today
and
tomorrow

The Report of the Growing Older with Learning Disabilities Programme
today and tomorrow

The Report of the Growing Older with Learning Disabilities Programme
## Contents

Preface .................................................. 4  
Acknowledgments ................................. 5  
Executive Summary .............................. 6  

**Chapter 1**  
**Introduction** ........................................ 9  
1.1 Why the GOLD programme? .................. 9  
1.2 Background: the national policy context ...... 9  
1.3 Who are the older people with learning disabilities and older carers? 11  
1.4 The work of the GOLD programme ........... 12  
1.5 What were the main issues for the GOLD programme? .......... 12  
1.6 The voices of older people with learning disabilities and older family carers 13  
1.7 *Today and Tomorrow*: aims and readership .......... 13  
1.8 Concluding comments .......................... 14  

**Chapter 2**  
**An Active Life: Friends, Day Opportunities and Leisure** .......... 15  
2.1 Introduction ....................................... 15  
2.2 Friendships ....................................... 17  
2.3 Day opportunities .................................. 22  
2.4 Social and leisure opportunities .............. 27  
2.5 Concluding comments .......................... 28  

**Chapter 3**  
**A Healthy Life: Health Care and Growing Older** .................. 29  
3.1 Introduction ....................................... 29  
3.2 The health needs of older people with learning disabilities ........ 30  
3.3 Promoting health in old age .................... 31  
3.4 The menopause .................................... 32  
3.5 Screening .......................................... 36  
3.6 Treatment .......................................... 38  
3.7 Staff issues ........................................ 38  
3.8 Concluding comments .......................... 39  

**Chapter 4**  
**Family Life: The Circumstances and Needs of Older Family Carers** .... 40  
4.1 Introduction ....................................... 40  
4.2 The circumstances and characteristics of older carers ............ 41  
4.3 Meeting older carers' current needs .................. 45  
4.4 Policy and legislation relating to older carers ............... 54  
4.5 Concluding comments .......................... 56  

**Chapter 5**  
**Living with Older Family Carers: Planning with Families and Preparing for the Future** .................. 57  
5.1 Fearing for the future ........................... 57  
5.2 Understanding older family carers of people with learning disabilities .... 58  
5.3 The Planning Ahead project ...................... 59  
5.4 Individual work with families .................. 59  
5.5 Carers' groups ................................... 64
| 5.6  | Written information | 65   |
| 5.7  | Life Books         | 66   |
| 5.8  | Lessons from the work | 67   |
| 5.9  | Concluding comments | 69   |

**Chapter 6**  
**A Home of Your Own**  
6.1 Introduction  
6.2 Meeting age-related needs  
6.3 Learning disability residential services  
6.4 Older people’s residential and nursing homes  
6.5 Security in the family home  
6.6 Concluding comments  

**Chapter 7**  
**Supporting People with Down’s Syndrome and Dementia**  
7.1 Background  
7.2 Introduction  
7.3 What is the link between Down’s syndrome and dementia?  
7.4 How do we know that it is dementia?  
7.5 Prevalence and progress  
7.6 Stages in dementia  
7.7 Common difficulties  
7.8 Supporting people with Down’s syndrome and dementia  
7.9 Issues for services  
7.10 Concluding comments  

**Chapter 8**  
**Supporting People through Terminal Illness and Death**  
8.1 Introduction  
8.2 The Project: services and individuals  
8.3 Features of a good death  
8.4 Guidance for good practice  
8.5 Concluding comments  

_A Charter of Rights for Older People with Learning Disabilities and for Older Family Carers_  

_recommended_  

Bibliography  

Appendix 1: Summary of the GOLD projects  

Appendix 2: Publications from the GOLD programme  

Appendix 3: Practical Guidelines for Setting Up and Running Groups for Older Carers  

Appendix 4: Planning Ahead: Continuing Family and Other Relationships in Later Life  

Appendix 5: Older People with Learning Disabilities: Facts and Figures  

106  
107  
109  
113  
117  
118  
123  
128
Everyone gets older; we celebrate getting older every year with our Birthdays. Some things are good about getting older; some things are difficult about getting older.

(GOLD Over 50 Saturday Group)

The Foundation for People with Learning Disabilities embarked on the Growing Older with Learning Disabilities (GOLD) programme in 1998. GOLD has looked at lifestyle issues, including health, social inclusion, and the needs of people with Down’s syndrome who develop dementia. A substantial part of the programme has focussed on people with learning disabilities living with older family carers.

We hope that this report and other related publications, together with the work of other organisations and individuals in the field who share our commitment to older people with learning disabilities and older family carers, will help to ensure that their needs will remain high on government agendas and continue to bring about change.

Recent policy initiatives in England, Scotland and Wales present a valuable window of opportunity to ensure that older people with learning disabilities have their health and social care needs met and families gain more support and can plan for the future.

This report seeks to convey, as the words of the GOLD Over 50 Saturday Group above suggest, that there is reason to celebrate, but there is also reason for concern. For example, this report shows that older people’s health needs are not always met, that they may be ‘retired’ from day services at an arbitrary age and that they may find themselves in older people’s residential services or nursing home at a much younger age than other residents leading very restricted lives.

Two stories (the names have been changed) illustrate the contrasting realities in people’s lives, when they live with older family carers. Jane, who has profound and multiple learning disabilities, lived until recently with her elderly parents, attending day activities and using a respite service. A few months ago she moved into residential provision linked to the respite service, where she is known and has friends.

Although her move has left an enormous gap in her parents’ lives they are reassured by the way she has settled into her new home. Keith, on the other hand, was devastated by the death of his parents within a short space of time. This led to the added loss of his home. The only emergency bed that could be found was in a respite service which he had not previously used. Not surprisingly, Keith was very disturbed and unhappy for a long time.

It is to be hoped that this report and the GOLD programme of work will contribute to making experiences like those of Keith the exception. If increased awareness results in more sensitive and appropriate support, older people with learning disabilities should be enabled to lead fuller and healthier lives, which maximises choice and control and minimises the inevitable difficulties which can accompany the ageing process. We are grateful to the 13 projects, to the GOLD Over 50 Saturday group, the GOLD Advisory Committee and to Dr David Thompson, the GOLD Programme Manager for all their work in making it more likely that this dream can become a reality.

Hazel Morgan

Head of the Foundation for People with Learning Disabilities
Acknowledgments

The Growing Older with Learning Disabilities (GOLD) programme was an important part of the work of the Foundation for People with Learning Disabilities between 1998 – 2002. The programme was managed by Dr David Thompson. This report was edited by Alison Wertheimer. It was written from a range of sources provided by the funded projects, the programme manager and a number of commissioned authors. We would like to thank them all for their contributions.

We would like to thank the many people who have supported the GOLD programme in numerous ways, including the Advisory Group, members of the GOLD Over 50 Saturday Group, and all those involved in the funded projects.

**GOLD Advisory Group**
Pat Case
James Churchill
Lady Euston
Maurice Harker
Professor Tony Holland
Tom McLean (Chair)
Dr Zenobia Nadirshaw
Dr Stuart Todd
Professor Linda Ward
David Ellis (Observer: Department of Health)

**GOLD Over 50 Saturday Group**
Roger Brooksby
Michael Brookstein
Patricia Charlesworth
Edna Day
Sylvia Dufeu
Corinne Hoyte
Tim James
John Phillips
Betty Steingold
Facilitators: Noelle Blackman and Sarah Wright

Daphne White, whose participation in the GOLD Advisory Group was greatly appreciated, sadly died in 2002.

The Foundation is grateful to the Bally Thomas Charitable Fund who made the GOLD programme possible and for their trustees’ ongoing support and advice. We would also like to thank the Charles Hayward Foundation, Comic Relief, the Bartley Trust and the Abbey National Charitable Trust for their generous support.
Executive Summary

Today and Tomorrow reports on a major programme at the Foundation for People with Learning Disabilities. Growing Older with Learning Disabilities (GOLD) was a wide-ranging initiative with externally funded and in-house projects spanning service development and research. GOLD’s main focus was on older people with learning disabilities. It also included six projects working with older family carers. Today and Tomorrow sets out the findings and lessons from the GOLD programme, sharing the views and voices of people with learning disabilities and their families. Projects were grouped into several topic areas and the main themes emerging from the projects are summarised below.

Inclusion

As they grow older, people with learning disabilities will still want an active, fulfilling life where they can see their friends and take part in enjoyable, rewarding activities of their choice. Like many older people in retirement, with too many unfilled hours, they can become bored and isolated. Ageing can have an impact on people’s friendships and activity patterns. Having to ‘retire’ from day services at 60 or 65 can exclude people from seeing friends and taking part in regular activities. If age-related needs result in a move elsewhere or getting out and about becomes physically more difficult, people will need support to access activities. Services have an important part to play in supporting the friendships of older people with learning disabilities and giving them the chance to meet new people and make new friends. Older people with learning disabilities can also enjoy socially inclusive activities. Two GOLD projects supported people to participate in activities as diverse as allotment keeping, carpet bowls, dancing, walking and keep fit, alongside other non-disabled older people. A GOLD project which talked to people in their 30s and 40s living with older family carers found that they too would like to have more friends and take part in more social and leisure activities.

Health

The life expectancy of people with learning disabilities has increased significantly in recent decades. This means they are now more likely to have age-related health problems (e.g. strokes, heart disease and cancer). People with learning disabilities also have more chronic health problems, physical and sensory disabilities and mental health difficulties than the general population. To maximise their physical and psychological well-being, people with learning disabilities need to be able to access primary care and secondary specialist health services for screening, diagnosis and treatment. Regular tests of eyesight and hearing and dental check-ups will all be important for older people and can improve their quality of life. They can also help to prevent or lessen some health problems by paying attention to their diet and taking regular exercise. GOLD projects relating to dementia and terminal illness addressed important health-related issues including screening, diagnosis and treatment (see below). A major project on women’s experiences of the menopause raised many issues of much wider relevance including: the need for accessible information; the provision of training and information resources on health matters for staff in learning disability services and developing the capacity and skills of mainstream health services staff to respond to the health care needs of people with learning disabilities.

Older family carers

Older family carers of people with learning disabilities need support for their caring role. This has often been a mutually satisfying and rewarding experience, but as carers grow older themselves, families may
benefit from receiving more practical and emotional support, whether from voluntary agencies or statutory services. People with learning disabilities are living longer so they are more likely to outlive their parents, making it important for families to start thinking ahead and preparing for the future. Several GOLD projects focused on older carers, demonstrating that careful work over time needs to respect families’ individuality and allow them choice and control about future options. Older family members have often cared for their relative single-handedly, making minimal use of learning disability services because they have lacked information about them or do not trust others to provide a quality service. With sensitive support and the provision of information about learning disability services, carers may become more confident about using services such as short breaks. There is no single optimum strategy of helping families start preparing for the future, but GOLD projects found that work with individual families and support groups were both of benefit. Other family members and close family friends can also play an important role in continuing to support and advocate for the person with a learning disability after parents are no longer able to do so.

Where people are living

As people with learning disabilities grow older, they should be able to choose where and how they live and with whom. Their living arrangements may also need to take account of age-related changes such as physical disability or illness in terms of support and the physical environment. Some people will want to continue living with their families or in some kind of residential service. Others will decide they want to move, either to live alone or with different people. If family carers have died or become too frail to continue supporting them, some people will want to remain in the familiar environment of their family home. A GOLD project explored how this could be organised, with owned or rented property and how the person with a learning disability can obtain the additional support they may need. The significant number of people with learning disabilities who are living in older persons’ residential care or nursing homes is a particular concern. Reasons for these placements include: the death of a family carer; reorganisation or closure of a learning disability residential service; or closure of another older person’s home. Most people with learning disabilities are younger than other residents and receive a poorer quality service than they would in learning disability services. There is an urgent need to increase substantially residential options for older people with learning disabilities.

Supporting people with Down’s syndrome and dementia

Compared with the rest of the population, people with Down’s syndrome have a greatly increased risk of developing dementia (especially Alzheimer’s disease), although many families and staff in learning disability services are unaware of this. Nearly half of people with Down’s syndrome will develop dementia in their 30s, 40s and 50s. Increased life expectancy makes it imperative that commissioners and providers develop services to meet this growing demand. New residential and day services and adaptations to existing services will be required. Screening is of crucial importance. Following diagnosis, people with Down’s syndrome and dementia will need flexible packages of care so that they can be supported through the stages of their illness. Careful attention will also need to be paid to the physical environment to minimise disorientation and maximise people’s skills and abilities. Staff will need information, training and skills development to offer high quality support at all stages. Family carers and other people with learning disabilities will also need information and support. A GOLD project has produced a training resource for staff and carers and a series of illustrated booklets for people with learning disabilities.
Terminal illness

A GOLD project undertook a series of case studies of people with learning disabilities who had died and the experiences of those who had cared for them. These provided signposts for how services can prepare for and respond to people with a terminal illness. Like anyone who is terminally ill, people with learning disabilities should have a ‘good death’, characterised by: prompt diagnosis; informed choice about treatment options; appropriate transition from curative to palliative care; well managed physical and psychological symptoms; seamless inter-agency working and support for relatives, carers and friends before and after the death. Good practice guidance has been drawn up to enable services to provide the best possible care and support. If possible, people should be able to die in their own homes. For people in residential services, resources need to be available to provide additional support, including extending the hours and roles of care staff. Annual audits of deaths can enable community teams to review inter-agency working, consider the involvement of specialist services such as hospice home care teams, and establish protocols for decision making about issues such as disclosure and channels of communication.

Recent national policy and strategy reviews offer an excellent opportunity to address the issues raised by the GOLD programme and Today and Tomorrow concludes with a series of recommendations addressed to service planners, commissioners and providers which can offer ways of instigating change and making progress. Since the 1970s, increasing numbers of people with learning disabilities have moved out of long-stay hospitals into the community. That, together with their increasing life expectancy, should be celebrated. The challenge facing us now is to ensure that the needs of these citizens are well met as they grow older.
1.1 Why the GOLD programme?

*Today and Tomorrow* is the report of the Growing Older with Learning Disabilities (GOLD) programme of the Foundation for People with Learning Disabilities. GOLD was set up to draw attention to the lives of older people with learning disabilities across the UK. By funding and co-ordinating a range of projects, GOLD aimed to increase our understanding of older people’s concerns and how services or older family carers can help them realise their aspirations. By supporting and disseminating innovative practice in this field, it was hoped to have a positive influence on future service developments.

The GOLD programme was set up in response to a number of recent reports which had highlighted the needs of older people with learning disabilities. For example:

- *Building Expectations*, the Foundation’s inquiry into services and opportunities for people with learning disabilities, had concluded that "the needs of the growing numbers of elderly people will require particular attention". The inquiry’s report also drew attention to the fact that some people will be living with parents who may be ‘elderly and frail’. (Mental Health Foundation, 1996)

- A review of the literature on residential services and family caregiving for older people with learning disabilities, commissioned by the Foundation, suggested "a number of areas in which new initiatives would be welcome". (Hogg and Lambe, 1998)

1.2 Background: the national policy context

The GOLD programme was timely, coinciding as it did with major learning disability policy reviews by governments in England, Wales and Scotland. These provided invaluable opportunities for the GOLD programme to help ensure that the concerns of older people with learning disabilities and older family carers formed part of the national agendas.

**England**

The White Paper, *Valuing People* (Department of Health, 2001a), is a major strategy document which provides a new vision for learning disability services based on the principles of rights, independence, choice and inclusion. The strategy emphasises the importance of effective partnership working between people with learning disabilities, their families, the statutory agencies and private and voluntary organisations. *Valuing People* specifically addresses issues relating to older people with learning disabilities and older family carers including:

- changing patterns of residential care for people previously living in long-stay hospitals and now living in a range of community-based settings;

- the development of person-centred plans which take account of people’s changing needs for health and social care;
developing plans around packages of occupational and recreational activities and residential supports for older people with learning disabilities who are more mentally alert and whose aspirations are more typical of younger people, but who currently may be misplaced in older persons homes;

- meeting the needs of younger people with learning disabilities who develop dementia in partnership with mental health services;

- partnership working between learning disability services and older people's services;

- planning ahead for those living with older carers.

Scotland

The Scottish Executive has published and consulted on a major review of services for people with learning disabilities. The Same as You? (Scottish Executive, 2000) acknowledged the concerns of older people. They should benefit from some of the review's broader recommendations including:

- better joint working between health and social services;
- the appointment of local area co-ordinators;
- support for local advocacy services;
- more short breaks for people with learning disabilities and their families;
- the closure of all long-stay hospitals by 2005.

Wales

The Learning Disability Advisory Group for the Welsh Assembly has published a review and consultation document (National Assembly for Wales, 2001) which included the following points:

- specific policies/strategies to meet the needs of older people with learning disability should be prepared both nationally and locally;
- the increasing longevity of people with greater and lesser disabilities must be recognised in the services provided;
- people of all ages should receive support commensurate with their needs to enable them to live in their own homes or with their families;
- policies and services are needed for day opportunities for adults above retirement age.

