightly lower than Moss et al’s institutional figure of 34%. With respect to the former’s other categories, the figures for the 50 years plus and 60 years plus groups respectively are: local authority - 9.0% & 5.1%; private - 31.2% & 41.7%; voluntary - 6.7% & 5.6%; at home with no carer - 8.8 & 10.2%

Both the USA and UK studies cited above must be viewed as snapshots at a particular point in time, and indeed in specific locations. Against a background of progressive long stay hospital closure see (Emerson & Hatton, 1994) the balance towards community care provision has been and is continuing to shift to the latter. Though some earlier studies indicated that older people with learning disabilities in long stay hospitals tended not to be selected for discharge to the community before younger residents e.g. Hogg, Moss & Cooke, (1988), as numbers reduce an increasing number of older people has been discharged. In a study undertaken in 1997, for example, Hogg et al., (1997) report highly successful adjustment to living in group houses by recently discharged residents ranging in age from 26 - 81 years (mean 53 years).

It is important to acknowledge, however, that some studies have expressed concern regarding the impact on older people of relocation. Hatton & Emerson (1996) in their review of studies on the consequences of relocation from hospital point to a general dearth of information on its impact on physical and mental health, and make no reference to the effect of age with respect to health. Similarly an important US study (Strauss et al., 1998) while showing increased probability of mortality following relocation to the community - particularly in the immediate period following discharge - does not relate this specifically to the age of the individuals. These authors consider their findings not in terms of any argument for the continuation of institutional provision, but with respect to the development of high quality medical input in community settings. Given the increased medical vulnerability of older people, this observation has particular relevance.

We will now return to the second proposal of Seltzer & Krauss, (1987) research agenda noted above, i.e. the match between specific sub-groups of older people with learning disabilities and types of residential provision. We have noted that such a match is hardly reflective of a needs led approach, but there are further arguments that may be advanced. First, research into specific models of residential provision, particularly staffed group houses, has shown that it is functional aspects of the residence, e.g. management practice, staff activities etc. that influence the quality of residents’ lives, not the specific model itself (See Appendix 1). Second, the movement to community provision has been accompanied by the development and extension of a variety of models generated by differing philosophical responses to the strengths and weaknesses of existing models. Thus, in addition to staffed group houses, we have the supported living movement, continued life in the family home following the death of family carers, adult placement, sheltered and very sheltered accommodation and the re-emergence of advocates of village communities. Any comprehensive consideration of residential provision for older people needs to be placed within this complex framework. A general review of the overarching issues related to these models is included for the interested reader in Appendix 1 and may be used as background to what little research bears specifically on older people in such settings on which we now comment.

Staffed group houses have constituted the principal model of community residential provision for people for nearly two decades, and providers report that this is still the principal form of accommodation for older people with learning disabilities (See Initiatives 6.1 - 6.3). Most studies of such provision indicate that these are no less effective settings for older people with learning disabilities than their younger peers e.g. Hogg et al., (1997). Indeed, in their extensive review of the literature on this subject, Hatton & Emerson, (1996) do not allude to age as a predictor of quality of life in staffed group homes. On the contrary, Felce,
(1996) has emphasised the potential benefits arising from properly managed group houses, an outcome equally applicable to many older people if we adopt a Third Age perspective as described above.

**Initiatives 6.1-6.3: Developing policy in service agencies**

While the majority of service agencies in the statutory and voluntary sectors do not have formal polices with respect to ageing and learning disability (see Hogg & Lambe 1998), some have begun to develop clear statements to guide their work. It is particularly noteworthy that where this has occurred, published academic research and national policy documents have often been used to formulate policy. Here three examples submitted in response to Hogg & Lambe’s survey are worthy of note:

**Initiative 6.1: Supporting Older People with Learning Disabilities:** “Living Prospects”, an organisation providing accommodation in group houses for people with learning disabilities, has prepared this document as a framework guiding support for people in its services for as long as possible as they grow older. It does this within the principles of personal value and essential lifestyle planning. The document draws on research to anticipate age-related change, and “Ageing Matters” (see Initiative 10 and p. 49 of the main report) to determine the requirements needed to achieve its objectives. Both resource and training issues are considered.

**Initiative 6.2: Working with Ageing Tenants** was prepared by Key Housing and lists the training needs of staff working with older tenants. The principal issues identified include attitudes to older people, age-related change, women’s health, dementia care, local services and inter-agency sharing.

**Initiative 6.3: The Getting Older Group** of Frenchay & Southmead Care Trust was formed in response to the needs of individual residents as they got older, in order to consider organisational issues with respect to operational and strategic planning. Work began with a survey of the 135 people within their service which attempted to identify predicted future needs. The findings of the survey were brought into conjunction with the Social Service Inspectorate & Department of Health (1997) document noted in the main body of this report and references (p. 5.).

We have not identified any studies dealing specifically with the issue of age and supported living arrangements. It is, however, in the very nature of the community living philosophy that there has been no need to focus specifically on the fact of a person’s age in making provision for them. Since the development of support begins with the individual’s needs, then age-related needs will be taken into account as part of the needs-assessment, and changing functions or abilities will be responded to accordingly. The option of remaining in a home owned by the family as home owner when family carers die or move on, as well opportunities for personal tenancies or home ownership, are natural outcomes for older people, and completely consistent with the paths that are followed by older people generally. Clearly an individualised life in one’s own home is viewed as desirable for all older people, though as Scottish Human Services, (1995) notes: “For older people, the situation is worse, with a rapid growth in provision of nursing homes and private residential care homes and very little attention to developing flexible personal assistance services.” (p.11). Clearly for older people with learning disabilities the range of needs to be met will be wide, and will change as an individual gets older. Given the relatively high level of competence and general absence of difficult behaviours among older people with learning disabilities, it may be anticipated that many will live with only the need for very limited support, and in circumstances to which they themselves aspire.
Similarly, King’s, (1996) description of both the philosophical and practical conditions involved in home ownership indicates that there is nothing in the arrangements described that precludes home ownership as an option for people with learning disabilities who are 60 years plus, though the examples of home ownership reported by King do not involve people older than their mid-50s. For some older people, home ownership will present itself as the option most likely to attain the objectives of supported living.

Research evidence with respect to adult placement is increasing, especially in the USA see (Dagnan, 1997; Bothwick-Duffy et al., 1992). Though the general findings from such research will inevitably be relevant to older people with learning disabilities, specific age related issues have received little attention. Newman, Sherman & Frenkel (1985) provide one important study of people between 45 to 92 year, with a similarly broad range of intellectual disability, including profound learning disability. Within the family, interactions with the person with learning disabilities was high, and the quality of relationships family-like. A number of measures of acceptance by neighbours and community participation were taken, viewed in relation to activities involving the carers as well as independent activities. In general, acceptance by neighbours was high though the level of acquaintance was relatively casual. Use of community resources was also high, including doctors’ visits, shopping, going out to restaurants, churches and entertainment. Of particular importance were the characteristics of the carers as it was their own level of socialising and engagement in outside activities which predicted the person’s engagement in these. With respect to the person’s characteristics, it was the younger and more able who showed greater independent activity than those who were older or less able. However, age per se was not related to engaging in activities with carers. These authors conclude: “...family care not only provides the residents with encouragement to use the community but that the care providers actually serve as facilitators of the participation. This is particularly important for elderly residents who tend not to participate as much in activities without the providers.” (Newman, Sherman & Frenkel, 1985) p. 375.

Adult placement schemes have also been widely developed in the UK, though to a lesser extent than in North America. Such schemes have typically embraced a wide age range. Figures provided by Hampshire County Council Social Services Department indicate that both older women and men have participated with 30% of the total receiving this service being 60 years plus. Robinson & Simons (1996) reviewed 168 adult placement schemes interviewing a total of 42 people with learning disabilities ranging from 18 years of age through to their early 70s. Nine were 60+ years. As there is no specific comment on the influence of age on the success of these placement, it must be assumed that the overall conclusion drawn by these authors is equally applicable across the age range, i.e. that such placements were valued by people with learning disabilities. However, a minority wished to live elsewhere, and little was being done to assist them in this aspiration. In addition, in some situations the values that we have discussed with respect to choice and individuality were not realised, and controls inappropriate for adults were employed. Carers themselves emphasised the value of family life, the personal nature of the care, the homeliness of the environment, and the lack of expense relative to residential environments. Robinson & Smith, however, note that these criteria were not invariably met, and in some cases there was confusion as to the caregivers role. The authors also give detailed consideration to the issue of registration.

Older people with learning disabilities do live in various forms of sheltered and very sheltered accommodation. Horne (1989a) identified three people with learning disabilities unknown to providers of learning disability services living in sheltered accommodation. Lambe & Hogg (1995) present a case study of a 59 year old woman who was a tenant in her own self-contained flat in a very sheltered housing complex living with people with a wide range of disabilities and supported by a home carer. This woman reported a high level
of satisfaction with her living situation. Despite the relatively scarce nature of such accommodation, it is an option which is consistent with the aspirations and criteria of supported living, and one which brings together services for people with learning disabilities and those for older individuals.

With respect to village communities, and significantly for the present review, Cox & Pearson, (1995) implicate the increasing population of older and ageing people with learning disabilities in their argument: “Life expectancy for mentally handicapped people is increasing. This is generating greater need for care for those who would not previously have survived for so long.” (p. 5.) In raising this issue the language employed is extraordinarily emotive to the point of hyperbole: “Demographic trends indicate a time bomb which will explode in the near future, causing widespread suffering for many mentally handicapped people and their families. This time bomb, now ticking away, has been created by a mismatch between need and provision.” (p. 5). It is of interest to note that similar language has been applied to the wider ageing population. We commented above on the gap between such rhetoric and the relatively small numbers in any given administrative area.

The extent to which age plays a part in the advantages or disadvantages offered by these different models has been almost entirely neglected in past studies. Nevertheless, it can reasonably be assumed that older people with learning disabilities are as likely to be subjected to these negative trends as they are to have benefited from the positive gains in quality of life that the move towards small group living has enabled. Good practice at policy development, management and practice levels are therefore of critical importance to the well-being of older people, and underpin all small scale models. A full consideration of these issues will be found in Initiative 7.
Initiative 7: Time for Freedom: Services for Older People with Learning Difficulties

This is a joint Centre for Policy on Ageing and Values into Action report written by Fitzgerald (1998) and supported by the Joseph Rowntree Foundation. The report focuses specifically on issues involved in where older people with learning disabilities live. Collection of information took place in two NHS Trusts and three social service departments. The report draws attention to the way in which some older people with learning disabilities are disadvantaged with respect to moving from long stay hospitals (relative to younger residents) and a lack of coherence in policy in some local authorities.

The report recommends:

- the need for hospitals to consider examples of good practice and for there to be a greater sharing of information with respect to successful resettlement and closure
- greater information for hospital residents on future opportunities
- clear policy direction from central government on resettlement of older people and on good practice
- greater recognition of the social needs and aspirations of older people with learning disabilities
- clearer directions by service managers to direct care staff on the philosophy of care
- improved representation including use of independent citizen advocate
- improved participation
- full acknowledgement that a person’s home is just that - not a place of work
- registration and inspection should place an increased emphasis of quality of care practice
- effective care management cognisant of the implications of ageing
- movement away from segregated services
- the development of cohesive person-centred services
- greater attention to personal financial choice and control.

3.4.3.3 The wider spectrum

The residential models described above, together with provision in the family home, will serve the majority of older people with learning disabilities. Though there is no research specifically in relation to older people with learning disabilities, attention must also be drawn to other minorities within this minority, specifically homeless people and those who may have come into contact with the criminal justice system or be viewed as “mentally disordered”.

Technically, the “homeless” refers to people who find themselves on the street, in a squat, in a hostel, in bed and breakfast accommodation, or in prison or hospital awaiting discharge without a home of their own to go to, whether alone or with family friends (Reed 1992) p.85. More typically, “homeless” is used to refer to “rough sleepers”. Reed, (1992) p. 85. cites the Governmental Statistical Service as stating that of 38,460 households officially accepted as homeless in the first quarter of 1992, 4% belonged to the priority need category of those “vulnerable as a result of mental illness or mental handicap”. It is also noted that among these are “mentally disordered offenders”. No breakdown of homeless people with mental illness vs. learning disabilities is available, and the possibility of the co-occurrence of both conditions (i.e. “dual diagnosis”) is probably high. In focusing in this report on the more visible individuals who spend their lives well within the ambit of social and health services, it is important not to lose sight of this small, but particularly vulnerable, group of
disadvantaged people, though there is no information on the age of homeless people with learning disabilities or the proportion of them over the age of 60 years.

In addition, a small number of older people with learning disabilities will be held in secure accommodation or in prison, following contact with the criminal justice system. The prevalence of people with learning disabilities in prison, however, is known to be low (Kiernan & Alborz, 1989; Gunn, Maden & Swinton, 1991) estimating that about 400 prisoners in England, a figure that would result in an estimate of about 40 people in Scottish prisons. There are no age breakdowns in these studies, though the decline in problematical behaviour from middle age reported by Moss, (1991) would indicate numbers are low. With respect to gender, Gunn’s study shows that women with learning disabilities outnumber men in prison by 2:1. Though again the number of women with learning disabilities in prison will not be high, Chesney-Lind’s, (1997) comment in relation to female offenders: “Small numbers don’t mean small problems” (p. 87), is highly applicable. The issue of gender, learning disability and imprisonment merits further exploration.

3.4.3.4 Projects, programmes and services

The increased interest in ageing and learning disability has led services to develop in two ways. On the one hand, there have been attempts to segregate further people on the basis of both age and learning disability, typically without reference to the individuals themselves or any attempt to explore more inclusive options. On the other use of generic services has been undertaken, more in the USA than the UK. Over a decade ago Seltzer & Krauss, (1987) reported 10.7% of all USA community residential provision as being mixed residential programmes as well as there being appreciable access to day services for elderly people by those with learning disabilities. In a study undertaken within a single state, Seltzer et al., (1989) found that 52% of services for elderly people had been accessed by people with learning disabilities, while in some programmes they made up at least 10% of the caseload.