Northern Ireland

The Department of Health and Social Services and Public Safety is responsible for the foundation of policy. A Department Review in 1995 made a strong commitment to inclusive services. It is due to be reviewed.

The GOLD programme was UK based. There are some differences in each country's social and health care systems, and all face continuing reform and reorganisation. In addition, developments in generic policy areas such as the National Service Framework for Older People (Department of Health, 2001b) will impact on the lives of older people with learning disabilities. There can also be widespread variation in the quality and range of services in a particular locality. The support older people with learning disabilities
and older family carers receive is dependent on the various services for people with learning disabilities, family carers and older people generally and the extent to which they work in partnership. Ideally all these services should be working together to provide consistent and high quality support and it is hoped that this report will stimulate greater cohesion, in the interests of older people with learning disabilities and their families, so that individual packages of support (including care) are informed by shared expertise.

1.3 Who are the older people with learning disabilities and older carers?

The main focus of the GOLD Programme was on people over 50. However, some of the findings will be relevant to younger people with learning disabilities because:

- approximately 11% of people with Down’s syndrome will develop dementia in their 30s or 40s (see Chapter 7);
- women with learning disabilities may experience an earlier menopause than the majority of other women (see Chapter 3);
- some people in their 30s and 40s are living with older family carers (e.g. Wandsworth Rathbone survey);
- among the Pakistani community, some school-age children are living in families where the male carer is in their 60s or 70s (although female carers are likely to be younger) (see Chapter 4).

It was necessary to adopt a flexible approach to defining ‘older’ people, but local service planners, commissioners and providers will also need to be aware of current and future trends. This is addressed in Appendix 5 which sets out:

- overall numbers of people with learning disabilities;
- factors influencing the numbers of people with learning disabilities;
- changes in life expectancy for people with Down’s syndrome, people with severe learning disabilities and people with mild learning disabilities.

The GOLD projects supporting older family carers were focusing on carers in their later 50s or older. It is important to recognise that older carers are a very diverse group; mostly they will be parents, but they could be grandparents or siblings, for example; some will be relatively healthy and active, while others will be more physically and/or mentally frail.

What they do share in common is the fact that being carers of a relative with a learning disability will inevitably have had some impact on their lifestyle. Caregiving by older parents can be a positive and rewarding experience but it can also bring added stresses and strains over the years, particularly when someone requires high levels of support and the carers themselves become frail.
1.4 The work of the GOLD programme

The work of the GOLD programme (1998-2002) was guided throughout by two groups: an advisory group of trustees, professionals and family carers, and a group of older people with learning disabilities: the GOLD Over 50 Saturday Group (for membership see Acknowledgments).

The main activities were as follows:

- 13 external projects were funded (see Appendix 1). They were selected on the basis that they met one or more of the following criteria:
  - to seek to fill gaps in research;
  - to develop innovative ways of meeting needs;
  - to produce training resources;
  - to provide a geographically representative spread.

- A series of in-house GOLD projects (see Appendix 1) which included:
  - the work of GOLD Over 50 Saturday Group;
  - a survey to gather the views of older people with learning disabilities and family carers about their circumstances and experiences;
  - a study of older people with learning disabilities in residential services for older people.

- The programme supported the development of a broad network of people committed to the well-being of older people with learning disabilities.

- The publications and activities aimed to disseminate information about GOLD's work are referenced in Appendix 2.

1.5 What were the main issues for the GOLD programme?

In developing the programme of work, advice was sought from the GOLD advisory group whose members identified a series of major areas for attention. These programme areas were grouped under the following broad headings (for details of the projects see Appendix 1):

- Social inclusion of older people with learning disabilities;
- People with learning disabilities living with older family carers;
- The needs of those who develop dementia, particularly people with Down's syndrome;
- Life changes for people with learning disabilities as they grow older (including the menopause, and support in terminal illness).

Within each of these areas, the GOLD programme has been extremely diverse. Projects focusing on older people living with family carers addressed areas as wide-ranging as housing, planning for the future, and use of adult family placements and supporting families from the Pakistani community.
1.6 The voices of older people with learning disabilities and older family carers

One of the Foundation’s strengths is its commitment to user involvement. In the GOLD programme:

- All externally funded projects were expected to find ways of involving users in their work and some focused specifically on ascertaining the views of older people with learning disabilities and their elderly family carers (e.g. the Planning Ahead project and the Looking Forward project).

- In-house GOLD projects were also committed to strong user involvement, notably through the establishment of the Over 50 Saturday Group as well as through a survey.

This report has sought to reflect this strong element of self-advocacy by quoting the views and experiences of people with learning disabilities as widely as possible so that their voices are heard throughout the document.

The members of the Over 50 Saturday group as well as others who participated in some of the GOLD projects, made a video in which they express what is important to them as they grow older. They talk about activities they enjoy, where they live, friendships and relationships, health issues and facing bereavements. This is another way in which the voices of older people with learning disabilities can be heard. (See Appendix 2)

1.7 Today and Tomorrow: aims and readership

This report has been written with the following broad aims:

- to share the findings and lessons from the GOLD programme;

- to outline the major challenges in supporting people with learning disabilities who are growing older and older family carers;

- to expound how their needs may best be met;

- to draw together work from a number of different sources, including the GOLD-funded projects.

The report has been written with the following readership in mind:

- policy makers
- commissioners
- care managers
- service providers including managers, front-line staff and other practitioners.
1.8 Concluding comments

Today and Tomorrow draws attention to some of the shortcomings in current service provision for older people with learning disabilities and older family carers. However, the GOLD programme also came across many older people with learning disabilities who were leading full and active lives or receiving excellent support for age-related needs.

Drawing on the rich and varied written and oral materials about the work, this report seeks to capture the experiences and learning of everyone involved in the GOLD programme. These experiences are illustrated at various points in the report in order to communicate something of that learning. Hopefully this report will help services enrich the lives of all older people with learning disabilities.

Today and Tomorrow underlines the requirement for services to think today about how they will meet people's changing needs and support them as they grow older. Many of the challenges of old age such as the death of family carers and the possible onset of health problems are predictable and so services should plan ahead in order to meet these challenges as they arise.

Current service planning will affect people's lives in years to come. If, for example, services invest in supporting people to maintain their family and other relationships there is more chance that people with learning disabilities will continue to have an active social life. But on the other hand, if people's existing relationships are undermined by, for example, being moved away from family and friends, the risk of isolation in old age is increased. Today and Tomorrow advocates facing the future and meeting needs when they arise, sensitively and appropriately.
Chapter 2

An Active Life

Friends, Day Opportunities and Leisure

When people get older, they can do lots of different things
(GOLD video)

2.1 Introduction

How older people with learning disabilities spend their days, evenings and weekends and who they spend that time with, formed an important part of the GOLD programme. As they grow older, people’s quality of life is often largely determined by whether or not they can enjoy an active and fulfilling lifestyle and have a network of friends and acquaintances around them.

GOLD funded two service development projects but research also enabled the Foundation to ask people with learning disabilities about their current activities and friendships and what their aspirations were. The views of family carers and staff were also sought. This chapter, therefore, draws on the following work in the GOLD programme:

- East Lothian Care and Accommodation Project (ELCAP) ran a project to enable older people with learning disabilities, with support, to become involved in leisure activities within their local community.
- Enable Scotland set up a Community Allotment Club for older people with and without learning disabilities which would offer a recreational activity and create opportunities for making new friendships.
- Wandsworth Rashbone’s Looking Forward project interviewed people with moderate learning disabilities living with family carers over 50. They were asked about their current lives and hopes and plans for the future including friendships, daytime and social/leisure activities.
- An in-house GOLD project carried out a survey, asking what was good and what was difficult about growing older. Social and leisure activities and friendships were mentioned by two thirds of survey participants (Thompson, 2002).
- The GOLD Over 50 Saturday Group acted as a reference group for the programme but those who were involved also valued the opportunity to make new friends and share social activities outside of the meetings.

From the GOLD programme it was very clear that as people grew older it was important to value and protect their activities and friendships; create opportunities for people to try out new activities and make new friends; and support people to take account of their changing and age-related needs.

For people with learning disabilities, activities and friendships are often inextricably linked. Services such as day centres, for example, are often people’s main point of social contact. When people have been attending a centre for many years, they are likely to have developed friendships with some other users through participating in shared activities.
Friendship patterns will vary between individuals depending on a number of factors including:

- Individual personalities - some people will be more sociable and outgoing than others, while others will find this kind of contact more difficult.
- People’s relationship networks will often reflect the services they have used. Where services have been re-developed or closed down, people may have lost contact with former friends.
- Where people live can affect the kind of activities they access, whether they live with their families, in residential provision run by learning disability services or in an older person’s residential or nursing home.
- The rate at which someone ages and the effects of the ageing process can make it difficult to maintain activities and friendships, for example, if they develop dementia or become seriously physically disabled.

The GOLD programme learned about good things which were happening for some people with learning disabilities, who were involved in a wide range of activities.

People who took part in the GOLD in-house survey (Thompson, 2002) were participating in many different activities:

- We go bowling and play darts
- I like going for walks with my friends
- Going out to the shops and to church
- Going to the pub
- I enjoy travelling on buses and going shopping
- I like knitting and organ music
- I have my own allotment
- I like Irish music
- I like going to the art group
- I go to church with my friends
- I go to concerts.
Some people were enjoying an active life, involved in lots of different shared activities, but for others, growing older had prevented them from taking part in activities which had previously been an important part of their lives.

Peter lives in a group home with three younger men but, when he reached the age of 65 he was ‘retired’ from the day centre he’d been attending for many years. The minibus still collects the other men each morning but Peter finds this very distressing, though staff in his house are trying to get help for him to talk about this with someone.

The challenge for the future is how to maximise people’s opportunities for participating in satisfying activities and spending time they enjoy with friends.

2.2 Friendships

The roles of friendships

Friendships can have a significant impact on people’s general well-being and quality of life. Michael Bayley (1997) suggests that, for people with learning disabilities, relationships with others can meet various needs including affection and security; knowing who we are; sharing feelings and ideas; opportunities to share activities and interests; and practical help. Friends can also be a safety net for support during some of life’s adverse experiences such as bereavements (which are increasingly common as people age). According to Hooyman (1983) ‘social support for older people appears to be related to higher morale, less loneliness and worry, feelings of usefulness, a sense of individual respect within the community and a zest for life’.

Mabel and Corinne are friends who met when they were living in the same long-stay hospital. Although they both moved out and live some distance from each other, Mabel still visits her friend and she is also planning to bring Pauline, another friend from hospital days, so they can all meet up.

(GOLD Video)

A quarter of participants in the GOLD survey (Thompson, 2002) also mentioned friends, including some of the people they were living with. Friends included people they socialised with and with whom they sometimes shared holidays.
Wanting more friends

Despite hearing about these positive experiences, many people with learning disabilities are acutely aware of their lack of friends and their limited social networks. As Wandsworth Rathbone’s Looking Forward survey found, this was a dominant concern for many people, who wanted to have more friends and, linked to this, would like to have taken part in more social and leisure activities. Nearly half asked for information about friendship schemes as they generally only saw their friends within structured activities. Several people said they would like to have friends round for supper; for example, one or two wanted to meet some new people and a few wanted relationships which could lead to marriage.

Among the parents interviewed for the Wandsworth Rathbone survey, some were aware of their son or daughter’s lack of friends which seemed to be related to lack of self-confidence, making it difficult for them to build friendships. As one parent said:

He’s very self-conscious, I think. He’s got no self-confidence.

Workers who participated in the survey also mentioned people’s lack of friends as an issue:

(Having) no friends was a very common issue. Sometimes this was as a result of isolation and loneliness… It seemed that people did not have the space or at times the skills and confidence in establishing and maintaining friendships. This could be simply asking someone for their telephone number or asking them round to their home for supper. This is an area that people were very keen to work on.

Risks to people’s existing friendships

Even though some people may lack the skills and confidence needed to make friends, there are other reasons why people may have few or no friends. The GOLD programme was able to identify a number of reasons why many people had limited social networks. Growing older, for anyone, is often associated with a declining social network: friends move away, retirement may mean loss of contact with friends at work, there may be fewer opportunities to make new friends, and, of course, older people begin to face the death of friends.

Bigby (2000) who tracked a group of older people with learning disabilities after they had left the parental home, found that because they could face several subsequent moves, they lost contact with local neighbourhood acquaintances. Many of those who initially continued to live in the vicinity of their family home regarded one or more neighbours as friends. These neighbours were an important source of informal support, providing emotional support and sometimes undertaking tasks such as taking the person shopping or contacting relatives on their behalf. Only two of the 46 people in Bigby’s study who had moved to a different locality had retained contact with previous neighbours. (See Appendix 4)
For people with learning disabilities, though, there are some specific reasons why they may become increasingly socially isolated:

- For those living with their family, older carers may be less physically able to support them to attend social events.
- If older family carers become physically or mentally frail, their relative with a learning disability may be reluctant to leave them alone, preferring to stay at home and look after them. Thus, the person with a learning disability may effectively become a carer (see Chapter 4).
- When an older carer dies or moves into residential care, the person with a learning disability may lose contact with the family’s former social network which they shared.
- If day or residential services are unable to meet people’s age-related needs, users may be prevented from continuing to access this provision. As a result, they may no longer be able to see friends if this was the main point of contact and often no support is offered to help people remain in touch with one another.
- The redevelopment or closure of services can mean that previous users become geographically dispersed and lose contact with friends.
- New service developments may shift the focus to facilitating opportunities for people to meet non-disabled people in the local community, despite the fact that their levels of satisfaction is directly associated with the amount of contact they have with other people with learning disabilities (Emerson et al., 2000).
- Moving to a more individualised residential service can be beneficial but people living on their own may become isolated and lonely unless they are supported to maintain their previous social networks.

**When Gladys was 67** she moved from her parental home to a local residential care home for older people. Responsibility for her case management was then transferred from learning disability services to the older people’s team. Gladys was able to continue attending the local Gateway Club where she had been an active member for many years. Two years later, though, she was no longer going to the Club. Neither Gladys nor staff in the home knew exactly why this had happened but they wondered if it maybe had something to do with the minibus that used to come and collect Gladys to go to the club.

**Supporting people’s existing friendships**

As the GOLD programme found, people’s friendship networks were usually very directly tied to service settings and they often lacked the skills and resources to maintain those relationships elsewhere. This was echoed in the findings of Bigby’s Australian research (Bigby, 2000; Bigby et al. 2001). Although two-thirds of the older people in her study named at least one person as a friend, contact
was usually tied to a specific day programme or residential service; exceptionally, several people had been actively supported to socialise ‘after hours’ but this was rarely the norm and family and service providers were often unaware of friendships or discounted peer relationships. They took the view that because of their poor social skills, an older person had no friends. Services have a role to play in protecting and developing people’s informal networks of friends and acquaintances.

When the GOLD Over 50 Saturday Group became established, the fact that its members had been able to meet new people and make new friends raised important issues about the need to find ways of facilitating and supporting these friendships.

Supporting friendships and the GOLD Over 50 Saturday Group

After the first year’s meetings, members of the group were asked what they liked about the project. It was clear that having the opportunity to make new friends and spend time with them was very important. However, since most of the group were unable to keep in touch or meet up without support it was decided to try and ensure this could be an option for everyone when the group was due to end three years later. Activities undertaken to meet this aim included:

Supporting people to visit each other’s homes

For some people this was the first time friends had visited. Over time some people were able to visit each other independently having found out where they lived and how to get there.

Supporting people to go out and socialise

Support was also given to enable people to set up other social activities such as meeting in a pub, watching a member’s drama performance, and going to a disco. An additional monthly social gathering was started at an entertainment complex, the idea being that after the monthly work meetings ended there would be a familiar opportunity to see each other regularly. There would be a year to support people to resolve any problems such as knowing when to meet, where to meet, how to get there, what to do together and what the costs would be.

The need for ongoing support

Despite this, it became clear that the group would need some external support if it was realistically going to continue to meet in any way. Some people (and one or two carers) still wanted the security of having someone there in a ‘staff’ role. There were also several other issues including: knowing how to involve the quieter group members; knowing what to do when arrangements for taxis, which some people needed to use, did not materialise.

From these experiences, GOLD has learned important lessons about resourcing people’s social networks. Resources have been obtained for continuing support to enable the group to meet and socialise together.
Apart from group activities, service providers will have to be more aware of the skills and resources people need to stay in touch with friends and see them outside services. This involves more than asking friends to someone's birthday party, but also recognising that most people socialise more frequently than once a year. Making phone calls, sending letters or e-mails and being able to travel on public transport are all matters which most non-disabled people take for granted but which can make all the difference to keeping up with friends. People with learning disabilities may need support to maintain and develop social networks.

**Creating opportunities and fostering new friendships**

Many people make friends through some kind of shared activity whether that involves work or leisure pursuits. Two of the GOLD-funded projects focused on creating opportunities for older people with learning disabilities to meet new people and perhaps make friendships through shared activities. Both projects also involved activities with non-disabled people as well as other people with learning disabilities, demonstrating that it is feasible to support people to access activities which promote their social inclusion.

**ELCAP** provides supported accommodation for people with learning disabilities, including older people who have moved out from long-stay institutions. Because they have been away from their communities for so long, they have missed out on natural opportunities to develop local acquaintances and friendships. Although other people of similar ages were often familiar figures in these small towns, the people with learning disabilities were rarely bumping into people they knew going down the street or in the supermarket, for example.

To try and tackle this relative social isolation, ELCAP sought to match the individual interests of a group of older people with learning disabilities with existing activities in the community. As a result, individuals are now participating in gardening and walking with the U3A (University of the Third Age), bowling, swimming, tea dances, a local environmental project, an art group and a pensioners' club—all activities which are accessible and affordable.

ELCAP also set up some new and inclusive activities for older people with and without learning disabilities. To date these have included carpet bowls and regular tea dances which are now enjoyed by the whole community:

- **Andrew** goes to the tea dances without support and always finds a dancing partner. Jim also attends the tea dances with support and although he only used to stay until the cup of tea, he now stays to the end and dances.

Increasingly the older people with learning disabilities involved are becoming familiar figures in their community and the seeds of a few friendships have been sown:

- **Isabel** who has been attending the tea dances regularly is now recognised and chatted with on the High Street whenever she is out and about.
Enable, Scotland was funded to set up and run an integrated Community Allotment Club which would provide an appropriate activity for older people with learning disabilities but also 'create an environment where friendships can be made between disabled and non-disabled people'. After two years, one of the two plots has been particularly successful in meeting this aim.

Two men with learning disabilities have shared a plot since the start and have worked together on preparing the ground. The following year they were joined by another local man. Although he has since moved on to work on his own allotment, two further non-disabled men have joined the Allotment Club and share the plot with the original two men.

Because this first plot is productive and well maintained this increases the contact and integration with people working on neighbouring plots. The Allotment Club members are seen as 'serious' about their gardening. Many fellow allotment holders are also retired and this provides a good opportunity for club members to meet and chat on a regular basis with others of a similar age and also have a shared interest.

All members were able to support one another. Although the men with learning disabilities needed help with tasks such as identifying when to sow and plant on their plot, the group who worked on the second plot included two non-disabled men recovering from heart attacks and one who had a mental illness.

### 2.3 Day opportunities

It can be difficult to separate out daytime activities from how people spend their time in the evenings and at weekends, but organised provision, is generally available on a Monday to Friday daytime-only basis, often leaving people with little to do at other times. This was highlighted by the fact that the GOLD Over 50 Saturday Group wanted to meet at the weekend. As one person said:

'[I] don't like staying at home, being bored ... [I]d rather go out'.

Traditional day centres have been subject to considerable criticism (e.g. Dowson, 1998) and recent policy reviews and day service developments (see below) place a question mark over the longer term future of these centres which, despite some shortcomings, can have an important part to play:

- Organised day services offer opportunities for regular contact with friends. For other people, the workplace can provide this kind of social contact and it can extend into evenings and weekends through social activities, but people with learning disabilities may not have these kinds of opportunities without support from others.
- Day services can provide a regular break for family carers and as they grow older the need for this regular 'respite' can increase. This is in marked contrast with older people's services which recognise the importance of day centres and other activities to provide carers with respite, which can counter their isolation or enable them to continue in employment.

- As people move into more individualised residential provision, they may be more dependent on regular access to day services for the social contact and activities they offer.

- Some older people enjoy going to a day centre and should be able to continue doing so until alternative options are available.

**Positive day opportunities**

GOLD-funded work such as the ELCAP project and the Community Allotment Club offered some positive alternatives to organised day services. And the programme also knew of other initiatives which were offering older people with learning disabilities interesting daytime activities.

Since 1996, *Age Concern Newcastle* has been working to increase the accessibility of its learning and leisure programme for older people with learning disabilities. They participate in *Age Concern*'s general programme and there are also activities targeted at their specific needs and interests. This has given people the opportunity to be involved in line dancing, music, keep fit, art, and bowls. Some groups are ongoing and others, such as first aid, are short term. To continue improving accessibility a user action group of people with learning disabilities was set up to steer future developments. Individuals have also contributed to staff and volunteer training within *Age Concern* and in the wider community.

Some older people with learning disabilities were content with changes to their days as the following comments in the GOLD survey (Thompson, 2002) illustrate:

*I go to the Help the Aged day centre. The day centre is better than the Adult Training Centre that I used to go to. They are more friendly and it is quieter.*

*I am* happy with retirement.

*I like gardening and go up to the garden centre to work. I've been going there about ten years.*
Others, like Ann who is in her early 60s, enjoy being active, want to continue with their current activities and are not contemplating retirement:

"I live in a nice bungalow, I do my own shopping on a Monday. I can go out when I want and nobody bosses me around. I go to Skills for People [a self-advocacy organisation] lots. I get on with everyone there and with the staff. There is one thing about them, they are very nice to you. I don’t think I will give it up. I’ve been going there since 1994 ... I want to go there for as long as I can. I help with the drop-in; it is nice and I like to wash up. I have learned a lot." (GOLD Nuggets 2:3)

Concerns about day opportunities

More worryingly, the programme also found that for some people with learning disabilities, growing older could mean they were left with many unfilled hours during the day.

The GOLD survey of people with learning disabilities living in older persons’ residential care or nursing homes which asked about their activities found that although nearly half of them had activities outside the homes more than three times a week, just under a third were going out less than once a week. Overall people could expect to be involved in regular activities for just two half-days a week outside the home. Health problems were cited as the reason for some people not getting out more, but the unavailability of day centres was also mentioned.

Participants in the GOLD in-house survey (Thompson, 2002) drew attention to their day activities, but although most were positive, others had few or no day opportunities. Family carers and staff were more critical of day provision, particularly inflexible policies of ‘retiring’ people from services and the lack of resources which were restricting people’s lives unnecessarily.

The college says we are now too old to attend.
If I’m well enough [I] would work after 65, but I don’t think [the residential service] will let me.

The Wandsworth Rathbone Looking Forward project found that some people had very little structure in their lives and even those who were attending some kind of day provision found it limited and wanted to try something a bit different: As the report concluded:

"It is vital that people ... are offered a variety of day provision services so that they are stimulated and encouraged to develop themselves and their skills, building ongoing and new relationships as others do."

Modernising day services

Increasing attention has focussed on developing positive alternatives to day centres in recent years (e.g. McIntosh and Whitaker, 1998) and there is a growing consensus that some changes are desirable. The Foundation’s (1996) Inquiry emphasised the need for reform, while recommending the expansion of alternatives to day centres. As the Inquiry’s report Building Expectations, explained:
We have a two-pronged view of the future of day centres. On the one hand we believe that they should be encouraged to change from within.... At the same time, however, there is a need to expand opportunities beyond day centres (Mental Health Foundation, 1996).

More recently, policy reviews in England, Scotland and Wales have set out new agendas for modernising and expanding day services:

- *Valuing People*, the White Paper for England, proposes a five-year programme to modernise day services so that resources currently committed to day centres provide people with learning disabilities with new opportunities to lead full and purposeful lives and enjoy greater social inclusion (Department of Health, 2001a).

- The Scottish review, *The Same as You?* (Scottish Executive, 2000) also discussed the modernisation of day services. Day opportunities were seen to be important to people with learning disabilities, but the review proposed that traditional day centres should be redeveloped as resource centres, supporting people to use more community resources such as further education, jobs, and sports and leisure activities. However, it makes no comment on policies which exclude users when they reach a specified age.

- The Welsh review of learning disability services (National Assembly for Wales, 2001) suggested that 'traditional large day centres cannot provide the range of occupation required', and the development of alternatives 'has not been consistent', recommending that 'further change is required'.

**Opportunities and threats**

As with any kind of change, the reform and redevelopment of traditional day provision presents both opportunities and threats. The GOLD programme's work identified some of these, particularly in relation to older people with learning disabilities.

Day centres provide a reliable and regular service for people living with older family carers who depend on this type of provision for a break from their caring role and withdrawing that service may jeopardise their continuing ability to provide care. As the Scottish review pointed out, it would be pointless if new developments placed heavier burdens on family carers (Scottish Executive, 2000).

The policy reviews' recommendations that resources should be invested in developing alternatives to day centres such as supported employment and education are welcome, but there is a danger that these new services could focus on working with younger adults at the cost of meeting the needs of older people with learning disabilities.

Where older people have been able to access new day activity programmes which are offer a better quality of service and are more able to meet individual needs and preferences, they may end up having a very part-time day service rather than attending a day centre five days a week.

There is already some evidence that existing users are being excluded from day centres when they reach a specific age. While this may be appropriate for and acceptable to some people with age-related needs, for others it is unnecessary and inappropriate, particularly if alternative activities are not made available.
New policies and service developments face the challenge of how to take on board the needs of older people with learning disabilities, including those who already use traditional day services as well as those who currently have no organised provision. Regardless of whether people are living with family carers, in learning disability residential services or in older person's homes, individual person-centred plans will need to consider how people are going to access fulfilling and enjoyable daytime activities which also provide opportunities to maintain contact with friends.

Accessing older people's day services and recreational facilities may be an option for some people. The Age Concern Newcastle scheme is one example of how this can work well, provided that the particular needs of people with learning disabilities are recognised and addressed. Other examples of good practice have been described by Janicki and others (Janicki and Ansello, 2000).

Other older people may prefer to continue using a day service specifically targeted at older users. One example of how day centres can be adapted to meet changing needs is described below and a further example (the COPE project) can be found in Chapter 7.

**The Greenhouse Project.** In the London Borough of Westminster, was developed on the same site as a larger day centre for people with learning disabilities, when the need for a facility specifically for older centre users was recognised. Having initially set aside a room, this new unit was then opened. People attend the Greenhouse on a sessional basis according to needs and interests; activities include keep fit, reminiscence work and maintaining existing skills. Some people also access mainstream day services for older people. Because of the shared site, people are able to make a gradual transition and remain in contact with younger friends in the main centre.

If more services like the Greenhouse Project are to be set up to meet the specific needs of older people with learning disabilities, they should have the following features:

- flexible ages of entry based on individual needs;
- offer people choices from a range of activities;
- offer people the choice of whether to learn new skills or activities;
- support people to stay in touch with friends from services they have previously used;
- have the capacity and commitment to continue supporting people who have age-related health needs;
- sensitively support people to make the transition from one day service to another and ensure new opportunities offer them clear benefits;
- find ways to support service users and staff through bereavements.
2.4 Social and leisure opportunities

As with day opportunities, it can be difficult to separate out activities in which older people with learning disabilities can participate in the evenings and during weekends. Although some day service providers are developing a more flexible pattern of activities to include evenings and weekends, the 'service culture' is reflected in a predominantly daytime, Monday to Friday, structure and staff do not, by and large, expect to work at other times. For the majority of older people with learning disabilities that leaves many unfilled hours.

For retired people the distinction between their former working day becomes blurred and social and leisure activities can be flexibly fitted in as it suits them. People with learning disabilities will often need support to engage in these kinds of activities but may not have access to people who can offer that support.

From the GOLD research it was clear that many people wanted more social and leisure opportunities. In the GOLD survey (Thompson, 2002), two-thirds of people mentioned social and leisure activities although some staff expressed concern about people's limited opportunities, mainly because of limited resources. For example:

*Doesn't have enough money to go on a cheap holiday.*

*Una gets very depressed and upset when she can't have things that the other residents have or when she sees the others going on holidays or trips.*

*Limited resources, particularly relative to younger persons' services restrict possibilities for outings and life enhancement generally.*

Although participants in the Wandsworth Rathbone Looking Forward survey were mainly younger adults (but over 30), people were wanting a busier and more varied social life. Various people mentioned going to the cinema, day trips, dance classes, yoga and bowling, as well as special clubs. Parents too wanted more activities for their sons and daughters and nearly half wanted information about social activities - mostly for their son or daughter's benefit but also to give them some 'time out'.

Gateway clubs and other clubs for people with learning disabilities can play a key role for some people, providing a regular opportunity for people to get out of the house, meet up with friends outside day services and participate in different activities.

These clubs vary enormously in terms of their style and the degree to which people with learning disabilities have a say in how they are run. Whatever their style or 'philosophy', the fact remains that they can be a precious resource in the community. They have enabled people with learning disabilities to develop long-term friendships and possibly more intimate relationships. For parents, who have often been instrumental in setting up and running these clubs, they can also be a vital part of their own support networks, enabling them to meet up on a regular basis with other parent carers as well as volunteers. As parents themselves become more frail, however, it will also be important to think about how these clubs will continue.

Some older people with learning disabilities will have been attending these clubs regularly for many years so it is important that funding decisions allow for their continuation. With moves to greater social inclusion, there is a danger that these special clubs will not be seen as a priority by service planners, commissioners and funders if they fail to acknowledge the importance of supporting friendships between people with learning disabilities, many of whom value these highly.
2.5 Concluding comments

From the work of the GOLD programme, it is clear that many people with learning disabilities value their existing friendships but would also like the chance to meet a wider circle of people and make new friends. This will be easier for some, but others will need support and practical help with making and sustaining friendship networks. Many also want a fuller life where they can take part in various activities, whether these are daytime opportunities such as attending a day centre which can adapt to their changing and age-related needs, community activities, or social and leisure opportunities during the evenings and at weekends. Policies which seek to re-develop traditional day services and replace them with a range of alternative activities in the community will need to consider what provision they can offer older people with learning disabilities. Otherwise they may face many unfilled hours during the day rather than participating in satisfying activities and spending time with friends.
Chapter 3

A Healthy Life
Health Care and Growing Older

As we get older, we may have more problems with our health. It's important that we look after our health.

(GOLD video)

Good health is an essential prerequisite for achieving independence, choice and inclusion.

(Valuing People)

3.1 Introduction

For all older people, maintaining their physical and emotional well-being is important to minimise the risk of developing age-related illnesses and health problems. The same is true for people with learning disabilities but they may need additional support to follow a healthy lifestyle, to use existing opportunities for regular health checks and, where necessary, access health care and treatment.

Apart from the GOLD projects which focused on dementia (see Chapter 7), a major health project was undertaken to improve the support available to women with learning disabilities at the time of the menopause. The findings from that work are described in section 3.4. of this chapter.

Health-related issues were also addressed, directly or indirectly, in several GOLD projects and illustrated at various points in this chapter:

- The in-house GOLD survey (Thompson, 2002) asked people about their physical and emotional health.
- BILD’s Older Family Carers Support Groups discussed issues relating to the health of people with learning disabilities as well as carers’ own health (see Chapter 4).
- Both the BILD project and the Pakistani Older Family Carers project identified issues relating to the health needs of carers from the Pakistani and Black communities (see Chapter 4).
- The Allotment Club and the ELCAP project (see Chapter 2) focused mainly on socially inclusive activities but were also promoting people’s physical and emotional well-being.

The in-house GOLD survey (Thompson, 2002) illustrated the varied physical and emotional aspects of ageing, experienced by individuals.

Physical aspects of ageing

I have slowed up a little. I don’t like a lot of noise – I get worked up. Now I am older I forget things, I keep losing my watch.
I have more aches and pains. I feel more tired.
I keep losing my teeth.
Going bald; wrinkles; can’t run.
I’ve slowed down a bit. I’m not as quick at digging as I used to be, but it doesn’t bother me.
3.2 The health needs of older people with learning disabilities

The White Paper (Department of Health, 2001a) pointed out: 'Most people with learning disabilities have greater health needs than the rest of the population'. They are also more likely to have chronic health problems, epilepsy, and physical and sensory disabilities as well as mental health difficulties. The White Paper also drew attention to the impact of people's increased life expectancy, pointing out that: 'age-related diseases such as stroke, heart disease, chronic respiratory disease and cancer are likely to be of particular concern'.

Recent years have seen a growing awareness that people with learning disabilities need to be able to access NHS services, with additional support if necessary, so that they can obtain prompt and appropriate help for their health-related needs, from both primary care and secondary (hospital) services, whether in terms of preventive measures, screening, or diagnosis and treatment.

Specialist NHS services have traditionally met the health care needs of some people with learning disabilities, but mainstream health services will have to develop their capacity and skills to provide a more inclusive service which can address the current shortcomings which include:

- poor uptake rates by women with learning disabilities for breast and cervical screening (Department of Health, 2001a);
- inadequate diagnosis for specific medical conditions such as heart disease and osteoporosis which are both age-related (Department of Health, 2001a);
- inconsistencies in primary care and hospital provision in different areas (Department of Health, 1999a).