A distinction may be drawn between what Hogg & Moss, (1993) have referred to as “adventitious integration”, and programmatic approaches to bringing together services for people with intellectual disabilities and those for older people. The former approach is readily identifiable in the UK while the latter has received most attention in the USA. Horne (1989a) found 32 people in a total population of people with learning disabilities over the age of 50 years not known to learning disability service providers. Of these, 12 were living in social services accommodation for elderly people, one in private accommodation for elderly people, one in Social Service accommodation for elderly people with physical disabilities and three (noted above) in sheltered accommodation. Thus, 17 out of 32 older people not known to learning disability service providers (53%) were already “integrated” in residential provision for older people, or 14% of the total over-50s population of this borough.

Horne’s study did not systematically assess the quality of life of these people. Given that provision for elderly people, particularly congregate provision, can be of poor quality, integration of this sort may result in residential provision occurring adventitiously that would not be deemed acceptable by providers of learning disability services. Indeed, Wolfensberger, (1985) was led to revise his use of the term “normalisation” because the poor quality of apparently “normal” residential provision for older people did not make it acceptable for people with learning disabilities (or the older people who lived there). In adopting “social role valorisation”, Wolfensberger was looking towards ways of life that would positively enhance the image of people with learning disabilities and enable them to live in a setting that would show them to be valued members of the community. Others have argued that where “valued” services for older people are available, integration into
these is feasible and desirable. The major examples of such programmatic work have been
successful integration of people with learning disabilities into generic services for elderly
people, including residential provision, was demonstrated. Importantly, these publications
deal in depth with the strategies for achieving successful integration and the barriers to
successfully achieving such outcomes. Janicki (1993) described the attitudinal barriers to
pursuing integration of both the providers of learning disability services and those in the
ageing field, family carers’ attitudes, the ageing service users’ attitudes as well as those of
the participants’ with learning disabilities. (For a fuller account of the NY State services see

Initiative 8: New York Building Futures Projects

Strategic planning in order to integrate older people with learning disabilities with their
elderly peers is beginning to emerge in the UK, but has been pioneered in a thoroughgoing
fashion in New York City for some years. There the plan was to integrate groups of people
with learning disabilities who had been together for some years into neighbourhood services
for older people. In approaching integration there were a number of advantages to be
gained - efficiency in use of time, increased cost effectiveness, continuation of supportive
relationships for the people with learning disabilities, the possibility of learning disability staff
complementing generic elderly staff in the new settings. It was noted, however, that
“selling” this model requires negotiation and diplomacy, the concerns of elderly people have
to be dealt with and true integration in the neighbourhood setting has to be facilitated.

Project staff have provided valuable guidelines, equally applicable to UK planners,
regarding this process, and may be summarised as follows:

- the quality of staff in the service for elderly people is crucial
- these staff need information on learning disability but people should be defined in terms
  of their potential not their disabilities
- minimise the increase in demands on staff in the generic setting
- give back-up and support and follow through on promises
- providing appropriate training for people with learning disabilities to enable them to adjust
  to their new setting
- select people with the potential to make it and who will enjoy and benefit from the
  experience
- monitor progress

Both terminology and service models differ in the United States. Nevertheless, descriptions
of the various facilities in New York State are in many ways comparable to similar models in
the UK. The integration experience described above has been undertaken in a wide range
of day services for elderly people as well as residential accommodation. The publications
below go into considerable detail on the processes involved, and subsequent evaluation
has been highly positive.

(1993), (copies of these reports are available free from Dr. Matthew Janicki).
3.5 Friendships and relationships

In this and the following section (3.6) we consider some of the important factors which contribute to a person’s quality of life in their home and in the community. It is these that give meaning to a person’s life and ultimately determine whether the home the person has been supported in making achieves what was intended.

The importance of both friends and family in the lives of older people generally is now well documented. While the support given by both groups has been shown to be important to the well-being of older people, recent evidence suggests that it is the former, friends, who contribute most to well-being e.g. Antonucci, (1990); Peters & Kaiser, (1985). This is not to say that relatives fail to contribute to the older person’s well-being, only that such relationships tend to have an element of obligation in them, determined in part by kinship relations, and often involving cross-generational links. In contrast, friendship is typically non-obligatory, i.e. chosen, and involves mutual gratification - usually between people of the same generation. One consequence of these differences is that a failure to give support by a family member is viewed in a more negative way than is the case when a friend fails to gives support.

This is not to undermine the importance of the family in later life, though it is important to emphasise that in the past 50 years the composition of “the ageing family” has changed as a result of what Bengston, Rosenthal & Burton, (1990) p.263. call “the demographic revolution and ageing families”. The specific consequences of the changing intergenerational patterns that have resulted from this revolution need not concern us here, though the point must be made that the intergeneration pattern for people with learning disabilities remains distinct for reasons noted above. People with learning disabilities who marry and have children are in a minority, and their family network typically differs from that of the majority of people in later life.

With respect to childlessness, however, there are points of comparison with the wider population. Bengston, Rosenthal & Burton (1990) p.268. observe: “Establishing intergeneration bonds and the options for receiving care within the family become quite limited for older childless adults. Often the childless elderly establish bonds with extended or fictive kin. Building such connections, however, may become more difficult as the frequency of kin concomitantly declines with fertility.” People with learning disabilities almost certainly have less opportunity to compensate for childlessness in these ways, and will be dependent on contact from siblings, in-laws, and to a lesser extent from nieces and grandchildren. Nevertheless, and sometimes despite long periods of institutional living away from their home town, a majority of people with learning disabilities do have family contacts. Moss, Hogg & Horne (1989) report that 65% of people in a 50+ years population with learning disability had family contact. They compared this contact across a range of different residential settings, i.e. hospital, independent living, hostels, sheltered accommodation and family homes. (In the last instance family contact was defined as contact with other family members not living in the family home.) No significant differences emerged either between these types of accommodation or between the hospital residents and those living in the community. A further unexpected finding related to the ability of the person with learning disabilities and the degree of their challenging behaviour. It was hypothesised that more able people would be better able to initiated and maintain family contacts, while family members would be more rewarded by contact with relatives without challenging behaviour. Neither hypothesis was supported. Family contact was unrelated to level of adaptive behaviour or degree of challenging behaviour, or indeed to the age of the person with learning disability. Moss, Hogg & Horne (1989) p.110. comment: “We would suggest that the failure to find correlations between relative contact and residential setting
or individual characteristics indicates that contact is maintained essentially on the initiative of relatives. Their commitment to their son, daughter, brother, or sister is such that despite widely differing places of residence (of which hospitals are the most displaced from the community) and extreme variations in the abilities and difficulties of their relative, they keep up contact.”

This pattern of support is particularly manifest where a middle aged relative with learning disabilities leaves the family home in middle or later life. Bigby (1997) reports on people 55 years plus moving from caregiving by a relative noting that informal networks continued to be dominated by family members, particularly siblings. This role of ‘key person’ involved a high level of commitment, and might also be occupied by more distant relatives or even friends.

With respect to friendship there can be little doubt that older people with learning disabilities are disadvantaged in relation to both their family and friendship networks. We have already seen that some of the typical supports in later life, e.g. a spouse or children are likely to be lacking. Research into the friendships of people with learning disabilities living in the community indicate that these are restricted to their immediate peers or staff who have a service-based relationship with them. For those living relatively independently Flynn, (1988) reported considerable isolation and indeed exploitation. The change from life in an institution has not resulted in a significant change in this state of affairs. Emerson & Hatton (1994) reviewing a substantial body of work show that people moving from institutional provision to the ordinary houses in the community do not automatically find themselves with an enhanced network of friends without disabilities. Indeed, Hogg et al., (1997) suggest that existing friendship networks may be depleted on moving to the community - unbeknown to well-intentioned staff in the new residence. However, with knowledge of such occurrences, support can be given to maintain and extend friendships.

We have not identified any literature dealing directly with issues to do with friendship and family networks relevant to older people with learning disabilities from ethnic minorities. That the subject of ageing and ethnicity is becoming a wider concern in the field of provision for older people generally is apparent from recent texts concerned with this subject e.g. Kumar, (1996). Studies are called for and should take as their starting points this wider field of work. With respect to learning disability, Azmi et al., (1997) note the neglect of people from ethnic minorities, here specifically those from South Asia, in relation to both policy and research. The issues they raise with respect to a younger group of people (median age 22 years) regarding services, social and recreational provision, friendships and relationships, identity and stigma will all be of relevance to the emerging population of older people from ethnic minority backgrounds.

### 3.6 Participation and decision making (including advocacy)

The significance of personal choice as an influence on quality of life has recently been demonstrated in an innovative study by Heller, Miller & Factor, (1998). Studying people in the age range 32-74 years in small settings (with eight of fewer residents) and larger (16 plus residents) she addressed the question: “To what extent do opportunities for choice and resident involvement in policy making influence adaptive behaviour and community integration among adults with learning disabilities in community based residential programs?” (Heller 1998, p. 2). Her principal findings showed that residents with more opportunities for choice displayed improved everyday living skills enhancing their independence. The size of the facility did not influence this finding. The greater the involvement of residents in making policy making, the greater was their integration into the local community. The residents of smaller facilities fared better in these respects.
Despite both the agreed importance of, and the rhetoric of, choice, it is clear that in reality important constraints do exist. These relate first to the conditions under which a person with learning disabilities is empowered to make meaningful choices. Bannerman et al. (1990) have argued that meaningful choice can only be made if the person has the experience of the various possible outcomes of their choice, and that choice-making should be seen as part of the educational curriculum, along with more conventional areas to do with everyday living skills. For those with communication difficulties, ways in which choices may be demonstrated require carefully worked out techniques and a systematic approach. This has been demonstrated particularly for people with profound and multiple learning disabilities in a growing body of literature reviewed by Lancioni, O'Reilly & Emerson, (1996) and Hogg, (1998).

The place of citizen advocacy and self-advocacy remain as relevant to older people with learning disabilities as to their younger peers, and typically the advocacy literature does not single the former out for special consideration. Certainly where older people are especially vulnerable or cut off, advocacy support may be deemed of particular urgency. Lambe (1992) in a study of residents in locked wards in a long stay institution identified people ranging in age from 33-63 years of age, concluding: “From interviews with staff, residents and parents, and my own observations, it is quite clear that there is an urgent need for advocacy services for all residents...(on these wards).” (p. 28).

What, then, are the key areas of choice that have a significant immediate and longer term influence of the life of the person? In addition to choice of relationships considered in 2.5 (above), choice of in-home activities, leisure and how the day is spent are all prime areas where autonomy may be exercised or frustrated.

3.6.1 Everyday activities: domestic and leisure

The importance of leisure as both a prime service objective and subject of research has come to the fore in the past decade, in part because such activities provide a significant means to achieve integrated activity in the community (Dagnan, Howard & Drewett, 1994). In addition, and from the perspective of the Third Age, leisure pursuits offer important paths to self-fulfilment (Hogg, 1994). Dagnan, Howard & Drewett (1994) in a diary study with middle aged residents who had moved from institution to community home found that while there was no quantitative increase in activities outside the home, the degree of integration in non-segregated settings improved significantly. That increasing community integration does not continue indefinitely should not surprise us, Dagnan, Ruddick & Jones, (1998) showing that a plateau is reached after about four and a half years. Hogg et al. (1997) also employed diaries but with an older group of people, finding that community residents accessed more outside activities than those remaining in the hospital.

The importance of individual choice making with respect to leisure is at the heart of both the very concept of leisure and its potential benefit to people with learning disabilities. In a USA study of “older adults with intellectual disabilities” (Rogers, Hawkins & Eklund, 1998) report on residents’ lack of opportunity to determine their own leisure activities, and the extent to which staff did this for them. Further, the activities selected are described as “…diversionary, and typically, passive…” (p. 125). Individual responses to this state of affairs varied, but the majority of people wanted greater control and autonomy. The extent to which this situation may occur in UK residences will vary, but it is clear that leisure choice must be a central concern with respect to provision for older people.

Brown, Bayer & Brown (1992) in a leisure intervention study in which the oldest participants were 60 years found no impact of formal intervention on involvement in a wide range of leisure pursuits. Browder & Cooper (1994) draw attention to a number of barriers that can
impede the involvement of older people with learning disabilities in inclusive leisure activities. They note how health and social status, lack of leisure skills and limited access to the community can preclude inclusion. An illustrative programme is reported together with recommendations on the development of inclusive leisure provision. An illustrative project appears in *Initiative 9*. With respect to competence to engage in leisure, it should be noted that this has become a focus of consideration in the wider literature on elderly people. Hawkins, May & Rogers (1996) (p.201). observation may be applied unchanged to older people with learning disabilities: “As life expectancy increases and the prospects for healthier lives continue to improve, the need for leisure education can also be expected to expand. Adults who reach later maturity will have increased opportunities to continue lifelong leisure pursuits, to explore new activities, and in some cases, to experience a rebalancing of life as their available hours for leisure increase, especially after retirement.”

**Initiative 9: Integrated Leisure: “Take Your Partners”**

Growing awareness of the leisure needs of older people with learning disabilities has led to a number of projects focusing specifically on this group. In “Take Your Partners”, two voluntary sector organisations concerned respectively with learning disability and ageing, the National Federation of Gateway Clubs and Age Concern (Age Concern Metro Oldham, 1995) joined with Manchester Metropolitan University in piloting one such innovative project. The principal aim was to enable the partners in the project to gain access to high quality leisure activities. At the heart of the project was the opportunity for partners to be put in a position where they could make informed choices about available activities. Information on possible activities came from partners themselves, people who knew them well, and clues from what they were actually doing. Taster days which involved participation in a residential home for elderly people extended awareness and were effectively a leisure activity in themselves. Dance and art workshops followed. The emphasis was on highly integrative activities involving members of the public.

Each partner was supported by a volunteers, and one finding from the project evaluation was the desirably of ensuring a match between partners’ and volunteers’ leisure interests. For the volunteers, informal support and enjoyment were found to be crucial. In the early stages of such a programme social events will be important in creating the conditions for productive relationships.

Special efforts were made to identify older adults from ethnic minority communities for participation. While no one within the age range was found, the importance of this awareness remains crucial, and future initiatives should follow the same strategy and not make assumptions regarding the absence or otherwise of people from minorities.