Ensuring that the health-related needs of older people with learning disabilities are met requires action on several fronts. Social care staff need to be more proactive in encouraging service users to adopt healthier lifestyles and supporting people to access health services. On a broader front, measures are needed to tackle root causes which are known to contribute to health problems such as poverty, social exclusion and discrimination, which people with learning disabilities share in common with other disadvantaged groups in society (Department of Health, 2001a).
3.3 Promoting health in old age

Certain health problems become more common in old age, but they are not necessarily inevitable. Accessible information, such as pictorial leaflets, is becoming increasingly available about the kind of measures which people can take to develop a healthier lifestyle and reduce their chances of developing certain illnesses and health problems. Taking regular exercise, following a healthy diet and stopping smoking can all play a part in health promotion. These measures are not necessarily particularly burdensome and activities such as taking regular exercise can even be enjoyable as some of the GOLD projects clearly demonstrated.

Studies of people with learning disabilities have found high levels of unrecognised ill-health and low levels of health promotion (e.g. Howells, 1986; Wilson and Haire, 1990). A more recent study (Emerson et al., 1999) found that the activity levels amongst adults living in learning disability residential services were equivalent to those of non-disabled people over the age of 75, which has serious implication for their cardiovascular health. The same study also found that the rate of obesity for women with learning disabilities was significantly higher than for the female population in general, which also has implications for their health and general well-being.

Physical exercise

Taking regular physical exercise helps to maintain muscle strength, reduces the likelihood of developing osteoporosis, and may reduce the risk of high blood pressure and heart disease. Exercise can also contribute to increasing people's mental well-being. Several GOLD projects provided examples of how older people can take regular physical exercise in many different ways.

The GOLD-funded Community Allotment Club in Edinburgh enabled a group of men to participate in a socially inclusive activity; work on the allotments also meant that they were having regular physical exercise.

The ELCAP project offered people a range of socially inclusive activities, some of which involved physical exercise; for example: carpet bowls, dancing, swimming and gentle exercise.

Diet

Eating an adequate amount of fresh fruit and vegetables every day, and avoiding excessive fat consumption and overeating, can help to prevent vascular disease (notably strokes), and disorders such as late onset diabetes. A good diet will also help prevent heart disease, some forms of cancer, and keeps people generally fitter and physically and mentally more able to lead an active life. Combined with regular physical exercise, a healthy diet can also help people to maintain a healthy weight.
3.4 The menopause

Attention is needed to the physical and emotional well-being of women during the menopause. Despite this being an experience common to all women, researchers have paid little attention to how it affects women with learning disabilities. Previous research has generally been from a medical perspective and has mainly aimed to establish whether women with learning disabilities reach the menopause at roughly the same time as other women or at a younger age (e.g. Carr and Hollins, 1995).

Remember that the menopause is called 'the change of life'. It's not the end of life; it's normal and nothing to be worried about. It's best to have a good time while you're here.

(Menopause video)

The GOLD-funded menopause study (McCarthy and Millard, in press) focused on the experiences of women with learning disabilities as they go through the menopause looking at:

- what they understood about what was happening to their bodies;
- what they experienced as they went through the menopause;
- what support they wanted, needed and received as they went through this transitional time.

The attitudes and practices of GPs, staff in learning disability services and parents of older women with learning disabilities were also explored.

The menopause study

Individual interviews were conducted with 30 women with learning disabilities:

- they were aged between 43 and 65, with an average age of 51 years;
- 25 were white British and five were from minority ethnic backgrounds;
- all the women had mild or moderate learning disabilities;
- all used specialist learning disability residential, day or community services;
- everyone was given an accessible information sheet which explained that they would be asked to talk about only their views and experiences (and no other procedures were involved);
- all participants signed a consent form.

Two advisory groups of women with learning disabilities helped the researchers to formulate the research questions and assisted with the development of specialist education materials, including a video and pictorial and accessible leaflets. Staff training materials were also developed and piloted with several staff teams.
The Menopause: As You Get Older, You Change is a video which the project made to help women understand what happens as they go through the menopause. The video features women with learning disabilities talking about their own experiences of the menopause, together with commentary and advice from the project leader Michelle McCarthy, and covers the following topics:

- What happens to your body; physical changes at each stage of life.
- What happens; hot flushes.
- What happens; changes to your periods.
- Keeping your bones strong; what is osteoporosis?
- Going to the doctor.
- What else can you do to help yourself?
- Feelings about loss.
- Getting older and enjoying yourself.

Findings from women with learning disabilities

Most of the women with learning disabilities who were not yet menopausal did not know that their periods would eventually cease. However, most of the women who were already menopausal did know that women eventually stopped having periods, although they did not know why this happened or what it meant.

As you get older you change, and then you go through the menopause and your periods stop. I might miss months and keep missing different months and I get a bit worried and the doctor said: 'Don't worry about it; it happens to everybody'.

None of the women interviewed had borne children and most did not express strong views about having wanted children or being sad that this was no longer possible. This is likely to reflect the fact that most did not lead independent lives. However, some of the women in the advisory groups, who tended to be more able and independent, did express sadness that they had been denied this part of their lives.

The vast majority of the women did not know anything about other women’s experiences of the menopause (e.g., staff or relatives). Most did not recognise or understand the commonly used terms ‘menopause’ or ‘change of life’. Although some women did, most did not know about the risks of osteoporosis and the importance of trying to keep their bones strong.

[You] have to eat healthily and drink milk to keep [your] bones strong. I drink milk before I go to bed at night. It helps the bones in my arms and legs to get stronger.

Almost all the women said they wanted other women to give them support through the menopause. This was usually staff in learning disability services, sometimes family members, and sometimes doctors. They saw little role for men in giving them advice or practical and emotional support. However, those women who had male partners wanted them to be aware and generally supportive.
I don’t get moody but I get kind of upset with these hot flushes ... my sister has talked to me, calmed me down and tried to help me relax ... once I relax I’m all right.

I take evening primrose oil tablets and they help to calm me down a lot and I’ve got a nurse I see once a fortnight and I speak to my keyworker as well.

No obvious differences were found in the physical symptoms experienced by women from Black and minority ethnic communities compared to white British women. However there were more social differences in that the Black women tended to have more contact with their extended families and get more social support from their communities e.g. church groups.

Talking to women about the menopause inevitably raised more general issues about ageing and ill-health and many women got upset thinking about the bereavements they had experienced (usually the death of one or both parents).

I cried when I lost my mum, when I heard that she’d died ... My sister says we are doing all right but it doesn’t matter who looks after you – there’s nothing like a mother and I miss her.

My mother ... was very old and she was getting ill ... and they tried to help her and she died. And I was so upset when they told me but I know she’s looking down at me and saying get on with the rest of your life, enjoy your own life with your friends.

**Findings from GPs**

The majority of GPs had little or no experience of treating women with learning disabilities for menopause-related concerns. GPs frequently suggested that they would recommend Hormone Replacement Therapy for troublesome menopausal symptoms. Some recognised the problems of obtaining informed consent to this treatment, implying that this may prevent them from prescribing it. Others said that they would prescribe it for women who could not consent, but would do so on a 'best interest' basis. A few GPs said that they needed to be proactive in trying to 'reach out' their services to older women with learning disabilities, especially those who lived just with their fathers.

Very few women in the study, except the most able and independent, saw the doctor alone. In most cases, a relative or care worker would usually accompany them. This could be positive, if they acted as advocates for the women, explaining and interpreting symptoms and treatment, but it could also have a negative effect when they acted as a 'filter' or 'barrier' by rationing women's access to medical help.

I’m going to the doctor’s ... and [I’ll] make an appointment for them to tell me about the menopause and tell me what’s going to happen because I’m getting a bit worried.

I don’t like telling men [doctors] about my problems. I like to have a woman [doctor] because they know more than men do.

I’ve been to the doctor and she’s going to refer me to a menopause clinic.
Findings from staff in learning disability services

Only a few staff were confident that women with learning disabilities generally understood what was happening to them during the menopause. Otherwise staff tended to emphasise the difference between women describing what was wrong and understanding what was wrong.

The vast majority of staff felt strongly that women with learning disabilities should be educated about the menopause and usually saw this as a more appropriate role for staff in residential rather than day services.

Staff were also concerned that doctors may not take women’s menopausal symptoms seriously.

Findings from parents

All the parents who took part in the research were mothers who said that they played a key role in observing and interpreting menopausal changes in their daughters. They also felt that they were the best people to educate their daughters about the menopause although they did also see a role for staff in learning disability services and for medical personnel.

About half the mothers saw similarities in their own menopausal changes with those of their daughters. Some of the mothers clearly recognised that they had influenced their daughters’ attitudes to menstruation generally and that this had usually been to pass on negative attitudes.

Conclusions from the study

A number of important conclusions emerged from this menopause project, highlighting the role that staff in learning disability services can play in supporting women through the menopause.

- Women with learning disabilities have the right to basic information about what is happening to their bodies and to learn about experiences they have in common with other women.
- Many women with learning disabilities will need help to alleviate some menopausal symptoms they find troubling (e.g. hot flushes; heavy periods).
- The women expressed very clear and strong views about wanting support from other women as they went through the menopause.
- Staff can provide opportunities for women to talk about their feelings and experiences and learn from one another: women’s groups can fulfil this function very well.
- Women who had hoped to have a baby and now realise this will never happen may need sensitive help in coming to terms with this.
- Older women staff could usefully share their experiences and feelings with women with learning disabilities to help ‘normalise’ the experience.
3.5 Screening

Like the general population, people with learning disabilities stand an increased chance of developing more health problems as they grow older but if their currently low uptake of mainstream screening facilities is to be tackled, screening needs to be accessible and to take account of their particular needs. As the following example from the BILD Older Family Carers groups illustrates, initiatives which specifically target people with learning disabilities can increase their access to health care and treatment by picking up on unattended problems.

A new health screening process for people with learning disabilities resulted in 500 referrals being made after the first 78 people had been seen. In another area, a new health care book for record keeping and assessments for older people with learning disabilities was introduced which one carer described as 'brilliant'.

Enabling older people with learning disabilities to have regular screening can enable health services to detect, and where necessary treat, potentially life-threatening illnesses such as cancer or heart disease.

Cancer screening

A recently published report on cancer and people with learning disabilities (Hogg et al., 2002) looks at: particular risks for people with learning disabilities; ways of making health education programmes accessible and improving rates of early diagnosis. The specific mention of people with learning disabilities in the National Cancer Plan now being implemented means that they should benefit from this wider initiative (Department of Health, 2001a).

Sensory disabilities

Regular checks of eyesight and hearing can make a positive difference if some of the inevitable problems associated with ageing are detected and remedied, either by wearing glasses or a hearing aid, or by surgical intervention.

If someone has difficulties with their hearing, this can make it hard for them to communicate with other people, but if this is treated and they can hear more easily, social contact also becomes less stressful and more enjoyable. Otherwise there is a danger that people will become withdrawn.

Betty, a member of the GOLD Over 50 Saturday Group, found it difficult to hear what people were saying to her so they tended to shout which she didn't like. After a visit to the hospital, she has now had a hearing aid fitted in one ear.
A specialist screening service for sensory impairment found that nearly 50% of the people with learning disabilities they tested had some hearing impairment, either because of untreated infection or because of previously undiagnosed problems.

Failing eyesight is a common problem as people age, but supporting people to have their eyes tested and, when necessary, wear glasses, can also make a positive difference. Someone who finds it increasingly difficult to read (however limited their reading ability) can improve their vision with a visit to the optician. If people have better vision, they may also feel more confident about getting around in their local community; otherwise, even a trip to the corner shop can become too daunting.

The Royal National Institute for the Blind (RNIB) has produced an excellent video, Right to Sight, which, together with a training pack, shows staff how to prepare people for a visit to the optician and explains the different parts of the eye test. Another video, Sight Matters (available with or without British Sign Language), has been produced to help people understand what happens when they go to the optician.

When Roger, a member of the GOLD Over 50 Saturday Group, went to the optician, he hadn’t had his vision tested for six years. After having his eyes tested and being prescribed new spectacles, he could read twice as many lines on the test chart as before.

Dental health

Regular dental check-ups can help to spot dental disease and enable problems to be treated as early as possible. As the recent White Paper (Department of Health, 2001a) pointed out, poor oral health can lead to chronic dental disease amongst people with learning disabilities. Good dental health can make an important difference to older people. If their teeth are well cared for, this can enable people to enjoy a more varied diet and can increase their sense of well-being.

The Development Group for Community Dental Practice at the Royal College of Surgeons (RCS) and the British Society for Disability and Oral Health have developed dental guidelines for people with learning disabilities. These include advice for service users, parents and care staff, and a resources section on where to obtain further help. The guidelines are published on the RCS’s website (www.rsceng.ac.uk) and the BSDH’s website (wwwbsdh.org.uk) and copies were distributed to relevant organisations.
3.6 Treatment

If increasing numbers of older people with learning disabilities are to use mainstream screening services which will sometimes pick up on previously undiagnosed problems, they will need to be able to secure any necessary treatment, whether this is delivered through primary care teams or through hospital in-patient or outpatient services. Having health problems effectively treated can make a positive difference to people’s lives as Pat, from the GOLD Over 50 Saturday Group, found when she needed to go into hospital:

I had a pain in my back and went to the doctor and the doctor said I needed to have a hip operation. I went into hospital [and] had the operation. [I] was in bed one day [and] was up the next day doing lots of exercises. I’m walking very much better now. Going up the stairs is great but coming down the stairs is a bit difficult.

Important concerns relating to accessing treatment were also raised by other GOLD projects: people with dementia (Chapter 7) and people with terminal illness (Chapter 8).

3.7 Staff issues

As the menopause project and other GOLD programme activities demonstrated, older people with learning disabilities need to have better access to health promotion, screening and treatment. Staff in learning disability services and NHS staff, including GPs and other primary care professionals will all need to make changes to their working practices if improvements are to be made.

Staff in learning disability services:

- Can play an important role in advocating for service users’ access to health care.
- Need opportunities to participate in specialist training and obtain relevant and appropriate resources to increase their awareness and enable them to more effectively support the health needs of service users.
- Can help people with learning disabilities to obtain accessible information (e.g. pictorial leaflets and videos) about health matters.
- Have a part to play in observing and monitoring where a person is receiving treatment, identifying any benefits of the treatment as well as any undesirable side-effects and reporting these back to relevant health professionals.
- Can obtain information about straightforward alternative/complementary treatments and therapies which may be of benefit to some service users.
- Could usefully develop working relationships with GPs and other members of the primary care team.
The Learning Disability Awards Framework (LDAF) (www.ldaf.org.uk) includes the following health-related units which will enable staff to:

- **Access health care services; support a physically healthy lifestyle;**
  help the service user to manage short-term illness; contribute to the management of medication; and respond to the health care and support needs of older people (Level 2 optional units).

- **Work positively with other agencies; support service users to access health care services; support service users to manage short-term illness; manage the health and support needs of older people.** (Level 3 optional units).

With recent wide-ranging changes in the NHS, GPs and other primary care staff are playing an increasingly important role in delivering primary care services and purchasing and commissioning specialist health care and treatment.

**Staff working in primary care:**

- Need to consider how they can make their services responsive to the ordinary and special needs of people with learning disabilities;

- Can encourage people with learning disabilities to register as patients, provided they live within the practice’s catchment area (which some operate more strictly than others);

- Should recognise that some patients with learning disabilities will need additional support to obtain the maximum benefit from using their services; for example: encouraging patients with learning disabilities to book double appointments so they have time to explain their symptoms and receive clear explanations of suggested treatment options.

### 3.8 Concluding comments

For everyone, growing older is associated with an increasing risk of health problems, often at a time of changing life circumstances. For women, there are particular issues relating to the menopause and the GOLD study (see 3.4) raised many concerns of wider relevance in terms of enabling people with learning disabilities to access health promotion and screening services and ensuring that staff in residential or day services are well informed about health issues and can support people in the most appropriate ways. Social and health problems may occur together leading to major life changes. However, these problems are not inevitable and strategies to maximise health throughout life may pay important dividends in later life. Those in services supporting people with learning disabilities need to think about the prevention, detection and treatment of mental and physical ill-health, ideally just as they would for themselves. People with learning disabilities may not always be aware of health issues, or even if aware, uncertain what to do. Paying attention to health in later life is part of good support.
4.1 Introduction

Increasing numbers of people with learning disabilities are living into middle and old age (see Appendix 5) and a significant proportion are living with family members, mostly with one or both parents who will continue to care for their son or daughter until they themselves become too frail or die (Walker and Walker, 1998; Ward, 1998; Department of Health, 2001c).

It is estimated that 40% of people with learning disabilities live with a family carer aged 60 or over and 10% live with a sole carer over 70 (Watson and Harker, 1993). Some of these older carers will be known to services, but an estimated 25% will only come to the attention of formal services when the carer becomes too frail to continue caring (Department of Health, 2001a).

The White Paper for England (Department of Health, 2001a) identified specific groups of carers facing additional pressures, including carers aged 70 or over and family carers from minority ethnic communities, drawing attention to the need for services to involve families in planning for the future and supporting them in their current caring role.

This recognition by Government of the needs of older carers (Department of Health, 2001a) is timely. Projects focusing on them formed an important element of the GOLD programme.

- The Planning Ahead project, run by the Sharing Caring project in Sheffield, provided practical and emotional support to older carers to help them begin to plan for the future. The experiences of this project are described in Chapter 5.
- The Sharing Caring project, in partnership with the Asian Disability Project also received funding to undertake a study of older family carers from the Pakistani community in Sheffield.
- The British Institute of Learning Disabilities (BILD) was funded to develop support groups for older family carers which were run in partnership with six local authorities. (See also Appendix 3).
- United Response, Northern Ireland undertook research to identify reasons why their adult placement services providing short breaks had a low take-up rate from other family carers and subsequently developed a service to meet their specific needs.
- The Looking Forward project by Wandsworth Rathbone was an action research project which interviewed adults with moderate learning disabilities and their family carers (all aged 55+). The report includes carers’ views about their current family life and their hopes for the future.
- Housing Options in Oxfordshire identified the range of options available to family carers to enable adults with learning disabilities to continue to live in the family home, whether the property is owned or rented (King, 2001). This project is discussed in Chapter 6.
This chapter is largely based on the experiences and learning from these projects as well as drawing on the literature on older carers, notably Walker and Walker's (1998) overview of research, policy and practice relating to service responses to adults with learning disabilities living at home with older carers which has made a major contribution to our understanding of this important issue.

4.2 The circumstances and characteristics of older carers

Each family’s experience is unique but older carers of adults with learning disabilities have some identifiable characteristics which distinguish them from other carers who may, for example, be looking after an elderly parent or partner (Prosser and Moss, 1996; Walker and Walker, 1998). Unlike these carers, most older carers of people with learning disabilities do not expect to outlive them.

Age of carer

With the possible exception of an elderly person caring for their ageing spouse or partner, older family carers with a relative with a learning disability, face their own ageing which can mean becoming more physically or mentally frail. Familiar aspects of caring can become difficult or impossible. An older carer may be less able to manage lifting or deal with difficult behaviours. There may be increasing difficulties with ‘hands on’ caring tasks but if older carers become more housebound this may directly affect their relative. One mother, for example, was no longer able to stand out in the road during the winter to wait for the minibus to pick up her son and drive him to his day service. Mobility problems may mean that a parent can no longer drive or use public transport. And as one of the BILD support groups found:

*Health issues were often as relevant for carers as their sons and daughters. This topic was meant to look at health questions that had arisen regarding their sons and daughters. However, group members found it to be of direct relevance to their own health issues as well and thus found it an extremely useful session on both fronts.*

Duration of caring

Most family carers are parents (Walker and Walker, 1998) so most older carers will have been caring since the birth of their son or daughter. Caring will have become a ‘career’, a way of life, extending way beyond the caring responsibilities that most parents expect to relinquish when their children grow up and leave home. Or as one of the parent said: ‘I’m never off duty, no!’

For some older carers, it can be difficult to imagine any other lifestyle. Caring will often be the main focus of their lives. They may have become used to keeping an eye on the clock for when the minibus drops off their son or daughter. They may even be used to spending 24 hours a day together. Families can be criticised for being ‘set in their ways’, but predictable routines can help carers make their lives more manageable. Being faced with free time when their relative uses respite can sometimes be difficult to adjust to.
Sole carers

Older family carers are more likely to be sole carers as spouses or partners need residential care or die. As the White Paper acknowledges, 'Many [of those over 70] are sole carers with reduced support' (Department of Health, 2001a). The pressures on these sole carers can be considerable. There is no one with whom to share day-to-day care and no one to look after emergencies if the carer has to be admitted to hospital, for example. Having proper arrangements in place to respond to emergencies was a major concern for older carers.

Smaller networks of family and friends

As carers age, their networks are likely to diminish. The carer’s own parents who may previously have provided emotional and practical support will almost certainly have died. Siblings may also have been a source of support but may have moved away and/or acquired their own family responsibilities. Some older family carers will have had mutually supportive relationships with other carers (e.g. through their local Mencap group), often going over many years. A new parent’s shared struggles and battles but, with ageing, these friendships are also vulnerable as people become frail or die. As the Windsor House survey found:

Caring in isolation was very apparent for some people as limited support was received from family or formal services. This was already resulting in depression and affecting people’s health. The danger here is not only on how it impacts on the parents’ day-to-day quality of life, but also on how it could impact upon their ability to continue caring on a long-term basis for their son/daughter at home.

This potential for isolation was movingly described by one parent, asked to participate in the survey, who said:

'I don’t think I’m going to have enough conversation. I haven’t got practice. I don’t have anyone to talk to... It was the first time I got a chance to talk to anybody... I never did get a chance to talk to anybody except sometimes when the family come.'

Interdependence

In many instances, the relationship between the older carer and the family member with a learning disability is an interdependent one (Walker and Walker, 1998). As the GOLD projects also found interdependence exists in different ways and can be emotional, financial and practical.

This interdependence can be social and emotional, both parties providing each other with companionship and love which can make the prospect of ‘letting go’ very difficult for some older carers (BRIDGES, undated). Like any close relationship, this interdependence can give meaning and purpose to the older carer, particularly when their own networks may be shrinking. Through their relative, carers may have met other people with learning disabilities and their parents who add pleasure to their lives.

Financial interdependence is common (Magrill et al., 1997), with the benefits of the person with learning disabilities often being pooled with any benefits the carer receives, such as their pension.
For carers (particularly mothers) who have not been able to take up paid work, employment-related pensions will not be available, although the recent Child Support, Pensions and Social Security Act 2000 has acknowledged this by offering some compensation for loss of pension entitlement.

As carers grow older, interdependence may increasingly focus on practical aspects of caring. There is considerable evidence that as carers age, the caring relationship is sometimes reversed (Walker et al., 1996; Magrill et al. 1997). Family members with a learning disability may be involved with domestic tasks in the home such as cleaning and cooking as well as shopping. One carers centre has recognised the responsibilities this can place on people with learning disabilities and which can cause them considerable anxiety.

The North Tyneside Carers Centre has designed and run a course aimed at supporting people with learning disabilities as carers, having been alerted to the need for this by the local Community Learning Disability Team. Five sessions were run with the following aims: helping people understand the term 'carer' and distinguish between formal and informal carers; enabling people to think about the sort of tasks a carer might do and how being a carer can affect their life; determining the most common accidents and emergencies carers might encounter, what causes them and what to do; identifying the stresses and strains of caring and ways of dealing with these; identifying sources of help for carers.

Pakistani family carers

As the GOLD-funded project found, while Pakistani family carers shared many of the same characteristics as other older carers (e.g. health problems, isolation, lack of trust in formal services), there were additional characteristics which need to be recognised and taken into account by those who could provide support.

Family composition

It is often the youngest child in a large family who has a learning disability, so while still at school, they often have brothers and sisters in their 30s and 40s. Male carers were often in their 60s or 70s, while the wife could be considerably younger.

Family support

The project found that there is often a false assumption that families from the Pakistani community 'look after their own', a misconception also pointed out in Yoking People (Department of Health, 2001a). The project worker found that there were a number of carers who had very little contact with other family members, particularly for women who had often moved to where their husband's home was located when they got married. Even where family members live nearby, carers are sometimes nervous about how receiving help might reflect on their family within the community.
Roles within the family

Traditional roles within the family, as well as religious beliefs, mean, for example, that a man will not help a female relative with personal care tasks. While there may be other people in the house, female carers may be responsible for cleaning and cooking as well as their caring tasks.

Experiences of using services

Older family carers of adults with learning disabilities differ from younger carers in terms of their differing experience of using formal services and their reluctance to seek help (Walker and Walker, 1998).

Changing philosophies and patterns of care

Older carers will have lived through radical shifts in the way services are provided, reflecting changing philosophies of care being translated into new forms of provision. Over the years they will have witnessed moves from segregation and control to integration and independence (Walker and Walker, 1998).

Lack of choices

For many older parents the choices offered when their son or daughter was born were stark—'take your learning disabled child home with you or put them away in a long-stay hospital'. Having chosen the former, these older carers may know little about the options currently available to younger parents. If their son or daughter was growing up before 1971, they may not even have accessed any formal educational provision.

Lack of confidence in and mistrust of services

Some older family carers will have used learning disability services, such as respite care. If they have had negative experiences of formal provision, or they feel that the quality of services does not match up to the care they provide at home, they may not feel confident about asking for help again and may decide to withdraw from services. As the Wandsworth Rathbone Looking Forward survey found:

Negative experiences of, or stories about, residential services had reinforced [the parents'] commitment to carry on for as long as they could.

Exclusion from the process of change

Despite the fact that there have been some very positive developments in learning disability services (e.g. family-based respite, supported living, Direct Payments), older carers and their relatives have often been excluded from policy debates and planning for new services. Where consultation had taken place, family carers often felt that their knowledge and experience were discounted (Walker and Walker, 1998).

Lack of information

The GOLD projects encountered many instances of parents not having access to good quality information. This was an important issue for the Planning Ahead project, the Pakistani Carers project, the Looking Forward survey, and the BILD support groups. Without good up to date information about what is available, family carers cannot start thinking about whether to use formal services.
Making their own provision

It is important to remember that, while older carers may have low expectations of formal services, parents groups have sometimes taken the initiative themselves, starting up social clubs or opening group homes. Their contribution needs to be acknowledged by service providers but parents may still believe that new services can only start up as a result of their own efforts. This contrasts with younger parents who are likely to have more expectations that services will play a part in their sons’ and daughters’ lives.

Two units of the Learning Disabilities Award Framework (LDAF) focus on enabling staff to work positively with families. Students being assessed at Level 2 will be expected to:

- understand the range of different patterns/structures of family life;
- understand the possible effects of having a person with a learning disability in the family;
- understand the range of different patterns/structures of family life;
- understand the possible effects of having a person with a learning disability in the family;
- identify ways to involve parents/carers in decisions about the support offered to them and to the service user;
- identify ways to encourage positive contact between service users and their families/carers;
- understand the boundaries of confidentiality in relation to families/carers;
- recognise the carer’s right to assessment of their own needs under the Carers Recognition Act 1995;
- understand how to enable families/carers to access and use complaints procedures.

Students working at Level 3 are expected to have a more in-depth understanding of these issues.

4.3 Meeting older carers’ current needs

One of the central findings from the various GOLD projects is that these older family carers are not necessarily looking for an early opportunity to relinquish their caring role. The Sharing Caring project’s Planning Ahead work found that unless and until carers’ existing needs and concerns were addressed, it was not possible to support them with thinking about and planning for the future (see also Chapter 5). The Pakistani Carers project and the BILD Support for Older Carers project found that there were a variety of immediate concerns for which help was needed.
Although carers interviewed for the Wandsworth Rathbone Looking Forward project were younger than those involved in some of the other projects, the parents and the people with learning disabilities generally felt that living together was the right thing for them at the time.

What many older family carers want is support to continue caring for as long as they can and for as long as they wish to. Thus although some of the project planned to address issues around planning for the future, it was often the case that they had to 'stay with the present' before they could begin to address the future with older carers. This does not mean that parents were not thinking about the future; indeed, thinking about this was never far from their minds but it was often a nagging worry, due to 'an inability to find an acceptable solution' (Walker and Walker, 1998). And as the Pakistani Carers project wrote:

*Although the remit of the study was to support older families ... to plan for the future, very little progress was actually made ... The issues [the carers] faced on a daily basis and the lack of support and services they access was top of their agenda. They needed support just to carry on coping every day and could not look too far ahead yet.*

While the projects raised many different issues about older carers' concerns, this section focuses on describing those which were often mentioned, namely: short breaks/respite; emergencies; supporting carers in groups; access to information; and the specific concerns of Pakistani and Black carers.

**Access to information**

Lack of information has been identified as a problem for family carers (Walker and Walker, 1998) who cannot start planning for the future when they are unaware of what options might be available. As a parent in one of the BILD project's support groups commented:

*We had had no previous information on residential homes or other care.*

Family carers participating in the Wandsworth Rathbone Looking Forward survey were found to have:

*limited knowledge on all the local services and options for both the present and future [which] clearly may prevent them from making the most of available support and services.*

Even those who made plans were sometimes uncertain as to whether they were best because they lacked information and specialist advice about all the available options.

From feedback from parents who participated in the BILD Support for Older Carers project, it is clear that being able to get hold of information was highly rated. With up-to-date information, carers were in a better position to make informed choices and feel more positive about using formal services for the first time.
We acquired a great deal of new information.
There was key information about Social Services and their new approaches.
I feel better informed and therefore better able to make any such changes in the future.
As a result of the information I have been able to approach Social Services and other agencies in a more positive way.
I’ve now taken advantage of respite care for four days at a time.
I find my daughter looks forward to this.

Lack of access to information was also an issue for some families. In almost all areas where BILD family carers groups were run, parents requested a session on benefits which worked well where it could include individual advice as well as general information. Council tax concessions and housing benefit were both areas where there was some underclaiming.

Respite/short breaks

The GOLD Adult Placement project was developed by United Response (Northern Ireland) to meet the specific needs and aspirations of older carers and their sons/daughters with learning disabilities. After researching the perceptions of older carers and people with learning disabilities about short breaks with the adult placement service, their views were used to inform the service’s development in two areas by recruiting placement providers and encouraging referrals from families. Ten placements have been made to date and the project has been extended to allow additional placements to be made.

Respite care, adult placement services and short break schemes can provide people with learning disabilities with positive and enjoyable experiences but they also have a double function. Provided they offer a positive and good quality experience for both parties, regular breaks can contribute to older parents’ ability to continue caring for their son or daughter the rest of the time. Use of respite can enable family carers to have a break from their routines as their comments from two of the GOLD projects illustrate:

That’s why when he goes into respite I can do just what I want to do and that’s nice … I can stay out all night if I want to.

[Using the adult placement service is] time when you can take your worry cap off … time out.

Carers need to feel confident that respite care staff have an understanding of and good familiarity with the person with a learning disability. As one parent using United Response’s Adult Placement Service said of the placement provider:
She has my son's best interests at heart.

Families who participated in the Pakistani Carers project also wanted respite services that were set up and run to take account of their specific religious and cultural issues.

From both the Planning Ahead project (see Chapter 5) and the Pakistani Carers project, it emerged that for some older carers, a break from caring routines could be more welcome and more valued when short breaks did not necessarily involve separation but offered shared activities.

Sheffield MENCAP worked with the Sharing Caring project to set up a monthly Sunday lunch club for older family carers and their relatives with learning disabilities and for some carers this is their only regular opportunity to socialise outside the home. A number of families involved with the Pakistani Carers project were supported to access funding for breaks through Social Services' 'Flexible Short Term Break Fund'. All applied for their relative to have day trips or weekends away accompanied by their usual carer. With day trips to the seaside, London, Bradford and theme parks, carers reported that it felt like a rest for them to have a change of scenery and a break from their usual routines.

Although short breaks do not necessarily involve family carers being separated from their relative, a 'temporary' period of separation can help everyone involved prepare for a time when the person with a learning disability is no longer being cared for in the family home. As one user of United Response's Adult Placement service commented:

You miss your family but you don't get homesick.

While respite can offer a 'taster' of what this might be like, it could lessen the distress and disruption which can occur when someone has to leave the family home in an emergency such as parental admission to hospital or death.

Short breaks of the kind provided by United Response's Adult Placement Service can be a rewarding experience for all the parties. One parent using an adult placement service described the experience:

You asked me to trust you. I have, and it has worked beautifully, and we are all happy.

And a placement provider had this to say:

She's like a part of the family, I get a great sense of achievement when I see how she has come on.

And another spoke of how the person with a learning disability was growing and developing independence.
Adult placements can enable people to meet new people, participate in new activities and widen their social horizons.

In some areas, recently established short break schemes are beginning to offer family carers more choice and greater flexibility about the kind of provision being offered. From the experiences of several of the GOLD projects, it was evident that older carers were wanting provision which respects their experience and is responsive both to their needs and those of their family member with a learning disability.

**Dealing with emergencies**

Crises will not necessarily occur in all families, but the anxiety of wondering 'what if ...' can be an added cause of stress for older carers unless, as has been suggested, there is 'the kind of emergency breakdown service offered to motorists by the AA or RAC', a safety net for when family care breaks down (Walker and Walker, 1998). Crises may require action in the short term, if an older parent has a fall, for example. Alternatively a more permanent solution may be needed, if a family carer dies unexpectedly; having some system already in place is important, whether it is having a named contact in social services, another relative or family friend, or triggering a personal alarm in the home.

The Sharing Caring project in Sheffield has arranged for the Social Services' teams to have the opportunity to access more information about people with learning disabilities living with older family carers. This information can be sought 24 hours a day through a central register of those who have completed a Life Book, or through contact with the Older Carers Support Scheme and details available from families registered with the City Wide Alarm service.

Sheffield City Wide Alarms have revised the information they collect from older carers using their service. They now collect specific information about the needs of the person with learning disabilities living with the older carer.