It was concluded: though the balance of activities was towards integrated leisure: “ The project showed that both specialist and integrated activities can be used to provide a wide experience of leisure for partners. Partners were able to try out together new areas, such as dance and exercise, whilst being involved in activities happening in their local area... As a result of these varied experiences, plus resourcing their initial leisure requests, the partners are more informed of what is available and therefore more able to make informed choices about leisure needs in future.” (p. 41.)
3.6.2 Employment & retirement

While employment of people with learning disabilities generally remains extremely limited, with respect to people over 60 years such opportunities are extremely rare. Even in a population over 50 years, Moss, Hogg & Horne, (1989) did not identify any individuals in open employment, and only 3.4% in sheltered employment. Even here, all four individuals were under the age of 60 years. Australians fared better in a study reported by Ashman, Suttie & Bramley, (1995) where 8% in a two-state population were fully employed and 11% in a national sample. Part time employment figures were lower, 7% and 8% respectively. The UK situation is perhaps unsurprising given that aggregate labour force participation by people over 55 years in the general population continues to decline in European countries (OECD 1989-1994). Given the association between life satisfaction and orientation and commitment to work in people with and without learning disabilities reported by Laughlin & Cotton, (1994) this is a state of affairs to be regretted. Day activities for over 60s with learning disabilities are therefore predominantly available in traditional day centres or are increasingly realised in more dispersed, person centred provision (Wertheimer, 1996).

Both employment and day centre attendance have been linked to transitions from such activities with the description “retirement”. While in the former case this term has the same meaning as for the wider population, its meaning for someone who has attended a day service may be considered more ambiguous. Seltzer & Krauss (1987) report positively on what they refer to as “supplemental retirement programs” (p. 85) in day service centres. In their survey they identified 30 such programmes, noting that most were clearly articulated and had the major objective of finding retirement options for individuals for whom reduction in formal programme activity was appropriate. such options typically involved leisure pursuits, though these continued to be centre based. Here, therefore, retirement involved the substitution of leisure activities by vocational activities within the same centre. A more radical transition considered in some UK settings e.g. Lambe & Hogg (1995) is for the person to leave the centre to continue life at home, a move that has been questioned by Wolfensberger, (1985), and may be a threat to the elderly caregivers’ ability to continue coping.

Ashman, Suttie & Bramley (1995) report that for their sample of older people in employment, retirement presented unknown and unwanted challenges. The factors underpinning attitudes to retirement, however, are complex, and go beyond simple changes in the type of activity engaged. Laughlin & Cotton (1994) explored attitudes to work, self and retirement in people with and without learning disabilities. They report marked similarities in attitudes to retirement among people with learning disabilities and a group of similar aged peers. Feelings of life satisfaction and preparedness for retirement were closely related, and financial preparedness, feelings about health and work attitudes all influenced attitudes to retirement. Ashman, Suttie & Bramley (1995) report that older people with learning disabilities who had retired had not been disappointed with the change or found it unacceptable.

Preparation for retirement is a widely accepted process in the general population, and Laughlin & Cotton, (1994) have demonstrated its relevance to people with learning disabilities, though such preparation, however, did not alter basic attitudes towards retirement or to life satisfaction. All authors concerned with this transition, however, urge the needs for pre-retirement preparation (e.g. Ashman, Suttie & Bramley, 1995); Laughlin & Cotton, 1994).
3.7 Implications for staff training

In the preceding sections (3.1-3.6) we have presented a summary of research relevant to both those working in residential settings with older people with learning disabilities, as well as paid staff and volunteers who support and encourage them in wider community and service settings. There has been increasing acknowledgement that a better understanding of the ageing dimension on the part of staff will contribute to the quality of the service they deliver and improve the sensitivity with which they meet the needs of their older clients. In a UK context Harris, Bennett & Hogg, (1997b) have recently published “Ageing Matters: Pathways for Older People with Learning Disabilities - Units 1-6”, open learning material that may also be employed in structured teaching settings. This material is complemented by Lambe, Moss & Hogg, (1998) “Ageing Matters: Pathways for Older People with a Learning Disability: Resource Pack” and Moss, Lambe & Hogg, (1998) “Ageing Matters: Pathways for Older People with a Learning Disability: Managers’ Reader.” (For fuller details see Initiative 10.) This last publication summarises much of the relevant research and policy material relevant to this field. With respect to dementia, Cairns & Kerr, (1994) have also produced: “Different Realities: A Training Guide for People with Down’s Syndrome and Alzheimer’s Disease”, and training issues with respect to dementia are discussed by Koenig, (1995a). (See previous Initiative 4.)

Initiative 10: Ageing Matters: Pathways for Older People with a Learning Disability

The need for training material for staff working with older people with learning disabilities has been acknowledged for some years. Ageing Matters represents the result of a close collaboration between the British Institute of Learning Disabilities, The Hester Adrian Research Centre (University of Manchester) and the White Top Research Unit and PAMIS (Profound and Multiple Impairment Service) (University of Dundee). The core material consists of six open learning units on the subjects of:

- working with people with learning disabilities
- providing effective day to day support
- maintaining good health
- working with families
- leisure activities
- service organisation and service options

Information about ageing and how it effects people with learning disabilities, practical advice and appropriate activities are covered in each unit.

In addition to the Units, there is a Resource Pack which provides addresses, additional references and case studies in six sections paralleling the Units themselves. There is also a Managers’ Reader in which each of the above topics is covered in more detail drawing explicitly on the research and policy literature. The Reader was developed to give service managers a fuller appreciation of the field of learning disability and ageing to enable them to support staff undergoing training more adequately.

The British Institute of Learning Disability has piloted Ageing Matters and is at present conducting training exercises in England and Scotland with the pack. The pack (Units-6, Resource pack and Manager’s Reader) is available from BILD.
3.8 Principal research findings and their implications for future service development

In the foregoing review we have emphasised that people with learning disabilities over the age of 60 years are part of the continuum of adults with learning disabilities, not a distinct sub-group. Indeed, we have drawn attention to the way in which a variety of factors have tended generate special concern with respect to older people with learning disabilities. In our judgement it is essential that future work does not encourage further segregation either within the total population of adults with learning disabilities or from the general population of adults, particularly their older and elderly peers. The adverse circumstances affecting older people with learning disabilities revealed in the research (and to be summarised below), however, merit being addressed for all adults though in a way which is sensitive to the generational and experiential aspects of the older person. In brief, research and background material suggest:

- improvements in medical and social provision have, as in the general population, increased the longevity of people with learning disabilities;
- people with either Down’s syndrome or profound and multiple disabilities, however, have a significantly lower life expectancy than other individuals with learning disabilities;
- however, in any given locality the number of people over 60 years will not increase dramatically in the next two decades, though there will be a more significant increase after that date when the baby boom generation come of age;
- of those surviving into later life, they will typically be more able than the overall population of adults with learning disabilities and in relatively good health;
- though decline related to ageing is evident, particularly from 70 years onwards, this is progressive and should be dealt with through improved care management in the individual's service setting, rather than through the development of segregated services;
- the prevalence of both challenging and criminal behaviour declines with age;
- people with Down’s syndrome, however, show earlier onset of age-related decline, earlier mortality, and an increased prevalence of dementia;
- wider conceptions of ageing which distinguish chronological, social and biological ageing have rarely been applied to people with learning disabilities, decision making tending to be guided the first of these concepts. It is important that age per se does not drive the response of service providers to an individual’s needs, but the person’s individual needs and aspirations predominate;
- as a result of changing policies and difficulties in continued family caregiving older people with learning disabilities tend to go through many residential transitions and lead residentially unstable lives;
- older people with learning disabilities have been shown to live in as wide a range of residential settings as their younger adult peers, and there are no indications that they are, or should be, ineligible to live in any high quality settings that will meet their needs;
- while it has been suggested that research should consider sub-groups of older people with learning disabilities with respect to their match to specific types of residential model, there is an absence of such research and it is also suggested that this approach would not be led by the needs of the individual;
- where change creates significant difficulties for the person, i.e. the onset of dementia, severe mental health problems or physical decline, residential decisions should be based on meeting needs not by automatic transitions into congregate care settings such as nursing homes;
- ageing in women with learning disabilities is a neglected topic with respect to both their healthcare needs and aspirations specific to their gender;
- the number of people over 60 years of age from ethnic minorities is at present small, but will progressively increase, more so in 20 years time than the immediate years;
• attention is drawn to a number of small groups of people for whom accommodation has special requirements, e.g. those in contact with the criminal justice system, who are a danger to themselves or others, have special mental health needs, or are homeless. With respect to older people, there is little information available with respect to numbers or needs;

• a minority of older people with learning disabilities will be found in residential settings for the wider elderly population; such adventitious integration may be contrasted with systematic programmes aimed at including older people with learning disabilities in generic programmes (residential, day and leisure);

• as with the wider population of adults with learning disabilities, friendship networks for older people tend to be restricted to other people with learning disabilities, staff and family members; while all such relationships are to be valued, there is wide agreement that a richer network involving friends without disabilities would improve the quality of life of older people;

• living in the community has been shown to enhance opportunities for both domestic activities and a wide range of leisure pursuits; the encouragement of inclusive leisure activities constitutes a central challenge with respect to the lives of older people with learning disabilities;

• very few people with learning disabilities over the age of 60 years are employed, a finding that needs to be set against the general decline in employment of older people in the general population throughout Europe;

• older people typically receive centre based day service provision, though they are equally able to benefit from the development of more dispersed and inclusive provision;

• preparation for retirement has been shown to be beneficial to people with learning disabilities, though the concept of retirement for unemployed people is an ambiguous one that may be used for the administrative convenience of service providers;

• learning disability staff are typically in need of greater understanding of the age-related needs of older people with learning disabilities and several staff training initiatives have been identified.

For all of the above points it would be possible to identify specific service and research developments that would benefit this population. Some that may be envisaged are noted below.

**Care management:**

◊ if older people with learning disabilities are *not* to be treated as a further segregated sub-group of the wider population, then the needs arising from age-related changes must be assessed and met on an individual basis. Care management should be informed by and geared to assessment and service provision that is mindful of this dimension;

◊ medical surveillance of groups vulnerable to age-related decrements, notably people with Down’s syndrome, is a controversial policy that has been mooted by some workers in this field. Given the adoption of strategies for surveillance of children with Down’s syndrome, attention should be given to exploring the value of and approaches to surveillance for Down’s syndrome people during adult life. (see *Down’s Syndrome Medical Interest Group (UK)* Draft UK Guidelines for Basic Medical Surveillance Essentials for People with Down’s Syndrome: in press);

◊ services should enable people with Down’s syndrome to remain within more inclusive settings rather than segregating them into yet more specialist groupings;

◊ though the concept of *permanency planning* has been invoked principally with regard to family caregiving, it has relevance to those in some form of residential provision who have been shown to lead relatively unstable residential lives. Continuity and consistency should be a priority in so far it is consistent with residents wishes.
• **Coping with transitions**
  ◊ there is a need to evaluate the suitability of existing residential accommodation for older people with learning disabilities and to consider whether a change arising from age related developments and the aspirations of the individual should be considered. At the extreme, significant changes, e.g. onset of dementia, mental health problems, physical decline, might be some of the determining factors, but so, on the other hand, might increased independence and competence;
  ◊ retirement from present day service provision as a concept requires fuller consideration where people attend centre-based provision. However, where a menu of non-centre-based activities are involved, it is questionable how meaningful the idea of such a transition is.

• **Integration of services and activities**
  ◊ there is a need to develop programmatic approaches to integrating services for older people with those for older people with learning disabilities with respect to residential, day and leisure service provision. Such integration may be total with the person with learning disabilities being fully served by the provision, or some part or aspect of their lives;
  ◊ initiatives concerned with opportunities for inclusive involvement in leisure activities in community settings are called for;
  ◊ initiatives to encourage wider friendship networks, particular through approaches such as *Leisure-Link* schemes are needed.

• **Staff training**
  ◊ there is a need for evaluated training programmes aimed specifically at increasing the understanding of residential staff and other service providers to both the dimension of ageing and its implication for needs led inclusive services;
  ◊ as older people with learning disabilities increasingly access generic elderly services, so training for non-specialist learning disability staff in those settings will be called for and such initiatives will be required.

• **Special considerations**
  ◊ there is need to consider older people from ethnic minorities within a given local authority, leading to culturally appropriate methods of meeting the needs of such groups;
  ◊ training with respect to service provision for older people from ethnic minorities is called for, though much of the information would be relevant across the whole age spectrum;
  ◊ greater attention needs to be devoted to the needs of women with respect to healthcare and personal and social development;
  ◊ in considering mainline residential services, small minorities who require continuing NHS care, supervised provision or who are homeless should be born in mind. However, we would anticipate that concern with these groups would embrace the under 60s, and ageing would be one dimension of concern.

4. Caregiving in the family home

4.1 *Demographic aspects*

McGrother et al. (1996) in a population study of 2117 adults with learning disabilities in Leicestershire reported 987 (43.5%) of these living at home with a family caregiver.
these, 435 live with family caregivers who are over 60 years of age (20% of the total population of adults with learning disabilities, 44% of all those cared for at home), with 166 (38%) are over 70 years and 33 (8%) are over eighty. Within the 60 years plus population, therefore, 62% are in their 60s and constitute the majority of older caregivers.

We have already noted in Section 3.4.3.1 that the number of adults with learning disabilities living at home with family members declines as they get older. Nevertheless, the age range of the adults cared for by caregivers of 60 years plus at home is very wide, with McGrother’s data indicating that they are from 21 to 82 years.

McGrother et al’s study was based on register data collected between 1987-1993 and it is therefore not possible to determine exactly the proportion of family caregivers in relation to the total population for Leicestershire during this period. However, in order to calculate an approximate figure that can be extrapolated to the wider UK population, we have taken the total population figures for Leicestershire in 1991 of adults over 20 years and employed this figure to establish the proportion of people in Leicestershire who are caring for an adult with learning disabilities in the family home. The OPCS Census of 1991 reports 638,164 adults 20+ years in Leicestershire. The 435 family caregivers who are 60+ years constitute 0.068% of this population. Drawing on the estimated resident population in June 1991 presented by Central Statistical Office, (1993a) (Table 2.2) of adults who are 20+ years in England & Wales, Scotland and Northern Ireland, we determined that the estimated number of adult caregivers over 60 years (i.e. 0.068% of these populations) are 25,835 in England & Wales, 2,585 in Scotland and 733 in Northern Ireland, a total of 29,153.