There may also be an opportunity for the person with a learning disability to respond to an emergency if they already have a caring role in respect of an older carer. They may know how to alert neighbours or trigger an alarm if a parent is taken ill or has a fall, for example. Looking at possible kinds of emergencies and how they might respond is one of the issues covered in the 'Looking after Yourselves and Others' course run by North Tyneside Carers Centre.

Many family carers involved in United Response's GOLD project on adult placement schemes were concerned about whether a place would be available in an emergency. This would have to be discussed with placement providers to see whether they would be in a position to offer this or whether alternative arrangements would have to be explored.
Support groups

Although the BILD Support for Older Carers project tackled issues which are discussed elsewhere in this chapter (e.g. respite/short breaks) it was evident from the evaluation of the groups that they could meet carers' other needs, including emotional support, problem-solving and accessing information (see also Harris, 1998).

Emotional and social support

Some groups shared telephone numbers as members got to know each other. Support and information was sometimes offered outside the home, including one instance where there was an offer to care for a group member's daughter when her mother wanted to attend a funeral. Other benefits of having this 'protected space' were also mentioned:

- Fellowship and sharing experiences and supporting each other.
- The willingness of all members to share their individual experiences.
- Everybody shared their experiences and difficulties.
- Being listened to, sharing experiences with others in similar situations, feeling supported and having time which was your own.

Practical suggestions and problem solving

As members got to know each other, emotional support could develop into practical help, for example: visits to each other's homes to discuss and look at equipment and adaptations and sharing information.

In some groups, members had useful information which they could share with the rest of the group. This included knowledge about benefits, council tax concessions, and up to date information on new developments such as the White Paper. In some cases, parents got hold of information to share with the rest of the group, rather than seeing the facilitator as the source of all knowledge.

While these groups were clearly valued by their members, they also provided an opportunity for service planners and providers to gain some unique insights into a group of carers whose voices have until now not always been heard. For some of the group facilitators, the BILD project offered them the opportunity to question the myths and stereotypes which so often surround older family carers and review them in a more positive light as these comments from the evaluation indicate.

Being involved in this project has totally changed my view of family carers .... I had developed a view of carers that I believe came from working in statutory services for too long as my main contact [with them] concerned 'problems' .... I was almost surprised to find that every member of the group was able to competently participate in a meeting setting with far more professionalism and articulation than some of my colleagues! .... they approached each issue in a focused, positive and productive way.
Having an older family carers' group raised awareness among commissioners and providers about the scale of issues, the absence of good information and the resource implications necessary to provide support.

**Meeting the needs of Pakistani family carers**

*Valuing People* drew attention to the particular issues facing family carers from minority ethnic communities (Department of Health, 2001a) and two GOLD projects were already addressing this: supporting Pakistani family carers through the Pakistani Carers project; and running a Black family carers group as part of the BILD project.

There were two main elements in the Pakistani Carers project. Intensive individual work was undertaken with eight families (with a carer aged at least 55+) and the worker ran a fortnightly support group for Pakistani women carers.

**Trust and confidentiality**

It was very important to carers that they could trust the project worker and not have to worry that she could talk about their situation to other people in the community. In two cases, the worker was questioned to make sure she was not related to them in any way and that she didn’t know people they didn’t get on with.

*One carer who spoke no English at all was visited by the project worker and raised many issues which needed addressing straightaway. The carer told her that this was the first time she’d been able to really talk to someone who understood what she was going through. She was happy to have been able to say what she wanted and know someone who could help had understood.*

**Communication**

This was a recurrent issue in the project. Few female carers spoke fluent English; though some appeared to understand what was said to them in English. Although more male carers had learned to speak fluent English from their education, work and socialising, many older female carers had not had the chance to learn English because of their family and caring responsibilities and as a result of having been educated in a system which was more focused on males. Younger women, on the other hand, were more often bi-lingual.

**Interpreters**

Although independent interpreters were available for meetings with statutory workers, many families preferred not to use them in personal situations because of previous negative experiences or fears about confidentiality. Once families trusted the project worker they often asked her to attend meetings with them but when interpreters were brought in anyway, the worker’s role could become confused; families wanted her to both interpret and advocate for them and roles needed to be clarified.
Written information

The majority of female carers were unable to read or write in English or Urdu but usually had other relatives who could translate relevant information. Although the worker was able to help translating correspondence about benefits or health matters, the lack of information and understanding about 'learning disabilities' was a major obstacle for some carers. The project was able to gather some written information in Urdu but the worker relied heavily on telephone communication. Translating and taping the project newsletter into Urdu was very well received.

Meeting cultural and religious needs

Many families wanted their relative to be able to access respite care and day services to provide a break from caring but found it difficult to trust services and feel confident that people would be supported and cared for in ways which met their personal, cultural and religious needs. As well as requiring facilities which met dietary requirements, these carers would prefer single-sex services and female care workers to provide personal care to women with learning disabilities.

I wish there was a respite centre for Asian clients where they understand the culture, have halal food, and [which] is single sex; either men's or women's but never mixed.

I look after my sons seven days a week, I do not get any rest. It would be nice if someone came and took them out for a few hours, someone that I could trust. How do I know that someone will look after them the way I do or care for them the way I care for them?

Extended families and family roles

Although some people had a great deal of support from their extended family, this was not always the case and some female carers had little contact from other family members such as siblings, particularly as they had often moved away when they got married. Some were also nervous about how accessing formal services would reflect on their family in their community. Some carers were unable to get help with domestic and caring responsibilities even where there were other adults living in the home. This was partly to do with traditional roles within the family, but carers seeking help would more often rely on other carers in their network, on the basis that 'no one knows what's needed like another carer'.

Carers' health

Many of the carers in the Pakistani Carers project had serious health problems including arthritis, high blood pressure, diabetes and other age-related illnesses. In addition, some female carers were also suffering from depression and a high level of stress. Accessing health care to address these problems satisfactorily was often difficult.
Black carers

In one of the six areas where BiLD helped set up older family carers groups, a need was identified for a Black carers group. A cross-section of Black carers were invited but the group members were predominantly of Afro-Caribbean origin. Since the project ended, the Black carers have continued to meet monthly on a less formal basis, expressing the view that a Black carers group should have been established years ago:

[The group members said] they would like a regular forum to air their feelings and be heard . . . and even if it turned into a coffee morning it should definitely continue as they needed this kind of support more than ever.

Like the other groups, the Black carers group shared experiences although these could sometimes be very negative as they

felt very cheated and isolated about the way in which they were treated when their sons and daughters were children.

Concerns were raised in the group about equal access to services, and members were asked to comment on Social Services’ draft ‘good practice guide’ for Black clients and carers. The local authority had made strenuous efforts to ensure equality of access but this did not always seem to be the case with agencies which the local authority had contracted to provide services. At one meeting with a provider, it emerged that very few of the Black carers were on the mailing list which would have been the main way for prospective users to find out about their service. Having explored these issues, the provider promised to act upon their suggestions.

Benefits issues were also raised in other groups, but the Black carers’ under-claiming seemed significantly more common as

the carers seemed surprised at some of the benefits they could claim.

As with the Pakistani carers (see above), the Black carers talked about

the fact that so many carers in the group had high blood pressure and diabetes and wanted further advice on managing these conditions.

The Black carers group facilitator was very positive about the experience:

I had wanted to run a Black carers group for so long . . . it has been so positive to be able to do it at last . . . Particular strengths have been people’s openness and willingness to share; even those quieter members were sparked off by each other after so long when they have learned to suffer in silence. The group has given them more faith in services and in themselves. People are now better at giving each other advice and following it.
4.4 Policy and legislation relating to older carers

Valuing People (2001)

Although the recent policy reviews for England, Scotland and Wales all addressed issues relating to older people with learning disabilities (see Chapter 1), the White Paper for England drew attention to the needs of older family carers as one of three priority groups of carers who face additional difficulties in carrying out their caring role effectively (Department of Health, 2001a). The chapter on Supporting Carers lists a series of key actions which should help to support all family carers of people with learning disabilities who will:

- benefit from all mainstream carers initiatives;
- have a named contact who will co-ordinate and monitor the services they receive;
- have access to the National Learning Disability Information Centre and Help Line;
- be represented on local and national planning groups, including the Learning Disability Task Force;
- benefit from new guidance on exclusions from services;
- benefit from implementation of the Carers and Disabled Children Act 2000.

In addition, Valuing People proposes that:

- [family carers] should be represented on all key planning bodies at local and national level;
- the skills and experience of family carers should be recognised as a valuable training resource for professional staff.

Specific provisions for older family carers include the following:

- payment of Invalud Care Allowance (ICA) will be extended to people over 65, and ICA will also be payable for up to eight weeks after the death of the disabled person;
- people living with a family carer over 70 will be one of the priority groups for developing a person-centred approach to planning and a performance indicator will monitor the percentage of carers over 70 for whom a plan has been agreed;
- revenue and capital elements of the Learning Disability Development Fund will prioritise the development of supported living for people living with carers aged 70 or over;
- local councils will be expected to prioritise older family carers in their local carers’ strategy.
Carers and Disabled Children Act 2000 (England & Wales)

The Act came into force in April 2001, and extends a carer's right to assessment, already provided for in the Carers and Recognition of Services Act 1995. Under the terms of the Act:

- A carer who provides a 'substantial amount of care on a regular basis' is entitled to a carer's assessment and can request an assessment.
- Local authorities have been issued with guidance on implementing the Act and the leaflet, The Carers Guide to a Carer's Assessment, is to be made available to all carers.
- Councils have been empowered to provide services directly to carers. Although 'services' are not defined in the Act, councils may provide any service that either supports the carer in their caring role, or helps the carer to maintain their own health and well-being.
- A new performance indicator will monitor how many people with learning disabilities are receiving respite/short breaks.
- Carers can be charged for the services they receive for themselves as carers.
- Carers can get direct payments in lieu of services they have been awarded as carers but they are not entitled to direct payments to buy services for the person they care for.
- Vouchers are being introduced to enable carers to access to breaks.

Similar legislation is currently being considered in Scotland.

The Carers' Grant

As part of its Carers Strategy (Department of Health, 1999b), funding is available to local authorities to provide breaks for carers, including lifelong carers, when they need it. Valuing People proposed that new guidance would shortly be issued to local authorities to encourage them to identify older carers as well as carers from minority ethnic communities. The Department of Health will be monitoring the impact of this guidance on breaks for older carers.
4.5 Concluding comments

The *Family Matters* report which accompanied the White Paper stated:

"Family carers should be able to access the support they need to enable them to undertake their caring role effectively and with minimum stress and disadvantage. [They should] be seen as people in their own right."

(Department of Health, 2001c)

From the experience of the GOLD projects targeting older family carers, there is evidence that many of them and their relatives with learning disabilities are not getting the support to which they are entitled. Addressing this requires a pro-active and focused approach of which Sheffield’s Older Carers Support Scheme is one excellent example.

The Older Carers Support Scheme (OCSS), part of Community Health Sheffield NHS Trust, aims to enable vulnerable older family carers of people with learning disabilities to build positive partnerships with statutory services so that problems can be addressed before they become crises.

OCSS is available to: single carers over 70; caring couples where both are over 80; and carers over 70 who are known to be experiencing difficulties.

Two visitors make a commitment to visit families on an annual basis and to keep in touch monthly by phone. They offer advice about various services including those for people with learning disabilities, carers and older people.

Where specific long-term support is required the OCSS visitors will refer on to the appropriate agencies as they are not expected to undertake detailed casework.

The GOLD projects demonstrated that relatively small resources can have a significant impact on families’ day-to-day lives. One of the most important findings to emerge from the GOLD programme was that it is difficult for families to be encouraged to think about their future, unless their existing needs are addressed.

A variety of approaches can be used to meet the needs of these older family carers. They may be supported by the local authority, as the BILD project discussed in this chapter demonstrates. Alternatively, a voluntary organisation may take the lead and the next chapter explores this second approach.
Chapter 5
Living with Older Family Carers
Planning with Families and Preparing for the Future
Carol Walker and Dalia Magrill

This chapter draws on the work of the Sharing Caring project (SCP) in Sheffield and in particular its Planning Ahead project, which was funded under the GOLD Programme and by Community Health Sheffield NHS Trust (CHS). SCP was one of the first organisations working with older carers of people with learning disabilities and is still one of the pioneers. It reports on SCP's experience of trying to provide practical and emotional support for families to plan for the future. The project reveals some of the challenges that services and families face in trying to find satisfactory solutions to the uncertainty which the future holds. It also provides some lessons on what can be done.

5.1 Fearing for the future

It is well known and documented that parents of children with any disability worry about their future from the moment they are born. As they and their children get older, this concern grows:

[It] starts off as an occasional niggle at the back of your mind when the child is young and builds up, year by year, relentlessly, to a constant crescendo of concern (Richardson and Ritchie, 1986).

There is a common misapprehension among many care workers and others that family carers are unwilling or reluctant to plan for the future. There is now growing evidence to show that this is overestimated and where it does exist, it does so for very understandable reasons (Walker and Walker, 1998; Bigby, 2000), including lack of confidence in the paid service sector and uncertainty about available options, not only immediately but especially in the medium and longer term. In order to plan for the future, families need to have the emotional space to deal with the uncertainty which the future will inevitably present. They need real options for alternative models of care and support and confidence that the needs of their relative will be addressed sensitively and consistently. This requires some fundamental improvements in the quality, scope and availability of service provision.

The fact that many family carers have not made plans reflects their past experience of the paid service sector as well as their uncertainty about what services will be available in the future. Older family carers have seen many changes in service provision — varying from what the service is called (mental handicap or learning disability), who provides it (NHS/ Social Services/ Primary Care Trusts), the service philosophy (from segregation and institutionalisation to community care and integration), from people with learning disabilities being dependent and controlled to being treated as individuals with rights, including the right to exercise choice and autonomy. Despite all these changes in nomenclature, service structure and service philosophy, many family carers complain that in practical terms little has changed in the quality of service they and their relatives with learning disabilities have received. However, they have seen longstanding day or residential services shut or close their doors to some clients. How can they be expected to plan for the future when they have no idea what will be available when the time comes?
5.2 Understanding older family carers of people with learning disabilities

In determining how services can best address the needs of and support older family carers, it is important to recognise that they differ in important respects from younger carers of people with learning disabilities and also from older people caring for a spouse (Walker and Walker, 1998). Service providers and policy makers must address these issues if they are to gain the trust and respect of families in planning for the future.

The Sharing Caring project (SCP), and the Pakistani Carers project, which has more recently run alongside it (see Chapter 4), have built up extremely good relationships with key players over a number of years and the project workers are held in high regard by all those they work with. The SCP workers have shown that it is possible to acknowledge and respect the role played by family carers, and also to recognise the interdependent relationship which they have with their relative and therefore to balance different points of views between carers and their adult relatives. In so doing it has built up trust with all of the key players: older carers, their relatives with learning disabilities and with agencies. The importance of this cannot be underestimated. Interviews with family carers as part of an evaluation of the Planning Ahead project revealed that families found the SCP workers reliable:

...they always get back to you; they explain but never push you; they let you go at your own pace; if they say they will do something, they do it.

The SCP has been working with older family carers of people with learning disabilities for over six years. During that time, they have provided a support service which is widely used by both carers and professionals. The evaluation project revealed that it was the first port of call for both if any issues regarding this service user group cropped up.

Over the years, the SCP has provided one-to-one support, liaised closely with other services, and has been instrumental in helping to set up a number of related services including:

- a Sunday lunch club;
- promotion of the use of government grants for short breaks;
- creation of the Older Carers Support Scheme, which now maintains regular contact and where necessary offers support to older family carers (see Chapter 4);
- the development of Life Books (SCP, 1999) for people with learning disabilities, which have been distributed to all people with learning disabilities living with an older family carer (see below);
- an Information Pack (The Key) on services and agencies in the city.
5.3 The Planning Ahead project

The Project covered five areas of work:

- Direct work with individual families.
- Establishment of five carers groups, which met for at least four sessions, in which different issues and options around planning for the future were discussed.
- A series of newsletters and supplements specifically related to planning ahead issues were sent to all older carers of people with learning disabilities on the SCP mailing list. This covered most such families in the city.
- Interviews conducted with carers and people with learning disabilities where the individual had already moved away from home.
- Sheffield Citizen Advocacy worked with a number of individuals with learning disabilities to discuss planning ahead. At the request of members of the local Gateway Club, group meetings were also organised to look at this topic.

The Sharing, Caring project worked closely with Sheffield Citizen Advocacy, who conducted separate interviews and discussions with individuals and groups of people with learning disabilities, and also with the Asian Disability project to explore specifically the future planning needs of families from the Pakistani community. In this chapter we draw out some of the key lessons from the findings which can be used by services commissioners, providers and practitioners to help offer this group of families a more secure future.

5.4 Individual work with families

The SCP Planning Ahead work identified eight key stages involved in supporting families to plan for the future.