These figures, however, are presented only in order to gain an overall impression of the extent of such caring in the UK in the absence of any comprehensive, formal studies. The use of population information from 1991 in relation to data collected over a period spanning this date is less precise than would be wished and inevitably introduces some measure of error. In addition, at least three other influences suggests that the figure is higher then that estimated. First, though McGrother et al., (1996) study is highly impressive in achieving a response rate of 93%, the non-responders will inevitably include some additional family caregivers. Second, it is unlikely that all people with learning disabilities will have been identified for the register, and again some will be living with family members (see above Horne, 1989a); Horne, 1989b). Third, taking 1991 as the base point, seven years have elapsed during which the number of caregivers entering the 60 years plus group will have increased in line with the general demographic trends noted in Section 2 of this report. Fourth, the sub-region of Leicestershire has a high proportion of people from ethnic minorities relative to other sub-regions (Central Statistical Office, 1993b), Table 15.1. Indeed, only Greater London has a larger number, though obviously specific districts (e.g. West Midlands Metropolitan County) will also have more. However, adults from ethnic minorities in Leicestershire are on average younger than their white counterparts and the percentage of those 60 years and older of each population are 7.1% and 28.6% respectively. Thus families from ethnic minorities will be under represented in the 60 years plus population. Since they have been included in the total adult population used to calculate the percentage of caregivers over 60 years this will have depressed further that percentage relative to an all-white population.

We are not able on the basis of available information to arrive at more specific or definitive figure, and must acknowledge that the basis for the above calculations is very imperfect. Ultimately, only formal demographic research within local authorities or sub-regions will provide more accurate estimates. However, as a starting point for the present review we suggest that there are 30,000-35,000 caregivers in the UK 60 years of age or older caring for an adult with learning disabilities in their family home.
Of this number, and irrespective of the nature of the disability of their family member, there is now extensive documentation to show that caregivers are predominantly women, mothers, sisters, wives or sisters-in-law. Therefore, though typically we refer to “caregivers”, it is almost invariably females to whom we are referring, and many studies do focus on a specific relationship, e.g. “mothers”. McGrother et al. (1996) report 89% of family caregivers were female, principally mothers (80% of the total population of family caregivers), while 6% were sisters.

Interest in older carers has therefore been considerable and continued to grow as exemplified in Initiative 11.


This Joseph Rowntree Foundation supported study has examined the:

- current state of knowledge and practice relating to older family carers of people with learning disabilities
- relationship between the family carer and their relative and the extent to which they share the same aspirations
- relationship between learning disability and elderly services networks.

The review was undertaken through a consideration of existing research practice and through consultation with academics, practitioners, policy makers and voluntary sector groups, as well as focus groups with family carers and people with learning disabilities.

4.2 Motivation, satisfaction and consequences

With the increased study of family caregivers has come a growing awareness of the complexity and diversity of what is involved in caregiving. Wenger, Grant & Nolan (1996) have noted that definitions of caregiving based exclusively on the tasks undertaken fail to acknowledge that caregivers not only ‘care for’ but ‘care about’ their family member. Even with this distinction family caregiving can be further conceptualised with respect what is entailed. Nolan, Grant & Keady (1996) suggest an eight-fold typology which described care that is: anticipatory, preventative, supervisory, instrumental, protective, preservative, (re)constructive and reciprocal. Grouping these categories into four overarching areas, Wenger, Grant & Nolan, (1996) note that anticipatory and preventative caregiving directed at preparing the person for the future is largely invisible to the person with learning disabilities who remains unaware of the caregiving activity. Such caregiving is often conducted at the same time as supervisory and instrumental caregiving which entails well developed strategies and routines for dealing with every day activities. Protective, preservative & (re)constructive caregiving is concerned with the caregiver maintaining the person’s sense of value and self-esteem concerning themselves, areas of activity particularly valued by the caregiver. Reciprocal caregiving involves the complementarity of caregivers’ role and that of the adult, and we discuss this in more detail in Section 4.3, below. In the literature we review these various facets of caregiving emerge in a variety of studies, and in varying degrees, though it should be said at the outset that as yet we have no “…theoretically rigorous and empirically relevant models of care.” Wenger, Grant & Nolan, (1996) p. 202. with which to integrate these findings.
Family caregivers of adults with learning disabilities, particularly parental caregivers, differ in distinct ways from other family caregivers. In the area of family dementia care, with which most studies of family care deal, looking after the person with dementia by a daughter or spouse is typically relatively short-term, while family care of a child with learning disabilities involves the perfectly natural parental role of raising a child. Again, the period for which a child with learning disabilities is raised at home is time limited. The duration of care for the adult with learning disability is of another order. In a study of such caregiving in three countries, Seltzer et al., (1995) comment on the shared “...common characteristic of extraordinary importance... (that the mothers) had a son or daughter with intellectual disabilities for whom they had cared for an average of three decades.” (p. 140.) Lambe & Hogg (1995) note “If a single word can capture carers’ views of their role it is ‘acceptance’ regardless of the consequences of engaging in long term caring.” (p. 28.) McGrother et al., (1996) confirm this view reporting that 76% of caregivers in their population were content with the caring role, 23% resigned, and only 1% expressed dissatisfaction. With respect to the intensity of the caregiving, Grant, (1986) comments on the families’ belief that they alone can provide high quality, reliable, care. By restricting the care activities to themselves, they ensure that outcomes are controlled, and that other family members, friends and neighbours are not obligated. Given the very distinctive nature of such care, Hong & Seltzer, (1995) rightly refer to family caregivers of adults with learning disabilities as “non-normative caregivers”. In passing it should be noted that this acceptance of the caregiving role has financial implications and raises important questions from both cost-efficiency and equity perspectives, and the part played by families as components of the overall service system, as well as issues of social equity (Fujiura, Roccoforte & Braddock, 1994).

Over the past decade there has been a distinct shift in both the tone and content of systematic studies of parental caregivers of adults with learning disabilities. The initial theoretical impetus to such work came from the wider study of elderly caregivers not involving people with learning disabilities on the one hand, and studies of families caring for children with learning disabilities on the other. Both fields pivoted on the concept of caregiver stress and UK studies e.g. Nolan, Grant & Ellis, (1990) and those in the USA e.g. Seltzer & Krauss, (1989) take as their starting points explicit models of caregiver stress. The change that has taken place has been a growing acknowledgement of the positive aspects of caregiving to adults with learning disabilities. Coupled with this change has been increasing attention to the non-normative nature of such caregiving. Care of adults with learning disabilities in later life following a lifetime of such involvement entails processes and experiences that differ from other forms of late life caregiving for elderly people or the care of children with disabilities.

In drawing attention to this shift in emphasis from stress and caregiver burden as the predominant concepts to greater acknowledgement of rewards and gratifications, it is obviously not suggested that the concept of caregiver stress is irrelevant to the study of such caregivers - far from it - only that the balance has been radically redressed. Heller, Miller & Factor (1997) emphasise, however, “Caregiving satisfaction and caregiving burden are different factors, not opposite sides of a continuum.” (p. 345). Thus, stress may be an inherent part of long term caregiving, and does not necessarily preclude a high level of satisfaction with the activity. The specific stressors that are involved are reported in some depth by Shearn & Todd, (1997) and Todd & Shearn, (1996), and relate to intimate care, issues of safety and protection, accessing social and leisure activities, but also dealing with the wider public and formal service providers. They note too the specific impact of behavioural difficulties of their daughter or son with respect to meeting the demands of caring tasks. Elsewhere they discuss the pressure of caregivers’ disclosure of information regarding the nature and consequences of learning disability to their adult child (Todd & Shearn, 1997).
The position with respect to stress and satisfaction is well illustrated by a study by Seltzer & Krauss, (1989) who took as their starting point the findings on caregiving in other (non-learning disability) populations. Specifically these authors explored the issues of adjustment and adaptation by mothers (mean age 66 years) caring for adult children with learning disabilities. These issues were approached from the perspective of factors that put mothers at risk and the supports that might enable them to cope which such risks. Employing four variables based on self-reports, they considered the relation between risks and support with respect to the mothers’ physical health, life satisfaction, maternal burden, and parenting stress. The mothers rated their physical health better than that of older women generally and both physical health and life satisfaction better than that of caregivers of elderly people. Both maternal burden and parenting stress were reported as lower than for a standardised comparative group. While Seltzer & Krauss, (1989) comparisons are with the caregivers’ age peers, Hayden & Heller, (1997) compared them with younger family caregivers of adults with learning disabilities, employing a cut of point between “younger” and “older” of 55 years of age. Older caregivers reported significantly less perceived burden of care and fewer unmet service needs. The authors speculate that older caregivers have reached a level of competence in caring that reduces the need for services, a view reiterated by Lutzer & Brubaker, (1988), though the experience of the older caregivers over the years may also have given them lower expectations than is the case for younger caregivers.

The principal risk factor jeopardising the four self-report concepts was the physical health of their daughter or son, with poorer health leading to poorer health in the mother, lower life satisfaction and increased maternal burden and parenting stress. Severe learning disability and poor functional skills increased parental stress. Demographic factors, too, were influential with fewer years of education, lower income and not being married influencing in varying degrees the mother’s physical health and life satisfaction. With respect to caregivers’ health it should be noted that in a UK sample of female caregivers of working age, McGrother et al.’s., (1996), respondents reported 40% more limiting health disorders than for the general population.

Seltzer & Krauss (1989) report that mothers were all significantly influenced by what the authors refer to as “family social climate”, with more cohesive, outward looking families being associated with greater life satisfaction, less maternal burden and parental stress. We will deal with Seltzer & Krauss’ findings on the impact of formal supports in the following section. In passing, possible relations between the concepts employed by Seltzer & Krauss should be noted. Smith, Majeski & McClenny (1996), for example, showed that positive psychological well-being diminished the subjective burden of caregiving.

In Seltzer & Krauss’ study, mothers of people with Down’s syndrome experienced less maternal burden or parental stress than mothers of other people with learning disabilities. In a more detailed study of these two groups, Seltzer, Krauss & Tsunematsu, (1993) found that, as in the case of caring for children with and without this syndrome, ageing mothers of daughters and sons with Down’s syndrome reported less family conflict, more satisfactory social support, less stress and burden of care, than the other mothers.

With the acknowledgement that inevitable stress as the outcome of non-normative caregiving is not the whole story, has come a redressing of the balance with regard to positive aspects of later life caregiving of adults with learning disabilities. Grant et al. (1998) represent this development in a recent paper which focuses on the rewards and gratifications of caregiving. Here family caregivers, principally but not exclusively mothers, reported on the satisfactions they experienced in giving continuing care. These authors identify three principal sources of satisfaction, interpersonal (e.g. maintaining dignity of relative), intrapersonal (e.g. seeing needs attended to) and outcomes (e.g. helping their relative to overcome difficulties). Some satisfactions are located specifically with respect to
the person cared for, others relate to the family caregiver, while others are shared. Stress, too, was also assessed in this study, the authors noting that stress factors were only half as prevalent in the experience of caregivers compared with rewards and gratifications.

Grant et al. (1998) p. 66. suggest their findings: “...would seem to confirm once again that pathological models applied to family caregivers are likely to misrepresent carers’ perceived realities. This does not mean that the experience and effects of stress are not important to very many people. What it does suggest is that, without the pervasive satisfactions and rewards experienced by caregivers, it may not be possible for many of them to contemplate continuing encounters with stressful circumstances. This may provide one set of powerful reasons as to why many caregivers continue caregiving under often challenging circumstances.” For those for whom stress is experienced, there may be a higher probability of negative consequences such as discontent with the caring role and depression McGrother et al., (1996).

The research focus in these and other studies on “caregivers” inevitably tends to isolate one particular role that the person fulfils from the total person. Conliffe (1995) emphasises that caregiving is not a discrete task but an integral part of the fabric of the family’s life. The acknowledgement of caregivers as individuals with a multiplicity of aspirations, functions and an identity as (usually) a woman, is important if we are to appreciate fully the reality of the individual’s life. We may ask the question, however, as to whether successful coping is dependent on paring down the number of roles that a person might be expected to occupy in their later years. Is psychological well-being dependent on avoiding overload by restricting activity to fewer roles, including that of caregiving? Such a prediction follows from what Repetti, Matthews & Waldron, (1989) call the “scarcity hypothesis”, i.e. that occupancy of multiple roles lowers psychological well-being. In contrast, Marks, (1977) proposed an “accumulation hypothesis”, with multiple role occupancy leading to greater psychological well-being. Here it is suggested that human resources may be deployed flexibly with resulting privileges, status security, and enhancement of status and self-esteem.

Hong & Seltzer (1995) tested these hypotheses in a longitudinal study with mothers (age range 57-87 years, mean 68 years) of daughters and sons with learning disabilities. They related the number of roles occupied to a measure of depression. Eight possible roles were defined, co-resident caregiver, spouse, parent of child without disabilities, employee, support group member, friend, relative and neighbour. In line with the accumulation hypothesis, Hong & Seltzer found that the more roles occupied by the mothers, the lower the level of depression. For women holding fewest roles, however, their scores approached the level of clinical depression. As in Seltzer & Krauss, (1989) earlier study, this group of mothers’ psychological well-being was better than in the general population of older women, including widows. Hong & Seltzer do not address the issue of multiple caregiving roles with respect to caring for more than one family member, though Smith, (1997) reported 4% of a large sample involved in such dual caregiving.

Shearn & Todd (1997) view the activity of combining roles as “articulation work”. Despite Hong & Seltzer, (1995) findings, these authors report on the difficulty caregivers experienced with respect to care activities in the time available, and the impact of this on their opportunity for wider activities. Life was dictated by the clock to the exclusion of their own personal aims and interests. Their daughter’s or son’s service provision did offer them non-caring time, but also dictated the framework in which such activity was possible, detracting from its quality and quantity. Todd & Shearn (1996) suggests that an avoidance of socialising (one aspect of the roles defined by Hong & Seltzer, (1995) results in less stress in adult caregivers than those for whom care competes with personal activities.
These authors point out that it is not the particular combination of roles that is important, but the number occupied. One outcome inherent in multiple role occupancy is increased social integration, and a situation at odds with “Popular conceptions of social isolation in old age... when one has responsibility for a family member with disability.” Hong & Seltzer, (1995) p. 396.