Stage 1: Thinking about the need to plan ahead

All the families in the project were at different stages in their readiness to plan for the future. Some families needed support just to get the right services in place to help them cope with the present before they could begin to focus on the future. All family carers said that they worried about the future and what would happen to their relative when they were no longer around. In addition, the relatives with learning disabilities were aware that their parents were ageing and that people do sometimes move on from the family home.
One carer (84) lives alone with her son (52) in a council property. The carer has poor health and she and her son look after each other with some support from extended family members. When the carer read the first SCP supplement about planning for the future she became extremely distressed. She had been managing alone for many years since the deaths of her husband and other child, but her anxieties had become overwhelming as her own health deteriorated. Once the SCP worker got to know the family better, it became apparent that the son had also been worrying about the future and had very clear ideas about this. He was anxious to stay on in the home he’d always lived in and didn’t want to be ‘taken away’.

Stage 2: Openly acknowledging that change is inevitable

The project found that it can be very difficult for family carers and their relatives to acknowledge that they have to begin to address their concerns concretely. People progress to this stage differently and sometimes there is disagreement within families about the urgency of planning for the future. The workers needed to build up trusting relationships with families. They had to acknowledge the enormous implications of the discussions that were taking place and let families set the pace. At first, some carers needed support even to talk aloud about this issue. Other carers needed support from an independent neutral person just to broach the subject with their spouse, other relatives and, most importantly, the relative with a learning disability.

A couple in their 70s were caring for their daughter with learning disabilities and communication difficulties. Mum was experiencing some confusion which her daughter was finding hard to understand so she was getting very frustrated and agitated with her mother. Dad was finding it increasingly difficult to cope with looking after his wife and daughter. When the daughter stated that she wanted to move to the place where she had respite, Dad accepted this but Mum found it far more difficult. Having been a carer for over 45 years, this was part of her identity. She ‘didn’t want to throw her [daughter] out like a piece of rubbish’. It took Mum many months to accept that change was inevitable.

Stage 3: Information gathering

At this stage, people used different methods to find out how to plan for the future and what sort of options were available. SCP provided individual support, group support, written information and a Thinking Ahead video which had been distributed to key professionals working in the area and which used a case study to illustrate how a family could begin to plan for the future.
One couple (78 and 83) had been under the impression that their son would be able to live permanently where he had regular respite. When this was found to be not possible, they had to start finding out about alternative options. They watched the ‘Thinking Ahead’ video, discussed it with the SCP worker and their social worker, read leaflets from various providers and visited different types of available accommodation to find out more.

Stage 4: Identifying needs

Although families needed to know and understand practical information about planning and options, the SCP project identified this stage as the most crucial. At this point the needs of the person with a learning disability and their family carer are identified and then fitted with the possibilities for accommodation, support packages and, most importantly, funding.

The SCP worker began working with a family where a single carer in his 80s was caring for his daughter with mild learning disabilities. Because of his ill-health, thinking about the future became a priority. The worker from Sheffield Citizen Advocacy was also introduced to the daughter and, together with father and the SCP worker, all four watched and discussed the ‘Thinking Ahead’ video. The daughter and advocacy worker completed a checklist, and the father, with support from the SCP worker, completed a separate checklist. These were then compared and discussed though there were some marked differences between father’s and daughter’s ideas about the support she needed. The daughter wanted to carry on living at home but the house was increasingly unsuitable for her practical and physical needs. Using the checklist, the workers were able to discuss other independent living schemes in Sheffield. Father was reassured that his daughter’s care and support needs could be met in more independent settings rather than in the 24-hour residential provision which he preferred but which his daughter dreaded.

Stage 5: Agreeing the way forward

At this stage families need to decide on their time scales and priorities for moving things forward. For some families health and age was a factor necessitating urgent action, but others could afford to wait. Stage 5 is the crossroads. Either families feel comfortable to leave things in abeyance until a later date secure in the knowledge of what is possible and practicable when the time comes, or they move forward and begin to implement this major life change.
A carer who said she preferred to ‘keep her head buried in the sand’ chose to go no further with planning her daughter’s future at this time. However, at this point, she and her husband had discussed their will and she had begun to talk more openly to her other daughters about the future. In addition, she and her daughter were regularly attending carers’ groups and, with the SCP worker, they had completed a Life Book. This took several months to complete but it allowed them the opportunity to begin discussing the reality that mum would not be around for ever and that other people needed to know how to support the daughter. Although no further planning work was undertaken, the family is confident about steps they would take when the time is right for them.

Stage 6: Addressing the practicalities

Once the decision is made to look at options for the person with a learning disability moving on, then a number of practical steps have to be taken: allocation of a social worker who will act as the intermediary in securing a placement and funding and looking at different accommodation options which suit the needs and aspirations of the family. A full needs assessment of the person with learning disabilities must be done to record the support needs of the individual and to give family members and involved professionals the opportunity to record their views and aspirations. A carer’s assessment may be done at this stage but is not automatic. The SCP ensured that they did occur for all the families in the study so that the family carer’s needs were clearly recorded and entered as part of the decision-making process. A Care Plan is then drawn up and submitted to a local Care Panel which determines whether funding will be made available. Unfortunately in many areas local authority funding is only available when the home situation has, or is likely to, break down. The participation of an advocate to ensure the family’s position is presented in the most coherent way is essential.

One family spent a considerable amount of time working through the first stages of the planning process. Soon after, their social worker left and the family was without a replacement. Meanwhile, the carers visited different options with the SCP worker. They eventually found somewhere they thought would be a suitable long-term option and their son also seemed interested in it. A referral was made for a social worker to be involved again. The social worker completed a full needs assessment and eventually secured the funding and placement for the son.
Stage 7: Moving

Once a suitable placement has been secured, the process of moving can begin. A gradual programme of visits and overnight stays should be introduced so that the person gets used to their new environment and the family carer can see whether they are settling in well. After a successful trial period then the permanent move can be made.

One man's move was built up over several months. He visited the residential home on a number of occasions with his parents and was invited to tea by other residents. He gradually built up his time there and took in his Life Book to show the workers when he started overnight stays. Gradually building up the number of nights a week, he started to build good relationships with other residents and workers. After a meeting between workers from the home, his day service, the SCP and the family to check progress, he went for a full month's trial, after which another meeting was held. The man was really happy in the placement and clear that he wanted to stay there, as long as he still saw his parents regularly at weekends. His parents were also happy that staff really cared for their son and he was being properly supported and since there were no other issues that couldn't be ironed out over time, the man moved permanently, and regular reviews were scheduled for the future.

Stage 8: Continuing contact, support and involvement

Moving out is the end of the first phase, but it does not represent the end of the family's need for support. When a family member moves out of the family home, the family relationship remains an extremely important part of everyone's life. Arrangements need to be made to allow contact to be continued between the family carer and their adult son or daughter. Keeping in contact proved to be a vital part of helping everyone to adjust to the new situation. Although some individuals benefited from not going back to the family home for a short time to reinforce the point that their move was more than just a short respite break, others visited home regularly for weekends or overnight stays, and families visited their new home. Carers do not stop caring when their relative leaves home and it is important for agencies to acknowledge their continuing involvement.

For those families where the person with a learning disability had moved on, it was important for support for the carer to continue. After the person with a learning disability has moved on, the carer can feel bereft: all the support and help coming into the home moves on with their relative while they are left to cope alone both with the emotional burden of separation as well as with numerous practical problems resulting from the change in their household composition, including a substantial loss of household income and lack of help with household tasks and their own needs.

The main contribution of the Sharing Caring Project was in stages 1-5: supporting people to openly explore planning ahead in relation to their own situation and to understand the process and the options. The project evaluation revealed that families felt able to do this better with someone
independent from the statutory service sector. They saw the SCP worker as an advocate and supporter, and in many cases a family friend. From stage 6 onwards, the role of the SCP changed as statutory workers took over in their official roles to conduct assessments and secure the provision of services. SCP continued as an advocate and often helped families negotiate and mediate with services during what is usually an extremely emotional transition in family life. Families reported that SCP provided a bridge between families and services. This kind of role was appreciated by workers also as few have the time or resources to provide the intensive and continuous support which families need.

From the interviews with carers whose relatives had moved away from home, a number of issues emerged which indicated family carers continue to have a monitoring role and can also see positive changes in the relationship.

"We are very supportive of our daughter, and if we feel something needs to be done, we will let staff know because we want things to be right. It's not about picking faults for the sake of it."

"I think she's a lot more self-assured now. She does all her own shopping and things like that and I think that if she had lived with me I would have done those things for her and held her back. I'm very glad she was capable of doing it."

"My advice would be to give it a try. It is a worry and for months we were wondering if we were doing the right thing but it was the right thing to do. Of course this will depend on where they go and if it's the right place for them, but if you are not happy for goodness sake speak up – it's the only way things can get better."

### 5.5 Carers groups

As part of the Planning Ahead Project, five different carers group were set up around Sheffield. Like many such groups, success was variable. The group sessions were held over and above several large events and/or information meetings which SCP ran in the city centre. The groups began with a session centred on the 'Thinking Ahead' video, which showcased some of the key issues confronting carers worried about the future. The group made a list of 'wishes and worries' for the future. Drawing on this, a range of speakers were invited to discuss relevant social services provision and support, and the range of accommodation options available.

Groups were held in different parts of the city, some being held during the day and others in the evening. Two groups met for the four allotted sessions, two ran beyond them and one fizzled out before the end. The success or otherwise of the group sessions reflects the widely different situations and needs and stages of thinking of carers, as reflected in the individual work. Appendix 3 reports on BILD's experience of supporting similar groups in different parts of England (see also Chapter 4).
5.6 Written information

The third element of the Planning Ahead project was the provision of accessible, jargon-free, large print information to all older family carers. SCP has a mail base of over 370 older family households. As part of the GOLD project, older carers were asked what information was of most interest. The priorities mentioned most frequently were information on where to get practical help with forward planning and on ensuring the financial well-being of their relative. Another high priority was finding out where the person they cared for might get help in the future and about the range of different options for accommodation that might be available.

Four special supplements to the SCP newsletter were produced focusing on the following planning ahead issues:

- An overview of the planning ahead process, including getting help in an emergency, assessment, and who to contact for help and funding.
- The different types of accommodation and alternative care available.
- Wills, discretionary trusts and leaving property to people with learning disabilities.
- Issues around advocacy, including ways of ensuring that future advocates feel empowered to speak up.

Overall interest in the supplements was very high. Most of those who responded to a questionnaire on the supplements, said that they had read them all and saved them for future reference. All those interviewed for the evaluation said that, they had the supplements to hand. Some said that these, together with the newsletters, were their main, and usually only, source of information (about learning disability matters). Most of those who responded to the questionnaires said that the written information had helped them: know who to contact in an emergency, feel more confident about asking for help and feel more confident about facing the future. A minority, however, still felt anxious. Although providing family carers with useful and accessible written information is needed and obviously valued, the Planning Ahead project showed that this cannot be done in a vacuum.

The need to back up written information

- How confident will families be to follow up information without support?
- Written information can raise anxieties as well as address fears.

  To some families, reading about how to plan for the future was extremely distressing and follow-up visits had to be arranged very quickly to support them to be able to relate the written information to their own situation positively. (SCP Supplement)

- Many carers saved the supplements for future use. It is crucial for information to be kept up to date so carers have a realistic view of what they can, and just as important cannot, get.
- Many people are unable to benefit fully from written information because of failing eyesight, poor English and literacy skills, or just lack of familiarity with the system and the jargon.
While written information about forward planning is essential, it can never be used or relied upon in isolation without providing any back-up to those who might need it. (SCP Supplement)

5.7 Life Books

Although the Life Books (SCP, 1999) were not a formal part of the GOLD project, they played a very important part in the planning ahead work. The Life Books were first developed in direct response to older carers telling SCP they were worried that, if something happened to them, important information about their relative with a learning disability would be lost. The Life Book is the personal property of the person with learning disabilities. It contains a wealth of information about their family and friends, their likes and dislikes, activities etc. It contains a personal information page which can be kept on file at a central location and which can be accessed by the social work teams and the Emergency Duty Team.

Life Books have become an integral part of helping families to both think about and prepare for the future. However, for many families completing the Life Book can be a very daunting and distressing task.

- It can remind the family carer of his/her own mortality and that they cannot provide care forever.
- It will provoke questions from the relative with learning disabilities about the future which might be upsetting for both.
- What to put in and what to leave out? Often what may appear to be the most trivial information can make all the difference to the way someone is supported and adjust to change in the future.
- The time needed is considerable. Most Life Books took at least eight hours to complete.

Both SCP and Sheffield Citizen Advocacy workers spent considerable time supporting families to complete the Life Books. Often it provided a forum in which to ask essential questions, like who will be an emergency contact or who will speak up for the relative with learning disabilities in the future. In many cases, workers assumed the role of ‘neutral go-between’ to support carers to ask other family or friends if they would be involved in the support and care of their relative in the future. This is a difficult question that many families avoid and tackling it openly brought great relief all round.

At the end of the Planning Ahead Project, it was concluded that:

Completing a Life Book is one of the biggest steps a family can take in preparing for the future. Even families who chose to take no further steps in planning ahead ... felt that they had begun to lay the foundations and prepare for the future. (SCP Supplement)
Where someone had moved on, workers reported that the Life Books were invaluable and they would simply not have known where to start... [without them]. It had given them... the chance... to get an insight into the life of the person with learning disabilities. Knowing how people have been supported at home has meant that services have been able to keep things as consistent as possible for individuals during times of trauma and upheaval. (SCP Supplement)

Whilst filling in the section about daily routine, it emerged that one woman always had a small whisky and three Ritz cheese biscuits before going to bed so this was written down in her Life Book. When a few months later, this woman went into residential care because of her father’s ill-health, staff used the Life Book and made sure she had her whisky and crackers every night to help her feel more settled.

5.8 Lessons from the work

The experience of the Planning Ahead project and other work of the Sharing Caring project in Sheffield, provides some important lessons on how to move forward in a sensitive and practical way.

Addressing current needs

Before anything can be done about the future the family’s current needs have to be considered and stabilised. Only then can steps be taken to provide family carers and people with learning disabilities with confidence in the future. Much can be done first to provide older carers with the practical and emotional support they need while still acting as primary carers and secondly to set in place processes which will offer greater peace of mind about the future.

Recognising individuality

People have different needs and different capacities for coping with planning for the future. The needs of families are very different and work with families needs to be conducted at a pace and with a sensitivity which reflects their anxieties.

The complexity of transitions

The individual casework with families as part of the Planning Ahead project revealed the complexity of helping families cope with the prospect and practicalities of the major transition when the person with a learning disability leaves the family home.

Pacing the work

Families, largely, have to set their own pace. Whenever a planned move took place with one of the families involved, the whole process from initiation to move could take a long time (for some up to the two years). People might need to take a break in the process during which time they can adjust to the idea of major change and consider possible options.
**The family's right to choose**

Families must have the right to choose when they are ready to move on to the next stage. Nothing can be forced. However, even in those cases where no move took place, most families had moved forward in preparing for the future during the duration of the project.

**Preparing for the future**

Steps which had been taken included making wills, exploring respite or short-break options and beginning to talk openly with other close relatives about what role they might assume in the future. In addition, many families had, often with considerable support from an SCP worker, completed Life Books on behalf of their relative.

**The value of Life Books**

Many key aspects of the person's life, their hobbies, their preferences and important people were recorded. These serve as a link between the past and the future should a change of care arrangements take place.

**Avoiding multiple losses**

The Planning Ahead Project showed that it is possible to ensure that when the family carer dies or is otherwise unable to provide care, the person with a learning disability can make a planned and sensitive transition into appropriate alternative care rather than (as often happens now) move in the midst of a major crisis when they have not only lost their closest relative and primary carer but their home and everything else that is familiar overnight.

**The changing role of statutory services**

Services need to move from crisis intervention to effective strategic planning. To achieve this on a broader scale, they have to be adequately resourced so that they (or an independent advocacy organisation) can work in a long-term preventative way with families, gaining their trust and giving them confidence that their relative's best interests will be protected in the future.

**Planning ahead or preparing for the future?**

By the end of the project, it was felt by the research workers that the title Planning Ahead was inappropriate. Plans can only be made when a family is ready for a move. Plans are too rigid and could be out of date when the time comes to implement them. Instead the team preferred to think in terms of 'preparing for the future'.

**Setting safety ropes in place**

The most important safety rope was that provided by the Sharing Caring project itself. Preparing enables family carers and their relative with a learning disability to become more comfortable with the idea of moving on at some stage; it also implies setting in place some safety ropes which will assist in any future transition. These includes: completing a Life Book; establishing the future roles of family and friends in terms of care, support and advocacy; having key telephone numbers and contacts at hand for an emergency; making use of respite services, short breaks and so on to get people used to change and to other people helping them with different tasks.
5.9 Concluding comments

The project raised a number of important challenges:

- The work merely touched the tip of the iceberg. There are more families wanting to explore future planning than the project could work with. How can these other families be supported?