The issue of individuality and identity over and above that of “caregiver” is also confirmed by Seltzer et al., (1995) in their cross-national study of these countries, on which they conclude: “The striking differences across the three countries suggest that the experience of rearing a child with a disability through childhood and into adulthood does not dominate negatively the identity of the mothers who were studied. Rather, their personal and social identities showed distinct cultural variability that apparently overrode the common experience of parenting a child with a disability.” (p. 417.)

Nevertheless, psychological distress is implicit for some mothers in this study, confirming other work indicating that not all parents are coping at the high level and with the satisfaction indicated in the studies noted. Maggs & Langharne (1996) express the extreme outcome for caregivers who lack both the psychological and material resources to cope: “The possibility that the older client may require institutional care as a result of the changing life circumstances of the family carer raises questions of costs and challenges the philosophy of a normal life for all. There is the added danger that the family household will, as both the client and carer age, become an island of isolated, institutional care in the community for carer and client alike.” (p. 249.) Allowing for some measure of hyperbole in this statement, it must be acknowledged that poor psychological well-being and lack of support networks will create extreme difficulties for what the research literature suggests is a minority of family caregivers. Though not typical of the wider population of caregivers of daughters and sons with learning disabilities, they are no less important for this, and Maggs & Langharne, (1996) rightly draw attention to the need for informed professional support. We return to this suggestion in Section 4.5.

It is also important to be mindful of possible situational differences that limit the generalisability of the findings from US studies. A clear indication of the need for such caution is given in Seltzer et al., (1995) study of mothers in the USA, the Republic of Ireland and Northern Ireland. While 40% of mothers in the USA and the Republic reported that health problems limited caregiving ability, 60% in Northern Ireland did so. With respect to social well-being, USA mothers reported larger social support networks than either of the Irish samples. Similarly, on measures of psychological well-being, USA mothers reported less parenting stress and greater life satisfaction than did the Irish samples, with those in the Republic showing less parenting stress than those in the North. It is not unreasonable to suggest the wider social and political conditions in Northern Ireland contribute further to caregiver stress, and indeed, C. Conliffe (personal communication) has found higher reported stress levels among caregivers in Belfast in comparison with Glasgow (where, in turn, caregivers reported greater stress than in Dundee). While social and material conditions in Northern Ireland cannot be taken as typical of the rest of the UK, the general point is made that there will be limits on the generalisability of findings on caregiving across populations, and replicability will always be desirable. As Seltzer et al., (1995) suggests: “...future research should be conducted to investigate these social, economic and political factors, and their direct influence on the lives of families with a son or daughter with intellectual disabilities.” (p. 417).

In concluding this section it is important to note that with respect to research findings there is a yet no definitive picture regarding the nature and consequences of caregiving in later life. Implicit in the reported work is a view that the lot of the older caregiver in the USA is better than that of her counterpart in the UK - certainly with respect to many facets of the person’s well-being and social life. In only one study, however, Seltzer et al., (1995) was a
formal comparison made. In other areas we are left to compare large scale, quantitative studies in the USA with clear methodologies to small scale UK studies using qualitative methods that frequently do not, at least in the reporting of the work, meet the standards specified in the literature on qualitative methodology e.g. Miles & Huberman, (1994). In the latter studies the word “some” occurs repeatedly, with “many” and “one caregiver” coming closest to any form of quantification. There is little doubt that such studies generate important questions and concepts, yet the tone and content veers heavily towards what Grant et al., (1998) refer to as “pathological models”. However there is a now a real need to address the issues of adult family care in the UK in a more systematic way that will inform policy and service development in a more thoroughgoing fashion.

4.3 Reciprocity and perspectives on adults who lives at home

Nolan, Keady & Grant (1995) and Walmsley, (1993) have drawn attention to the reciprocal nature of caregiving and the interdependence that develops between family caregivers and their relative with learning disabilities. Such interdependence involves instrumental, practical contributions to everyday life, as well as emotional support, and Grant, (1986; 1990) reports on how common it is for adults to assist in a wide range of everyday tasks. Heller, Miller & Factor (1997) note the contribution of daughters and sons to the non-statutory support of family caregivers. They show that the availability of such support led to greater parental satisfaction and less perceived burden of care.

Conflict related to such interdependence has also been commented on, however. Walmsley (1993) reports on families who reject services that remove their relative from the family home or reduce the level of companionship. Hill et al. (1987) also note the adverse impact on family income of a daughter or son moving into paid employment, while Grant, (1986) comments on the extent to which families may depend on the person’s benefits.

Conflicts of interest, too, may exist between family caregivers and their relative. While the literature consistently supports the view that adults living at home value their situation, for some more independent alternatives would be welcome e.g. Cooke, (1987). From a professional perspective, such disagreements present difficult ethical and practical issues (see Blacher & Baker, 1992; Orlowska, 1995) and raise issues with respect to autonomy and choice. Regarding protective, preservative and (re)constructive, aspect of caregiving referred to above (Section 4.1), Wenger, Grant & Nolan, (1996) p. 200 raise a series of fundamental questions: “What kind of life chances and independence do carers want for their disabled children of adult age? Whose right is it to decide, the parents’ or the children’s, if the children are unable to speak for themselves by virtue of their disability? Should conflicts of interest emerge in this regard, how are these best mediated? These remain open questions to which elderly carers of sons and daughters with some learning disability, for example, display very varied attitudes.”

Where transitions from the family home are properly managed, there is little evidence of adverse effects on the person with learning disability. Against a background of service support small but dense informal networks evolve as described by Bigby, (1997), while Lambe & Hogg, (1995) present a case study of the benefits and difficulties involved in the transition and its aftermath. Where the transition is enforced by the inability of the caregivers to continue through illness or death, the consequences are likely to be less positive. In the latter case a move from the family home may be coupled with bereavement in a damaging manner. The issue of bereavement has received increasing attention in recent years, with James, (1995) providing a detailed picture of responses to bereavement among people with learning disabilities and guidelines on how staff should respond to support the person. See also Hollins, Sireling & Webb, (1992)
4.3.1.1 Families from ethnic minorities

We indicated in Section 2 of this report that the percentage of individuals in the wider population of the UK who are over 65 years of age is itself relatively small. We also noted that in some groups, notably Asian communities, the prevalence of severe learning disabilities is at present higher than for the general adult population. Taken together, these findings suggest that with respect to the present criteria (i.e. people with learning disabilities over 60 years and caregivers over 60 years) numbers are at this time relatively low. We have found only a limited, principally USA published literature defining clear issues and policies with respect to ethnic minority populations over and above the general literature on ethnic minority families with a member with learning disabilities. Heller, Miller & Factor (1998), for example, compared black and white family caregivers (mean age 63 years) with respect to their wish to make a placement outside the family and preparedness to undertake future financial planning. Black families had less wish for their relative to move out of the family home and had undertaken less financial planning. Heller et al. (1994) undertook a similar comparison involving Hispanic and non-Hispanic families. The former not only considered that caring for their family member with learning disabilities was less of a burden than did non-Hispanic caregivers, but also judged that the experience of care had increased their religiosity and that caregiving was a religious duty. Similar comparisons would be welcome in the UK, particularly in areas where there are relatively high numbers of people from specific ethnic minority backgrounds, e.g. Leicestershire, the West Midlands or Greater London, and would support both good quality professional practice and policy.

Planning for the future

Planning for the future, also referred to as “permanency planning” and “transitional planning”, is a recurrent theme in the research literature of several countries. Here residential, financial and legal planning is entailed, often with consideration having to be given to the interdependency of all three areas. It is generally acknowledged that in extreme cases a failure to plan can lead to serious family crises, with emotional trauma for the person with learning disabilities and other relatives (Kaufman, Adams & Campbell, 1991). And yet, as we review below, studies of future planning are unanimous in recording the difficulty or unwillingness of caregivers of adults with learning disabilities to engage in such activity.

Several topics have been identified that are crucial to any consideration of this subject. Two are of central importance: First, there is the issue of the individual characteristics and the circumstances that lead family caregivers, particularly parents, to plan in a positive manner for the future, as distinct from continuing caring without specific plans. Second, there is the response that is required from professionals working with both families and their daughters and sons with respect to future planning.

The difficulty for many older family caregivers to plan for the future is well documented. In a series of studies in the UK and USA, Cooke, (1987), Heller & Factor, (1991), Lambe & Hogg, (1995), Prosser, (1994), Prosser & Moss, (1996), Richardson & Ritchie, (1986); Richardson & Ritchie, (1990) have all confirmed a general unwillingness on the part of older caregivers to enable their daughter or son to leave the family home before they are no longer able, through illness or death, to continue caring. In broad terms the caregiving role is accepted not only as one in which they have chosen to engage, but also one which they consider themselves uniquely qualified to undertake, and to a far higher and more reliable standard than professional caregivers. This situation, of course, may be compounded by lack of knowledge of options and how to proceed, an issue we address more fully below. As Essex, Seltzer & Krauss, (1997), note: “...families efforts to engage in planning for the future may confront their deep-seated ambivalence and fear of the unknown.” (p. 614.) Nevertheless, differences in circumstances have been shown to affect the extent to which
parental caregivers are prepared to consider their daughter’s or son’s future, e.g. by placing her or his name on a residential waiting list, or enabling the person to move from the family home.

It is also important to note that planning for the future involves a process which unfolds, or fails to do so, over time. Smith, Tobin & Fullmer (1995) propose five, ascending stages to planning:

- no discussion of future residence had taken place;
- early discussions had occurred but not serious;
- serious consideration of alternatives but no resolution;
- provisional plans but indefinite and tenuous;
- definitive residential plans established.

The age of both caregiver and daughter or son with learning disabilities does predict the likelihood of out-of-home placement e.g. Borthwick-Duffy, Eyman & White, (1987); Freedman, Krauss & Seltzer, (1997); Heller & Factor, (1991); Sherman, (1988), i.e. the older, the higher the probability. Information on income and socio-economic status, however, is conflicting. Grant (1989) in a UK study found that higher income and social class predicted planning or placement, supported by Kaufman, Adams & Campbell, (1991) in a US study. However, other work has reported the reverse situation, e.g. Black et al., (1985), in the USA. Research has focused, too, on the influence of the characteristics of the daughter or son on the decision to plan a move. This influence, however, may change across the life course, with younger families whose relative with learning disabilities has severe behavioural or functional difficulties more likely to seek a placement, and older families more likely to seek a placement for more able individuals e.g. Freedman, Krauss & Seltzer, (1997); Kaufman, Adams & Campbell, (1991). With respect to this last point, Heller, Miller & Factor, (1997) note that higher dependency led to increased caregiver satisfaction. The health and well-being of the family caregiver, too, has been shown to be an important influence, with good health and well-being associated with less concern with residential placement (Freedman, Krauss & Seltzer, 1997; Grant, 1989; Smith, Tobin & Fullmer, 1995). Freedman, Krauss & Seltzer (1997) also found that single mothers were more likely to pursue out of home placement. These at times conflicting findings have recently been addressed by Smith, Tobin & Fullmer, (1995) within a single predictive model of family stress and coping. The progress made in permanency planning (see above) was related to nine predictor variables. Four principal variables were directly predictive:

- the greater the extent of use of services;
- non-use of coping by avoiding issues;
- greater help from other adult children;
- the greater the extent to which age-related changes of self are perceived.

Indirect predictors included perceived service needs, subjective burden of care, extent of caregiver tasks, and degree of both mother’s and offspring’s degree of functional disability. There was, however, considerable variation in what predicted progress in future planning, and these authors conclude: “Objective demands of the caregiving situation, for example, were found to be less critical for permanency planning than were appraisals of the situation and use of resources” (p.490).

Models of stress and coping typically invoke the influence of the availability or otherwise of external supports. Thus, unmet service needs may influence parents to seek residential placements (Freedman, Krauss & Seltzer, 1997; Heller & Factor, 1993). Evidence on the effect of informal supports, however, is conflicting with some studies suggesting that informal support increases a desire for placement outside the family home, while others indicate the opposite. (See, for example, Freedman, Krauss & Seltzer, (1997) in contrast to Kaufman, Adams & Campbell, (1991) and Smith, Tobin & Fullmer, (1995).) With respect to
support through formal services, a distinction may be drawn between services to the individual with learning disabilities and those to the caregivers. It has been suggested that the former reduces the likelihood of parents seeking residential provision, while the latter may encourage the willingness to undertake such plans (Sherman, 1988). Essex, Seltzer & Krauss (1997) note that the type of service may have an important influence, since experience of respite, for example, may encourage willingness to look at out of home options.

In a longitudinal study lasting 4.5 years, Essex, Seltzer & Krauss, (1997) explored the predictors of parents putting their daughter’s or son’s name on a residential waiting list. They employed an explicit stress process model, arguing that increased family stress arising from a variety of causes would lead to registering on a waiting list. Three distinct groups of parents emerged, who may be characterised as a “normative launching group”, a “stress-related group” and an “anticipatory planning group”. They first saw the waiting list as the start of the usual transition adults make from the family home to living elsewhere. Families in this group tended to have higher incomes and mothers were in better health. The second, fitted closely with a stress process model, and had acted in order to cope with their own failing health, age related changes in their family member with which they could not cope, or the death of the mother, though challenging behaviour was not associated with an entry to a waiting list (but see also Heller, Miller & Factor, 1997) who reported decreased satisfaction as the result of behavioural difficulties). The third group were not registering for normative or stress-related reasons but because they wished proactively to ensure a future placement. In line with what we have said above, however, almost two thirds of families had not put the name down on a waiting list at the start or finish of the 4.5 year period. Over half did not see a need for out of home placement, while 17% expressed dissatisfaction with the residential options. 16% saw future family support as the principal option, sometimes involving co-residency with a sibling. Families of people with Down’s syndrome were more likely to put their daughter’s or son’s name on a waiting list. (though studies cited above suggested that there is less stress involved in caring for adult children with Down’s syndrome).

Given the extreme difficulty most parents have in engaging in planning for their daughter or son to leave home, it will be anticipated that this is an emotional issue. Freedman, Krauss & Seltzer (1997) refer to “…interpersonal turmoil, fluctuations in parental well-being, and disequilibrium in the family.” (p. 114.) What then are the consequences for well-being of engaging in planning, or not, as the case may be? These authors investigated this question by considering well-being in four groups of 340 mothers who were at different stages of planning. These were (with the percentage of the sample in each group indicated) those who: (i) had a residential plan and hoped for a move within 2 years (21.2%); (ii) had a residential plan but intended the move to occur after two years (24.1%); (iii) had no plan, but hoped for a move within two years (16.8%); (iv) had no plan, but hoped for a move after two years (37.9%). Taken together the 45.3% of mothers in groups (i) and (ii) had made some form of plan, whether by putting their daughter’s or son’s name on a waiting list or having an arrangement with another relative. Those in group(i) had the poorest well-being, with greatest worries about the future and least sense of purpose, while their daughter or son had declining health. They were also the group most likely to achieve an out of home placement for their daughter or son within three years, though only 22.2% of the group had done so by a three year follow-up. Group (ii) had the greatest well-being of the four groups, i.e. those who had set planning in motion but on a longer term time scale. Group (iii) mothers, referred to by Freedman et al. as the “wishful thinkers” group in that they anticipated out of home placement without planning did indeed achieve the move for their daughter or son in 14% of cases. Group (iv) the “status quo” group had only slightly lower well-being than group(ii) and 9.3% had achieved out of home placement. Clearly lower well-being is associated with higher probability of out of home placement but even here only about 1 in 5 families who intended that their adult child should make the move and had
made specific plans had achieve this within a three year period. Nevertheless, the results
do show that planning increases the probability of the placement, though non-planning can
still result in this outcome.

The process leading up to the adult relative leaving the family home has received more
attention than the consequences of such moves. McDermott et al. (1997) report that such
moves did not lead to fewer objective burdens or gratifications from caregiving in a sample
whose adult child had left the home, when compared with a sample where she or he had
remained at home. As these authors note, however, this was a cross-sectional study and
we do not know whether changes within this group had occurred following the transition.
As noted earlier Bigby’s, (1997) study showed continued intense involvement on the part of
a relative following the move from the family home. In a longitudinal study Klieg, Seltzer &
Ryff, (1997) did demonstrate change, with women whose daughter or son had left the family
home showing improved well-being over time and more problem-focused coping. However,
the women whose daughter or son had not left home showed stronger relations between
coping and well-being, perhaps indicative of increasing expertise in caregiving with the
passage of time.

4.4 Help and hindrance from service providers

While a small and undetermined number of families will continue supporting their relative
with learning disabilities at home without any formal services, the majority will receive in
varying degrees some services from the statutory and/or voluntary sector. However, as
increasing age makes the task of caring more difficult, family caregivers while seeing the
need for additional services do not necessarily seek them out Grant, (1990), and indeed
may choose not to report gaps in provision that may be assumed by a person independent
of the family. Lutzer & Brubaker (1988) in a study of the full age range of families caring for
an adult with learning disabilities found that older caregivers (over 56 years of age) seemed
more interested in services which would not involve them, the caregiver, directly, and would
decrease their personal interaction with social and professional systems related to their
adult child. Englehardt, Brubaker & Lutzer (1988), however, showed that self-reports of
decreased ability to care were related to increased use of services, while Caserta et al.,
(1987) found that the main predictor of unmet needs in the caregivers’ 60s is health status.
Nevertheless, there is no simple relation between services provided and caregiver burden of
the “more services - less stress” variety. Smith (1996) reports that objective stressors and
resources were unrelated to older mothers’ reports of caregiver burden. This point
highlights the subjective nature of the experience of stress arising from the burden of care.
Englehardt, Brubaker & Lutzer (1988) comment, like Grant, (1986), on the under-utilisation
of services by older family caregivers. Neither level of disability nor caregiver characteristics
were found to be related to amount of service utilisation, though caregivers’ self-
assessment of their ability to care was. These authors comment: “It is neither (sic) health, income, nor education of the caregiver, nor dependant’s level of disability that is related to the amount of service use. Rather, it is the caregivers’ own assessment of their ability to care that is related to the amount of service use.” (p. 194.)

Smith (1997) provides a useful itemisation of the services of relevance to the older
caregiver, i.e. benefits, day services, transportation, recreational activities, case
management, specialised therapies, residential provision information, support groups,
financial-planning information, guardianship information, parent training, home services,
out-of-home respite, family counselling, in-home nursing, in-home respite and availability of
special equipment. In broad terms this USA-derived list can readily be transposed to a UK
context.
Smith (1997) conducted interviews with mothers between the ages of 58 and 96 years (mean = 70.3) caring for adults with learning disabilities (21-68 years, mean 38.2 years) to establish the factors affecting caregivers’ use of the range of family support services noted. Though mothers were generally knowledgeable about such services, their use of them was relatively low. The explanation for this outcome was that mothers felt they were competent in caring and not strained by the activity, a result consistent with that of Englehardt, Brubaker & Lutzer, (1988). However, this general finding requires some qualification, in that the depth of knowledge about available services may not have been great.

Within Smith’s sample, however, individual differences were reported. Mothers caring for daughters used fewer support services than caregivers of sons, a finding possibly explained by Krauss, Seltzer & Goodman, (1992) view that females tend to attract more informal support than males, consequently needing fewer formal services. Older caregivers tended to receive fewer services than their younger counterparts, perhaps because the former have learnt to cope over the years without services which may have been unavailable when they were younger. In contrast, Hayden & Heller, (1997) report no differences in the services received by younger and older caregivers, though the suggestion that the latter have learnt to cope effectively receives some support in this study, as they reported less personal burden of care, and fewer unmet needs. Nevertheless, a focused consideration of receipt of specific services may be more germane to informing service development across the life span. McGrother et al. (1996), for example, suggest that among younger adults living at home, unmet need was for long term social support and social work, while for older adults chiropody and physiotherapy were viewed as unmet needs.

We noted above the commitment and intimacy involved in family care giving, and the belief that the caring role could only be provided adequately by the family itself. This view will condition parents’ willingness to admit service input even when intensive care is required. Englehardt, Lutzer & Brubaker (1987) report great concern amongst older parents about accessing respite services, for example, seeing staff as not adequately qualified to meet the special needs of their daughter or son.

Smith’s study, however, makes an additional important point by showing that there are several factors that predict both use of services and the extent to which needs are met. These include the age and gender of the person with learning disabilities, the age, health status and perceived burden of care of the mother, as well as family income. For example, caregivers of younger daughters in low income homes, where high level direct care is required by the daughter, are relatively more likely to use services. Here a cohort effect may be evident as differential mortality (see Section 2) may have resulted in a more able group of daughters surviving into the later years and requiring fewer services. Smith also notes that the daughters and sons of older mothers reporting poor health access services less.

The impact of the wider informal support network on the degree to which needs are met is also of importance. With respect to care by mothers this will typically involve support from other daughters and sons. Seltzer et al. (1991) comment that such support can be practical (instrumental) or emotional (affective), though Begun, (1989) studying sisters suggests that while relations between them and their sibling with moderate to profound learning disabilities are positive, they tend not to be intimate. Zetlin (1986), however, pointed up the importance of relationships with siblings to the person with “mild” learning disabilities and the diversity of relationships that exist. The consequences of differing relationships between siblings and people with profound disabilities is, however, of some importance. Seltzer et al. (1991) describe the sibling with high involvement as typically older than her or his peer with a disability, living near the family home and having regular contact. Such families tended to be more cohesive, independent and involved in active leisure pursuits. The impact of such involvement is demonstrated in Smith, (1997) study in which the more support mothers received from their other daughters and sons, the fewer unmet service
needs were reported. He goes on to note that it is intuitively reasonable to see such “secondary” support as diminishing the need for formal services, concluding: “...these findings suggest that it may be cost effective for policy makers to encourage the efforts of secondary caregivers who attenuate the need for costly formal services.” (p. 24.) This conclusion perhaps requires some qualification in that there are aspects of formal support that are unlikely to be replaced entirely by secondary support, e.g. full time day services or technical legal and financial planning, though others may be replaced entirely, e.g. out-of-home respite and community leisure pursuits.

Again, generational influences will make themselves felt. Hayden & Heller (1997) reported that younger caregivers tend to use other family members to acquire and accept help, older caregivers being more likely to seek spiritual support.

The picture that has emerged from the foregoing account of research into the lives of older caregivers of adults with learning disabilities is of a group of people who over the years have developed strong coping strategies and expertise, and who see their role in continued caregiving as one which gives them great satisfaction. For most it is not viewed as a time-limited activity but one which stretches some way into the future. That stress is involved in such caregiving cannot be disputed, and many factors will increase stress, not least changes that are an inevitable concomitant of both caregiver and the adult child getting older. The research shows us, however, that there are no simple equations relating characteristics of the caregiver and the person they care for on the one hand, and the formal and informal networks available as resources on the other, to caregiver satisfaction and stress. The family situation is complex, and it is questionable whether satisfaction can be increased and stress diminished without professional workers being aware of this complexity. This overall position is captured by Hayden & Heller, (1997) p.370: “...service providers should strive toward adapting service plans to families rather than adapting families to service plans.” The mismatch between caregivers needs and aspirations and the manner in which services are delivered is reported by Shearn & Todd, (1997), where services, though valued, create additional time pressures and demands on caregivers. This situation highlights the contrast between the family caregiver as against the professional caregiver. For the latter the intensive engagement with other services is a legitimate part of her or his role, part perhaps, of multi-agency working. For the former it can add to the pressures of caring by constraining the person’s life within a timetable not of their own making, at the same time as creating extra demands. The value placed by professional caregivers and other service providers on family caregiving also merits comment. Shearn & Todd (1997) report on a lack of sensitivity to the nature of the caring role on the part of service providers, with the parental contribution being negatively valued.

Even where a professional wishes to relieve the caregiver’s stress, well-intentioned interventions may cause difficulties for parents. Grant et al. (1998) (p.60) comments with respect to offers of respite provision that these may induce “…guilt about the thought of handing over responsibilities to third parties, ‘a sense of grieving at the departure of a family member who is loved’ and a sense of loss at not experiencing the ‘uplifts’ of sharing everyday mundane things in life with their relative.” As noted earlier, Englehardt, Lutzer & Brubaker, (1987) report similar findings from the USA. Shearn & Todd (1997) comment with respect to respite the degree of forward planning typically entailed. It may be inferred from these studies that there is a need for a radical reappraisal of the way in which services for both adults with learning disabilities and their caregivers are negotiated and designed. The need for, and benefits of, close and sensitive consultation are illustrated in Initiative 12.
**Initiative 12: Listening to Older care-givers**

The wide consensus on the need to listen to and consult with carers has led to a number of consultative exercises that have informed specific services and more generally community care plans. The way in which consultation is conducted, however, remains crucial if it is to be meaningful. Skelton et al (1997) have reported in detail on a consultative exercise in a single local authority that drew on the methods of qualitative research to undertake and analyse caregivers’ views. Twenty eight members of 11 families took part in interviews the outcome of which was organised into a range of themes organised around:

- aspirations for future support
- resource issues
- inclusion in the community
- removing barriers in order to support family aspirations
- ensuring improved relations between caregivers and service providers

Workshops involving both older caregivers and service providers proved particularly effective for both parties in improving communication, as well as leading to practical outcomes. The authors note: “At the workshops, in addition to pledging to develop an information leaflet to clarify their roles, responsibilities and powers, service providers developed many other Action Plans which will help to overcome the problem of perceived distance between themselves and service users. Letting care-givers know about alternative care arrangements and holding information sessions were two such suggested innovations.” (p. 69.)

Equally important was the involvement of the relatives with learning disabilities in this consultation exercise. The authors emphasise that it is imperative that the voice of relatives is heard in setting the agenda for ways forward.

This detailed consultation exercise led to significant changes in service development and service providers’ views and awareness, and offers an important insight into the methodology that needs to be employed if tokenistic consultation is to be avoided.

**4.5 Training and informational implications**

Certainly the needs of older parents caring at home have been widely acknowledged by professionals, as have the training implications. McCallion & Tobin, (1995) surveyed US social workers with respect to their views on their role in assisting parents in future planning. The importance and appropriateness of such assistance was acknowledged, though the need for specialised training and additional resources were urged. This acknowledgement of families’ needs with respect to planning has recently led to the production of material aimed to assist professionals working with family caregivers as well providing information directly to families. British Institute of Learning Disabilities (1998) has recently published *Working with Older Carers: Guidance for Service Providers in Learning Disability* as well as a study unit in “Ageing Matters” on this topic (Harris, Bennett & Hogg, 1997a) while Janicki, (1996) and colleagues have produced *Help for Caring - for Older People Caring for an Adult with a Developmental Disability*. Both documents offer general guidance to professionals working with family caregivers, and both focus on the issues involved in future planning. In varying degrees they reflect the literature reviewed above. Kaye et al. (1994) present a comprehensive curriculum for work with older people with learning disabilities based on person-centred planning. On the same subject, but directed at managers, Moss & Patel, (1997), pp. 69-77 discuss issues related to family caregivers. In parallel, material targeted
specifically at the caregivers themselves is becoming available, e.g. British Institute of Learning Disabilities, (1988)

Of particular concern at the present time is how professionals can assist caregivers with planning for the future. A number of reports have identified a range of issues related to such planning about which a majority of caregivers have informational needs e.g. Caserta et al., (1987); Heller & Factor, (1991); Heller & Factor, (1993); Janicki, (1996); Hogg & Lambe, (1997); Smith, (1997). From the viewpoint of the professional, it is essential that consideration is given to the way in which a response is made to these needs. First, it is important that the value inherent in this situation is acknowledged. In wishing to support families and assist where relevant in their exploration of residential options, it is critical that no explicit or implicit parallel is drawn between relocation from long-stay institutions and the family home. The process of leaving the family home is in no way akin to that of relocation from a hospital. The former has been based on valued, familial bonds involving deep seated acceptance of the relative. The latter has been determined by a policy of rejection from society with professionalised care offered on a minimal basis. Families have typically retained their daughter or son in the community, while institutional provision involves removal and isolation from the community. The need, where it arises, for a relative to leave the family home is determined by a number of processes inextricably bound up with family values and competencies. As we have seen in the Essex, Seltzer & Krauss, (1997) study, these processes may involve a belief in normal transition from family to the wider world or an inability to cope because of age-related factors. Movement from the institution has ultimately been determined by the demonstrated unacceptability of such environments, concerns reflected in legislation and policy. Professionals in helping families, therefore, are not involved in some kind of process of relocation that parallels institutional closure.

With respect to direct services related to future planning, recent years have seen several developments. First, workshop models have been undertaken by both Mencap (Sinclair & Mount, 1995) and PAMIS (Profound & Multiple Impairment Service) (Lambe, 1995), at which legal, financial and residential planning were dealt with in group sessions, followed by individualised planning. Workshop participants indicated a high level of satisfaction with the usefulness of this approach, with clear practical outcomes being demonstrated leading to out-of-home placements for some daughters and sons, as well as wills being made and trusts established. In contrast, Smith, (1996) report successes in what they refer to as a “Psychoeducational support group program” for parents of average age 65 years.

There is little in the traditional mechanisms and design of services that has evolved to ensure that the contribution to family caregiving is both sensitive and optimal. Marsh (1992) offers one perspective on how such an agenda might be approached.

Despite these reservations, research over the past fifteen years has led to a number of conclusions with an important bearing on support for older caregivers, as well as identifying subjects which still require further study and appropriate service responses.

4.6 Principal research findings on family carers and implications for future support

Although there is a wide range of issues related to caregiving on which systematic research is called for in the UK, discussed more fully in 3.8.1. below, the situation described above gives clear pointers as to the direction in which future work should be taken. The following summary of findings and recommendations are based on overarching conclusions that can be drawn from that literature, i.e.:

- family caregivers of adults with learning disabilities represent a unique (non-normative) group of caregivers;

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Older People with Learning Disabilities: A review by James Hogg and Lorretto Lambe
• family caregiving is a valued activity for the mother or other relative involving both satisfaction and stress;

• for the majority of family caregivers their role is fully accepted by them and is not seen merely as an unavoidable option;

• a variety of stresses have been demonstrated that increase the burden of care, and some of which are specifically linked to the ageing of the caregiver and her adult child;

• services to reduce stress and hence the burden of care do contribute positively, but not optimally and are often insufficiently tailored to individual need to do so;

• service providers fail to understand and appreciate the nature of long term family caregiving for adults with learning disabilities;

• there are important cultural differences in attitudes to family care and what motivates it, of which service providers needs to be acutely aware; however, in a UK context research information is very limited;

• in the same way that it has been emphasised that adults with learning disabilities are people first, so caregivers must be considered people first, and consideration given to their full identity and multiple roles;

• planning for the future is extremely difficult for family caregivers, though there are marked individual differences among them in their ability to do so;

• motivation to plan for the future and the conditions in which this is undertaken vary significantly among family caregivers;

• there are cultural differences in attitudes to future planning which must be understood if appropriate assistance is to be given to family caregivers;

• adults living at home with ageing caregivers can in their own right become significant resources for their caregiver;

• adults living at home may have different views regarding their future from those of their caregivers, raising complex issues for mediators;

• the wider social and economic context in which caregivers provide has an important bearing on the caregivers well-being, over and above the specific satisfactions and stresses of caring.

• What are the implications of these findings for future service development, based on what has been learnt from the research reviewed?

• Service development:
  ◊ service developments directed to improving or introducing services for older family caregivers should demonstrably have been based on collaboration between caregiver, family member with learning disabilities and the provider of the service. Account should be taken of the way in which the service will increase satisfaction with caregiving and reduce specific stresses, particularly with respect to time-constraints and service accessibility;
in developing services it should not assume as self-evident that certain types of provision will be equally welcome to family caregivers, particularly where out-of-home or in-home respite is concerned or where specific caregiving support is on offer. The basis for the need should be determined and specified.

- **Improved professional practice:**
  - there is a need to increase the understanding of service managers and front-line staff of the nature of family caregiving should reflect knowledge of the nature of family caregiving;
  - service planning should involve direct input from family caregivers.

- **Information for caregivers:**
  - there is a need to provide information on service availability and eligibility in a way that permits parents to assimilate what is relevant to them into their pattern of caregiving;
  - in providing information, there should be no suggestion that they have an obligation to take up any particular service.

- **People in their own right:**
  - there is need for service providers to move away from the focus on caregiving and offer support to the caregiver as a person in her own right, enabling her to fulfil wider aspirations in a way that encourages autonomy without guilt.

- **Ethnic and cultural issues:**
  - in populations where caregivers are from differing ethnic and cultural groups, cognisance of differing values and attitudes is crucial;
  - this point is equally relevant where a service focuses on a specific ethnic group. Community members should be actively involved in developing such initiatives.

- **Social and economic stressors:**
  - there is need to take into account wider social and economic stressors that add to the burden of care, particularly with respect to Northern Ireland, inner-city areas and other areas of high unemployment and social deprivation.

- **Future planning:**
  - services aimed at future planning should demonstrate that they are responsive to and aware of the caregivers’ needs and difficulties with respect to this activity, and do not confront the caregiver with the view that “the crisis is coming” and that there is an obligation to plan;
  - expert input with respect to technical aspects of planning should be available in carrying out the work, e.g. qualified legal staff, knowledgeable financial advisors etc.; where possible the work of these individuals should link with the family’s own advisors where they are available;
  - parent-to-parent support in planning for the future should draw on family members who have successfully accomplished the transition of the person with learning disabilities from home;
  - support for family caregivers through and after the transition from home should indicate sensitivity to the difficulties inherent in this experience for family caregivers.

- **The Adult with Learning Disabilities:**
  - services for family caregivers should ensure that the cared-for daughter or son is directly involved in planning.

- **Published information:**
where published information and advice is offered it should derive directly from experience of this field, including use of relevant research findings;

◊ written material should be intelligible and employ “Plain English”. Similar principles should apply where languages other than English are involved;

◊ there is a need to target specific professional or service provision groups who have a need for information. Possible target groups (not considered in the above review) might include General Practitioners and other members of the primary healthcare team, members of Community Learning Disability Teams, Care Managers and members of the wider elderly service provision network.

- **Evaluation and monitoring:**
  ◊ the evaluation or monitoring of existing services for older caregivers should employ criteria compatible with the general principals noted above with respect to caregiver involvement and where relevant the views of the older person with learning disabilities.

4.6.1 Research directions

Small scale qualitative studies of caregivers have contributed to our understanding of the range of concepts through which caregiving needs to be explored. Such studies will continue to make their contribution if adequately formulated and documented. They remain difficult to interpret, however, with respect to social policy and the extent of specific difficulties in this population that may be met through service provision. Though focusing intensively on individuals for the purpose of the interview, they tell us little about the range and distribution of individual differences. There is also a danger that the very nature of the interview process leads to a pathologising of the caregiver’s life which is quite inconsistent with the wider literature as reviewed by Grant et al., (1998) and here. What is now called for are consistent, replicated studies undertaken in a UK context. There is nothing to compare in the UK to the large sample, longitudinal studies from the USA reported above. A first recommendation would therefore be to establish a similar cohort of older caregivers whose well-being and needs were explored using valid and standardised instruments. A second consideration which links specifically to this is the issue of variation even within the United Kingdom to which we have already referred. A large scale study of the sort proposed could usefully sample across areas contrasted in social and economic conditions. Closely related to such social factors is that of ethnicity, which while meriting research in its own right, could also be incorporated into a larger scale study.

Given both the nature and scale of funding for learning disability research a programme of this scope would need to be formulated on the basis of a consortium of research workers in selected areas of UK. Agreement would be achieved on standard measures and procedures, and the work would be analogous to the Seltzer et al., (1995) study in the USA, Ireland and Northern Ireland described above.

Epidemiological research, too, is called for. There are no accurate estimates of future trends in family caregiving, though issues of the sort raised by Parrott et al., (1997) in their Sheffield study with respect to increased numbers of older people with learning disabilities in future decades implies increases in family caregiving. A thoroughgoing epidemiological study which embraces the issue of caregiving for adults with learning disabilities is called for.

4.6.2 A comment on methodologies
Before outlining the key findings, we will briefly comment on some of the methodological difficulties in undertaking comparative research in this field. As in other areas of real life it is not easy to compartmentalise the various aspects of the family situation in such a way that neat experimental control is achieved. Comparisons between younger and older caregivers relate not only to their respective ages, but also to cohort effects, one important aspect of which is the different life-history of the respective groups. Comparative studies are also confronted by difficulties in matching all the various variables, Stoneman, (1989) raising the issue of the demographic equivalence of groups, matching strategies, differences between the populations from which samples were drawn, appropriateness of tasks/instruments across groups, and the role of theory in comparison group selection. They caution against the translation of comparative research findings into intervention targets for families with a member with learning disabilities. Finally, Hogg, (1997) discusses the literature on cross-cultural comparisons and the inherent difficulties of undertaking these in a valid way.

5. Concluding comment

People with learning disabilities over the age of 60 years are not a distinct sub-population clearly differentiated from their younger adult peers with learning disabilities or the wider population of older and elderly people. Nor in the next two decades will they present themselves as an extensive and problematic emerging population. In later life their health tends to be good and their abilities on average higher than for younger and middle aged adults with learning disabilities. The problems they encounter with respect to lack of community inclusion and limited social networks are the same problems as those of their younger peers. With respect to the suitability of different models of residential provision this point is equally applicable. This picture only requires qualification for people with Down’s syndrome in whom premature ageing, vulnerability to Alzheimer dementia and other medical conditions is of particular concern with respect to the services and support they require. The message of this review is to identify individual needs in older people with learning disabilities rather than problematising them as distinct homogeneous population, and to ensure that their continuity of needs and experience with the wider population is acknowledged. The specific service initiatives we have suggested that would benefit their lives should be needs-led rather than driven by an urge to provide for people on the basis of their meeting the dual criteria of learning disability and age.

It is significant that the difficulty of identifying problems unique to older people with learning disabilities disappears when we consider families who continue to give care in the family home. Here the non-normative nature of this situation raises several specific issues that research has addressed, not least that of planning for the future. If not unique, the situation of continued family caregiving is closely associated with caregiving to adults with learning disabilities. However, it is important not to problematise family caregivers. We have pointed particularly to the shift in emphasis in research from exclusively stress-based models to a greater acknowledgement of the rewards and satisfactions in such caregiving. Even here, however, where support to groups of family members is suggested, this should be based on a full understanding of diversity and individual needs.

With respect to older people with learning disabilities in residential settings, in the family home, and indeed those living independently, we have suggested a number of areas in which initiatives would be welcome. Ultimately, however, these can only be developed at local level in response to needs identified in collaboration with older people with learning disabilities themselves and those who support them. The future agenda should be theirs.
6. References


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7. Contacts

David Thompson
Project manager/ Researcher
Growing Older with Learning Disabilities: The GOLD programme
The Foundation for People with Learning Disabilities
20/21 Cornwall Terrace
London NW1 4QL
Tel. 0171 5357412
Fax 0171 5357412
e-mail davidthompson@mentalhealth.org.uk
Website www.mentalhealth.org.uk

The Association for Residential Care
ARC House
Marsden Street
Chesterfield
Derbyshire S40 1JY
Tel: 01246 555043
Fax: 01246 555045

Prospects
PO Box 351 Reading,
Berkshire
RG1 7AL
Tel: 0118 950 8781
Fax: 0118 939 1683

Key Housing Association
Savoy Tower,
77 Renfrew Street
Glasgow G2 3BZ
Tel: 0141 332 6672
Fax: 0141 332 7498

Frenchay & Southmead Care Trust
Unit 4
Eclipse Office Park
Staple Hill
Bristol BS16 5EL
Tel: 0117 9562821

Dr Carol Walker
School of Health and Community Studies
Sheffield Hallam University
Collegiate Crescent
Sheffield S10 2BP
Tel: 0114 2532390
e-mail:C.A.Walker@shu.ac.uk

Centre for Policy on Ageing
25-31 Ironmonger Row
London
EC1V 3QP
Tel: 0171 253 1787
Fax: 0171 490 4206

Values into Action
Oxford House
Derbyshire Street
London E2 6HG
Tel: 0171 729 5436
Fax: 0171 729 7797

Dr Matthew Janicki,
c/o NYS OMRDD
44 Holland Avenue
Albany
New York 12229-1000
USA

Dr John Harris
British Institute of Learning Disabilities
Woverhampton Road
Kidderminster
Worcestershire DY10 3PP
Tel: 01562 850251
Fax: 01562 851970

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Appendix 1 General trends in residential provision

The movement towards institutional closure with a progressively declining hospital population has been clearly documented by Emerson & Hatton, (1994). There is now a plethora of studies on the quality of life of people with learning disabilities in different types of community residential provision from which two principal points emerge. First, the move from institutional settings to smaller community homes has in general markedly enhanced the quality of life of people with learning disabilities. These studies also demonstrate that age \textit{per se} is no bar to such an improvement, with people across the age range and in later life sharing in this. Second, however, the move to small community settings does not guarantee that such gains will be maintained nor that institutional practices will be abolished. Both of these contrasted outcomes are clearly documented in several of the chapters of Mansell & Ericsson, (1996a). With respect to the re-emergence of institutional practices, Mansell & Ericsson, (1996b) suggest: (a) increased bureaucratisation of services; (b) loss of the original visionaries who developed the services, with less motivated people taking their place; (c) expansion in the size of the service with multiple agency involvement; (d) failure of management to see the relation between management practice and staff behaviour and residents’ quality of life; (e) lack of real commitment by policy makers to high quality services and therefore neglect of important procedural issues.

Mansell & Ericsson (1996b) also draw attention to the growth of expenditure in making good quality, small-scale accommodation available in the community. This, they suggest, has created incentives for change in two quite contrary directions. First, a return to congregate care with lower staff : resident ratios and hence reduced expenditure. The principal example of such congregate care is the private sector residential home on which the deinstitutionalisation movement has had little or no impact. In addition, concern over institutional closure coupled with perceptions of inadequate community provision have fuelled the movement to establish village communities in place of, but often of the site of, existing long-stay hospitals. In contrast, the community or supported living movement has focused on highly individualised accommodation the exact form of which is determined by the needs and wishes of the individual and the extent and nature of the support they considered. As we shall see in more detail, \textit{supported living} is not a model of residential provision but an approach that can generate diverse and individualised networks of support. Among these may be the opportunity for an individual to remain in her or his family home after the death of family carers, or life with another family through adult placement arrangements.
These models and approaches are not exhaustive, however, occupying an intermediate place between larger scale nursing home provision and small scale community housing comes sheltered and very sheltered housing.

Specifically we consider: staffed group houses, supported living, continued supported life in the person’s family home, adult placement, sheltered and very sheltered accommodation, and village communities.

A1.1 **Staffed group houses**

Staffed group houses (also referred to as staffed group homes or supported housing) have become the principal model of residential accommodation in the community to which hospital residents have moved. Others leaving hostels or in some cases the family home have also moved to such group houses. Typically the house or flat will accommodate a small number of co-residents, from two up to eight with support from staff members. In many cases both houses and support will be provided by the same agency, though this is by no means essential. In the latter case the resident may have the status of tenant or licensee.

The emphasis in developing staffed group houses has been on ‘ordinary homes’ with ‘ordinary environments’. However, Felce, (1996) has emphasised the pursuit of quality requires much more than ‘ordinariness’: “It also involves changing performance away from the traditional allocation of activity to residents, on the basis of their ability to carry out activities independently and creating an alternative which emphasises the absence of exclusion of residents from participation and provision of support to help those people who lack skills to accomplish activity successfully. It also involves changing performance away from traditional laissez-faire attitude to what activities residents may or may not do and creating an alternative which gives positive motivation to achieving that level of functional activity which everyone else needs to achieve to live an ordinary life. Finally, it involves changing performance away from the traditional low emphasis on the organisation of opportunities to participate in activity and to receive individualised instruction and behavioural or treatment programmes creating an alternative which establishes a level of commitment, staff competence and managerial monitoring to ensure that these happen.” (p. 133.)

This is an important statement as Felce’s emphasis is on active and goal-directed management and support. The staffed group house is seen to have an intervention or
educational function and what goes on within it is in no sense ordinary. It is failures in these respects that have led in some measure to the reduced effectiveness of such provision noted above.

A1.2 Supported living

Both ideological principles and research findings have contributed to dissatisfaction with the staffed group house model. At the heart of the critique that has been offered is the view that group houses are far from ‘ordinary’ and are basically led by service imperatives, rather than the needs of those who become residents in them. The solution offered is one that is not a specific ‘model’ of residential provision, but a consideration of where the person has her or his home within a wider framework of a life in the community. This movement, for such it is, is perhaps best known internationally through the term community living, though the terms supported living and independent living have also been employed (Scottish Human Services 1995).

Proponents of community living focus their criticism of the group house model on several features of the way in which such homes are established and subsequently run. A key issue with respect to these processes is the lack of separation of housing and service provision, since it is typically the same agency that provides and manages both aspects of the service. Simons (1997) offers three principal reasons why provision of housing and support should be uncoupled. First, there will be greater attention to the support the person needs to live a full life in the community regardless of the particular setting in which she or he lives. By focusing on required support at the outset, it is hoped that the disparities in receipt of services documented by Walker, Ryan & Walker, (1996) will be reduced or eliminated. Put differently, where you live will not be the determinant of the services you receive; rather where you live will be one important outcome of the overall range of supports required. Second, the community living model will protect tenants’ rights. It is staff in the residence who will change or move on in the event of problems, not the resident. If a move does occur, staff can move with the person, ensuring stability of the support network. Third, by taking need as the starting point, a wider range of options will be opened up including tenancies in mainstream housing and indeed home ownership.

This last mentioned option has been described in detail by King, (1996). While noting certain limitations to the approach related to changing property values, dangers of isolation and lack of statutory registration and independent inspection, he draws attention to a wide range of benefits including increased security, control and choice relative to other forms of
tenancy. King describes the diversity of home ownership arrangements that have been achieved, including:

- outright purchase with interest-only mortgage met through income support;
- shared ownership of an existing property;
- shared ownership of a new, purpose built property;
- joint ownership;
- limited company and share-holding ownership;
- trust inheritance.

King discusses the financial, legal and management issues involved in home ownership.

The wider framework of community living is also emphasised by Simons, (1997). *Person centred planning* is viewed as being at the heart of the approach, with community orientated support determined on the basis of need through *circles of friends or support tenants*. Importantly, and partly because the degree of support is determined by the extent of need, community living is intended to be *inclusive* and involve *zero rejection* of individuals.

There is now a growing number of initiatives throughout the UK and abroad in which community living has been implemented in a variety of ways e.g. Fitton, O’Brien & Willson, (1995). It is perhaps inevitable that informal reports on the success of such schemes, invariably by proponents of the approach, should tend to be so positive e.g. Scottish Human Services, (1995); Simons, (1995). Rightly, however, critical views have also been expressed. Hatton & Emerson (1994) draw attention to the rhetoric that pervades much writing on supported living and the danger of rejecting the knowledge that has been accumulated over many years on the structures that enable effective support for people with learning disabilities. These authors have also expressed concern about the informality of the arrangements that are put in place in developing supported living initiatives, and the consequent lack of structure (Hatton & Emerson, 1995; Hatton, 1996). In addition, part of the lesson on the group house approach - only learnt because of the intensive research to which it has been subjected - has been that good intentions and overt features (e.g. size, staff ratio etc.) do not predict a good quality of service. The same could well be true of the community living approach, though the nature of the support may make this even less apparent.

Considering these criticisms Simons, (1995) emphasises that “... ‘supported living’ is not some kind of magic wand. As with any other way of organising support, it will be perfectly
possible to do supported living badly.’ (p. 129). What then of evaluation, monitoring and inspection? There is a real feeling of unease among some proponents of community living with such concepts, which do not fit comfortably within this approach. Scottish Human Services, (1995) while making constructive suggestions on how standards can be maintained notes: “Community living is not readily amenable to standard models of inspection and external control...” (p. 45) and “Observing and reporting how people spend their time is OK for a rehabilitation project, but not when people are really living in their own home.” (p. 45). Simons (1997) notes that a split between housing and service provision leads to exemption from registration, an advantage from proponents’ perspectives but a point of criticism by opponents. He acknowledges the need for safeguards suggesting: intensive care management and contract compliance; close management contact with people with learning disabilities; and the involvement of citizen advocates.

A1.3 Continuing in the family home

As considered above, King, (1996) has described a variety of home ownership options for people with learning disabilities, including those who move from their family home to owning their own house. Where the accommodation is suitable and financial arrangements permit, the person with learning disabilities can on the death of parents inherit the home and continue living there with appropriate support arrangements. Here legal provision has clearly to be made prior to the parents’ death. King describes the way in which parents can set up a trust in order to secure their daughter’s or son’s future. This arrangement can be made with respect to a new home or continued support for the person in the family home. Here support will be directed to and drawn to the person in a familiar and probably well-loved setting. Though relatively few people over 60 years are still cared for by their parents, such preparation by older parents for their adult children ensures suitable arrangements when they do attain that age.

A1.4 Adult placements

As Scheerenberger, (1983) has noted, the arrangement by which a person with physical or intellectual disabilities lives with another (non-related) family is not a new one, and has been employed since medieval times, though was not adopted in the UK until the nineteenth century. With respect to people with learning disabilities, the intended benefits were cited as early as the 1930s in the USA by Charles Vaux: “...the residents can enjoy a happier, more normal kind of life with more liberty; the majority of families will take a greater personal interest in the welfare of the patient than their contract implies; that many patients will
improve and some sufficiently to raise their economic status; ...and that the total average per capita is less than for institutional residents.” (Quoted by Scheerenberger, 1983; p. 201.) Similar arguments have continued to be employed.

The adult placement option has not been exploited to the same extent in the UK as in the USA, though a wide range of such schemes have now developed. Robinson & Simons (1996) have shown the appropriateness of the approach to some individuals, though they have questioned the level of quality of provision in other instances. Certainly in terms of the kind of security that is aspired to in supported living arrangements, this is typically lacking giving the absence of tenancy rights.

**A1.5 Sheltered and very sheltered accommodation**

Sheltered accommodation may involve a self-contained flat in an integrated complex, or relatively dispersed housing located within an ordinary district. Conventionally there will be support from a warden, hence the terms “warden-assisted” or “warden-controlled” housing. Tenants pay rent or purchase the property. With respect to buying such a property Age Concern have produced guidance which is relevant to older people with learning disabilities (Bookbinder, 1991, pp. 22-25, 42-44; Age Concern & NHTPC, Undated).

**A1.6 Village communities**

Supporters of the development of village communities have taken as their starting point findings that we have already noted that emerged from existing research with respect to outcomes of life in small group houses. Cox & Pearson (1995) acknowledge, for example: “They (residents) have flourished with new independence, more autonomy, and the associated enhancement of dignity and self-esteem.” (p. 3.) They comment, however, on the lack of acceptance into the community, the social deprivation experienced and the occurrence of both sexual and physical abuse of some vulnerable individuals. Though research workers have typically not drawn the inference from these negative findings that village communities are the preferred alternative, Cox & Pearson, (1995) selectively cite Wing, (1990) as concluding: “For many in this group with moderate and severe learning difficulties, sheltered communities would offer more opportunities for an interesting life than a small house in an ordinary street, always provided that the autonomy of staff and residents in each living unit was protected and high standards of care maintained.” They argue, therefore, for village communities which: “...can provide humane, individualised care, offering many advantages, and that they should be readily available as an option, alongside
others form of provision. Furthermore, continuous specialist nursing care for those who need it can be provided most appropriately in such communities.” (p.3.) Critically, integration into the local community is viewed as an adjunct to, not a primary aim of, providing care.

While a concern with vulnerability and high quality care are both clear aspirations, the attempt to assimilate the language of community care to the village community is also apparent. Getliffe (1996) refers to “...a wide range of community-based opportunities and experiences...”, “...developing the concept of a circle of friends...”, “involving residents in the meetings where decisions are made that affect their lives...” and “involving residents in choosing the staff they want to have engaged” (p. 188), all aspirations with the exception of a few nuances straight from the vocabulary of supported living: or again: “Villages are part of the community and should not be perceived as being separate.” (p. 189). While the sincerity of such claims need not be doubted, the extent to which they obfuscate the real principles that are at issue needs to be kept clear.

The initiative for this reappraisal has come essentially form The National Society for Mentally Handicapped People in Residential Care (Rescare), an organisation principally of parents of people with learning disabilities, though with parental support from a wider constituency of family members. In presenting their arguments the emphasis is on choice, but the choice of parents as to where their adult daughters and sons should live. Getliffe (1996) asserts parental choice, though briefly mentions the right to choose of the person with learning disabilities. The way in which such choices are made, however, is not addressed, and the approach advocated stands at the opposite end of the continuum to the supported living philosophy. Mental Health Foundation (1996) commented on views of residents in a village community who “...expressed strong reservations about their lives there” (p.53).

In line with the argument that has been advanced with respect to all types of residential provision discussed above, it is important to note that the village community model of itself does not necessarily avoid the pitfalls that have been demonstrated in some community settings. Poor quality social and medical provision may equally be made in village communities, and it would be naive to think that sexual and physical abuse cannot occur in such settings, or is inherently less likely to occur than in any other managed setting. Illustratively, Mental Health Foundation, (1996) refer to examples of institutional practice
and “heavy-handed staff” in relation to a visit made as part of the development of their report.

The reservations which are implicit in the above account of village communities are ones which are equally applicable to the placement of older people with learning disabilities in such settings. However organised, they remain effectively staffed, congregate accommodation, not evolved from individual, needs-led assessments. Their driving force is parental concern regarding deinstitutionalisation which in relation to the present population of 60 years plus also reflects the concerns of brothers, sisters or more remote relatives. If personal choice by older people with learning disabilities is to be a prime concern in enabling a person to live where they wish, then the onus rests firmly with the proponents of village communities to show that it is such choices that have brought so many people into one location under such uniform conditions.
APPENDIX 2  Residential provisional: Continuing care and constraints

Three overlapping groups for whom decision making regarding where they live will be restricted or curtailed are (a) those deemed to have “continuing healthcare needs” Department of Health, (1995); (b) people with learning disabilities who have come into contact with the criminal justice system or are a danger to themselves or others; (c) people who have been detained under the Mental Health Act 1983 or the Mental Health (Scotland) Act 1984.

With respect to the first group, Reed, (1992) pp. 21-22 noted: “There are, however, likely to be a small number of people with severe or profound learning disabilities and physical, sensory or psychiatric conditions who need some term residential care in health settings. Where this seems to be the case a multi-professional assessment and consultation with parents or carers are necessary to determine whether the services they need can only be provided by the NHS or whether other alternatives would be more appropriate and cost effective.” While the reference here is to “health setting”, it may be suggested that “continuing NHS care” is related more specifically to the nature of the staffing (i.e. NHS staff, typically nurses) rather than particular models of residential provision. These range from traditional institutional hospitals through to community residences, with various types of unit ranged between. Health Boards and local authorities vary in how far the necessity of continuing NHS provision on purely medical grounds is accepted, a tension implicit in the preceding quotation. Such a model may be abandoned in favour of social care provision but with essential medical tasks undertaken by qualified medical staff who also provide training for other staff and monitor medical needs and how they are met. The Semiahmoo House Association of Vancouver have pioneered the concept of “nursing judgement” as distinct from “nursing care” which embodies these principals (Hendren, 1996).

A second group for whom choice of residence may be constrained are people with learning disabilities who come into contact with the criminal justice system. Where they live will vary as much as do the specific behaviours that bring them into contact with the law. Some will live in ordinary houses in the community and others in secure accommodation in a variety of settings. There is general agreement on the overall conditions which should be available to them. Reed (1992) p. 7, dealing specifically with England though with reference to Wales and Northern Ireland, and Bryce, (1995) (pp. 7-8) with reference to Scotland, emphasise individualised care, noting:

- residential provision in the community rather than large institutions;
• conditions of no greater security than is justified by the degree of danger they present to themselves and others;
• care that maximises rehabilitation and sustaining an independent life;
• proximity to their own homes or families.

The third group overlaps with both the preceding groups, and consists of people who are detained under the Mental Health Acts. A small proportion of these will receive high security accommodation, typically in a special hospital. Others will be placed in Medium Secure Provision. In line with the principles just noted, decisions as to which option is applicable should be based on the least restrictive alternative. Accordingly, there have been transfers of people from special hospitals to medium secure provision in both institutional settings and the community. Campsie House in Greater Glasgow demonstrates how medium secure provision for relocated residents of a special hospital can be developed in an ordinary detached house (though here physically located within the grounds of a large hospital). Here environmental design, staff training, operational policy and management all combine to provide a socially therapeutic setting in which decreasing restrictiveness is the principal objective.

It should be added that there are some people with learning disabilities who though not detained under the Act or in contact with the criminal justice system nevertheless require medium secure provision in order to prevent injury to themselves or others.