- The project concluded that securing funding and placements was a ‘lottery’. Placements were simply not there for some people, particularly for people with more complex needs. Personal preference and person-centred planning often seemed to be overruled by financial considerations.

- How far can people plan realistically for the future, if they are not ready for an actual move to happen? Both family carers and people with learning disabilities want reassurance that help will be provided in an emergency and in the long-term, and yet the paid service sector cannot provide any concrete answers on what will be provided.

- How far can people be given peace of mind? Are they being asked to make a gigantic ‘leap of faith’ that there will be support there when the time comes. Families need greater certainty.

- The future care of an adult son or daughter with a learning disability is the main concern of any older carer. Most benefit greatly from the assistance of an independent advocate, who not only knows their way around the system, but who can mediate, negotiate and provide a shoulder to cry on during the hard times. How can this be provided on a wider scale?

Supporting older family carers and people with learning disabilities to plan for the future is neither easy nor quick and there is no one path of action which will suit everyone. The work described in this chapter and the previous one confirms that significant steps forward can and should be made. If this does not happen, there is increased likelihood of being forced to act in a crisis, with all the emotional costs that this entails. As the GOLD Programme has learned, voluntary organisations (such as Sheffield Mencap’s Sharing Caring project) and statutory agencies such as social services (who ran Older Family Carers Support Groups with BILD) both have a part to play in supporting families to plan for the future.
6.1 Introduction

In Volving People a stated objective is

To enable people with learning disabilities and their families to have greater choice and control over where and how they live.

(Department of Health, 2001a)

At the same time, the White Paper draws attention to the current shortage of housing options for many people with learning disabilities, particularly those living with older carers and sets out an agenda to improve the quality and choice of housing to meet their objective.

Older people with learning disabilities are currently living in a range of different accommodation. They may be living:

- with one or more family members in the family home;
- in specialist learning disability residential provision, including group homes and large accommodation, with varying levels of staffing, ranging from a few hours a week to round-the-clock support;
- semi-independently in ordinary housing alone or with others with differing levels of support;
- in an older person’s residential care or nursing home.

People who took part in the GOLD video had a range of different homes:

- Betty lives in her own flat where she does the cleaning, washing up and other housework as well as her own shopping.
- John has the tenancy of a council flat which he shares with his sister and brother-in-law.
- Roger lives in a house which he shares with two other men with learning disabilities.
- Edna was used to live in her own flat but had to move into an older persons’ home when she was no longer able to manage on her own.

Not everyone will have stayed at home with their families. Some will have moved out of long-stay hospitals into the community. Some will have chosen to leave home and move on when they were young adults. Others will want to exercise the choice to move on as they grow older. Choosing where to move is an important decision and advice is available in accessible form to help people with learning disabilities and their families reach the best decision for them (The Foundation for People with Learning Disabilities, 2000).
Reasons for wanting to move can include: wanting to have the experience of setting up their own home; moving to more suitable accommodation which can meet age-related needs such as decreased mobility; or wanting to choose who they live with or deciding to live on their own.

Government policy relating to older people in general, increasingly recognises the fact that many will want to remain in their own homes for as long as they are able to do so, rather than entering residential care or nursing homes. This undoubtedly has some advantages, in terms of staying on in a familiar setting, in a familiar neighbourhood and being able to keep in touch with local family members, friends and acquaintances more easily.

Where people currently live and how they might live as they grow older was addressed in several GOLD projects:

- Housing Options explored how the family home, whether owned or rented, could be used to provide secure accommodation in the future for the person with learning disabilities (King, 2001).
- An in-house GOLD survey, Misplaced and Forgotten looked at the experiences of people with learning disabilities using residential services for older people and tracked their moves into these homes.
- The work with older family carers undertaken by the Planning Ahead project and Pakistani Carers project in Sheffield and the support groups run in six areas by BILD included issues about possible future moves. (See Chapters 4 and 5 for the main discussion of these projects)
- In the Wandsworth Rathbone Looking Forward survey, people with learning disabilities were asked about their aspirations regarding a move from the family home at some future point.
- Three projects focused on people with Down’s syndrome and dementia (see Chapter 7) and one on terminal illness (Chapter 8), both of which can trigger moves to other residential settings.

### 6.2 Meeting age-related needs

As people with learning disabilities grow older, a number of different health-related needs may make it difficult for someone continue living in their present home whether that is the family home, a residential home or some other type of housing. The physical environment may pose difficulties or those providing care (whether family members or staff), may feel unable to meet additional demands.

#### Decreased mobility

People can become less physically mobile as they age, perhaps because of arthritis or other changes to their state of health. This can make it difficult to get around and unless accommodation is on the ground floor, people may have problems using stairs. Although adaptations such as stair lifts or installing grab rails and other modifications may enable people to remain in their own home, family carers (who themselves are ageing) may be unable to lift or support someone who is becoming more physically dependent.
Responding to illness

Illness may change people's support needs. It may no longer be safe for someone to be left on their own. People who were previously fairly independent may need help with their health care such as taking medication on a regular basis. The capacity of services and carers to meet people's needs at such times varies enormously. Paid staff may feel they lack the knowledge or experience to support people who are unwell, and funders may be reluctant to pay for any additional support from outside.

Jane, a 45-year-old woman with Down's syndrome, had been living in a group home for 12 years when she developed dementia. The group home provider felt unable to meet her increasing health care needs so an alternative placement was sought. After a great deal of searching, a place was found for Jane in a large residential home for older people. The home was some distance away and after the move, Jane deteriorated rapidly and died a few months later. Afterwards, the group home staff regretted the move and felt they would like to have been able to do more to enable Jane to remain with them.

Supporting someone who has a terminal illness can be demanding at times and the findings of the GOLD project which explored issues around supporting people who are dying are discussed in Chapter 8.

When Peggy, an older woman with learning disabilities was found to have a terminal illness, her residential service provider was keen to ensure that she did not have to move to an older person's nursing home. They had already had to move a previous resident but felt this had been unsatisfactory as the man in question had died shortly afterwards.

To meet Peggy's needs during her terminal illness, new shift patterns were introduced for care staff and she was moved to a ground floor bedroom. Arrangements were also made for her to receive support from the local palliative care team. To avoid her becoming isolated, it was possible to remove the partition between her bedroom and the lounge so that she could still feel a part of the life of the home. The needs of the other residents and of the staff were also addressed. Peggy was ultimately able to die at home and although caring had sometimes been demanding, everyone involved in looking after her was pleased that they had been able to make this possible.
For older people with learning disabilities living alone who become ill, even if practical arrangements are put in place to enable them to be supported at home, it is important to ensure they do not become isolated if they are no longer able to access day services or other activities where they have had contact with friends.

**Dementia**

The GOLD project which focused on supporting and caring for people with learning disabilities who develop dementia is the subject of Chapter 7. The onset and development of dementia can pose challenges for the physical environment as well as making demands on staff and others who share the home. For people with dementia, staying in a familiar environment can also help to maintain skills and avoid the inevitable upset and disorientation of a move.

The kinds of support required for people who develop any of the age-related needs described here will depend on where people are living and with whom, and the extent to which services are able to respond to those needs while giving people real choices and control over how and where they live.

**6.3 Learning disability residential services**

**Changing patterns**

In the late 1960s, shortly before the previous White Paper appeared (Department of Health and Social Security, 1971), there were over 58,000 people with learning disabilities living in NHS hospitals and units. Despite the many inadequacies of these large institutions, they had the capacity to meet age-related needs, providing a lifelong service to their residents. As people became more frail, these long-stay hospitals continued to care for them until they died, there being no other options available at that time such as moving them to older people’s services. Older hospital residents may have had to move elsewhere on the same site but by and large they remained amongst familiar faces in a familiar setting.

By 2000, 53,400 people with learning disabilities were living in various kinds of residential services, with less than 2,000 still living in NHS long-stay places (Department of Health, 2001a). In many cases, the development of community-based alternatives has immeasurably improved their quality of life but planners and providers are now faced with developing the capacity to meet people’s age-related needs. This is the challenge now facing residential service providers.

**Meeting the challenge**

As the GOLD programme found, developing age-related needs can result in someone having to move elsewhere if their current service is unable to accommodate their changing needs, but anecdotal evidence suggests that it can be extremely difficult to find appropriate alternatives because of the shortage of residential provision. Some care managers had struggled to find any new residential service, regardless of its suitability and staff in learning disability services were rarely positive about the alternative provision which had been found.
The GOLD survey of people with learning disabilities living in older persons' homes looked at the reasons why some of these moves had taken place. 27% of the people surveyed had moved from residential provision run by learning disability services, and although some of these moves had been necessitated by the reorganisation or closure of their previous service, others will have had to move because learning disability services had been unable to meet age-related needs. Moves of this kind mean that not only are people no longer part of learning disability services but they may also have had to move to larger congregate settings from more individualised accommodation (as was the case with Jane) as promoted and encouraged by current learning disability policy.

**Shortage of residential provision**

Attention has been drawn to the shortage of residential provision, with an estimated 25,000-27,000 shortfall in places (Mental Health Foundation, 1996). Recent policy reviews have also drawn attention to this lack of provision and the need to increase the range of accommodation options (Department of Health, 2001c). The Welsh review, for example, stated that:

> The Advisory Group considers that there has been no significant expansion of residential supports to promote and develop independence. We believe that a considerable expansion of service availability will be required. Effective planning and significant investment will be needed. (National Assembly of Wales, 2001).

Valuing People also noted that expanding the range and choice of housing, care and support services would be ‘key to giving individuals more choice and control over their lives’ (Department of Health, 2001a).

As a result of this shortfall in residential places, current services may face competing demands for places when existing residents become more frail, triggering a move elsewhere. Older people living with family carers may be unable to access a residential placement until the frailty or death of the carer results in a crisis move rather than enabling them to move out as part of a well-planned transition.

**Reorganisation or closure of residential provision**

Some older people with learning disabilities will face moves because the residential services they are using are being redeveloped or closed down. With existing policies generally supporting more individualised housing and support services which currently cater for larger numbers may be redeveloped to house fewer people, without taking into account the views and preferences of existing residents.
Developing the capacity to meet age-related needs

Joyce was 63 when her father died and she moved from the family home into her own flat, where she received support from a community worker who came in several times a week. Things were going well until Joyce had a fall on her way to the shops and the service provider and the local authority felt that it was unsafe for her to continue living by herself. Even though she was still in her early 60s and relatively independent, Joyce moved to an older persons' home where she remains, in the absence of any plans for her to move elsewhere.

Joyce does not appear to have any significant age-related needs, and moving to live in her own flat may have seemed the right option at the time. However, people who move into older persons' homes rarely have the opportunity to return to being supported by learning disability services. In Joyce's case there is little evidence that the following issues were considered:

- What age-related needs might she subsequently have?
- What resources might be put in place which could enable her to remain in her own home?
- If Joyce is unable to remain in her flat, what appropriate alternatives might be available to her?

As has been stated, the GOLD survey of people with learning disabilities living in older persons' homes found that 27% had moved from learning disability services. While about a half of these moves had been triggered by service reorganisation and/or closure, presumably others will have had to move because learning disability providers were unable to meet their age-related needs. This raises a series of important questions such as:

- Do learning disability services have a strategy relating to older people with learning disabilities and is the strategy based on clear and agreed principles?
- Is there a shared approach involving health, social services, and other stakeholders?
- Are there flexible policies and practices for meeting age-related needs rather than allocating services on the basis of age?
- Do staff have training opportunities to enable them acquire the skills and understanding to support older people with learning disabilities appropriately?
- Do older people have access to primary and secondary health care?
- Can existing learning disability provision provide accessible and adaptable accommodation to meet the needs of older service users?
In Oxfordshire, a group of stakeholders involving representatives from health, social services, a self-advocacy group, a carers forum and a range of providers came together to develop a strategy for services for older people with learning disabilities.

The strategy's purpose is to give direction to future developments, identify gaps and draw together a shared vision. The key principles aim to enable people to remain in their own homes as far as possible, to keep active and healthy, and to be involved in their local communities.

Although some use is made of older people's generic services, they are accessed through learning disability services who provide assessment, care management and service commissioning.

The strategy addresses the following areas: accessing services, places to live, making and keeping relationships, staying healthy, being listened to, adapting to growing older, support and enablement, carers and getting around.

A number of projects have been identified to help put the strategy's principles into practice. These include: working with housing partners to increase the availability of accessible and adaptable accommodation; and working with residential and nursing homes to develop a more customised service for individuals with a learning disability whenever this option becomes necessary.

### 6.4 Older people's residential and nursing homes

**Recent policy developments**

Recent policy reviews have drawn attention to the use of older people's residential provision for people with learning disabilities.

*Voking People* (Department of Health, 2001a) pointed out that some

> older people with learning disabilities who are more mentally alert and have aspirations more typical of younger people ... may be misplaced in older people's homes... alongside much older and more incapacitated people.

The White Paper proposed that plans for these individuals should be developed around packages of occupational and recreational activities and residential support which takes account both of their learning disabilities and the ageing process and enables them to be as actively engaged as possible. The White Paper does not propose that these placements should be stopped, although elsewhere an expansion of housing and support is recommended.

As the Scottish review (*Scottish Executive*, 2000) pointed out, one in ten people with learning disabilities using residential provision are already living in older people's residential services, many
having moved there from long-stay hospitals. The review is unclear whether older people leaving long-stay hospitals will benefit from the proposed shift from residential care to supported living but says that 'some [hospital] residents will be older, and so more likely to be suited to nursing or care homes'. It therefore seems that there is the possibility that some people will continue to be 'misplaced'.

The Welsh review (National Assembly for Wales, 2001) proposes that people should receive support commensurate with their needs and also talks about 'other age appropriate provision'.

The GOLD survey

In the early stages of the GOLD programme, attention was drawn to the unsatisfactory circumstances of people with learning disabilities living in older persons residential and nursing homes, concerns having already been raised in an earlier study which had looked at these placements.

A substantial in-house survey was therefore undertaken as part of the GOLD programme, with the following aims:

- to ascertain how many people with learning disabilities were living in older persons homes;
- to identify why and at what age they had moved in;
- to find out about their current lives including activities, friends and relationships, and contact with professionals outside the home.

The study involved a cross-section of 53 local authorities. Information was collected from their registration and inspection units, and questionnaires sent to over 2500 residential care and nursing homes within those areas.

Main findings

Policies on placements

13.50% of registration and inspection units reported that they would never accept the placement of any person under 65.

Where people had been living

39% of people with learning disabilities had previously lived in the family home and moved following the carers’ illness or death: 11% had been living alone; 27% came from learning disability residential services and 23% had moved from an older persons home. Half of those who had previously lived either in older people’s homes or learning disability residential services had been moved because the homes had closed down or been redeveloped.

Age when admitted

People who had been living in the family home had an average age of 63 years when they were admitted; those living alone were the oldest group to move, with an average age of 67.6 years on admission.
Current age

The average current age of residents with learning disabilities was 71 years; 38% were over 75; the youngest person was 33 and the oldest 95.

Day activities

49% of people were going out from the home more than three times a week but 31% went out less than once a week. Only one third of people with learning disabilities were participating in regular day activities outside the home. Use of learning disability day services was slightly greater compared with use of older persons day services but average attendance was four half days each (See also Chapter 2). However, compared with their peers in learning disability services (Emerson et al., 2000) their day activities were considerably less.

Families and friends

81% had surviving family and 47% had a friend who was neither a staff member nor a service user. 43% saw a family member or friend at least once a month. Contact with family or friends ranged from birthday cards and occasional telephone calls to weekly visits. 36% of the people surveyed had not had any contact with family or friends and some homes did not know if people even had family or friends.

Contact with professionals outside the home

68% of people had a named social worker or case manager. However 36% of all people had not had contact with any one in these roles over the last year. 28% had had access to key learning disability professionals (e.g. community nurse, psychiatrist, psychologist) over the previous year.

Size of homes

The homes had an average of 30+ residents. Although learning disability policy recommends the development of individualized residential supports, this meant that people were living in large congregate settings with staffing levels which made it more difficult for homes to support people to participate in activities such as staying in touch with family and friends, going out shopping or participating in other activities outside the home.

Vera, an able 67-year-old woman with learning disabilities has been living for six years in a residential home for older people, following her mother’s death. Having always gone out with her mother, she is nervous about going out alone and the home’s staffing levels make it difficult for them to help her become more confident or support her by going out with her. Apart from visits to the doctor, Vera’s only outings are the home’s annual visits to the seaside and the pantomime with other residents. Staff shop for Vera’s clothes and toiletries on her behalf.

Evidence from the GOLD survey suggests that many of these people with learning disabilities who are living in residential or nursing homes lead relatively impoverished lives. The survey also demonstrated
that once people had moved into older people’s homes, they were unlikely to return to learning disability services.

As previous sections of this chapter highlighted, there are a number of reasons why these frequently inappropriate placements are being made:

- a shortage of places in learning disability residential provision which restricts the range of choice for older people with learning disabilities;
- the inability of some services to meet people’s age-related needs;
- lack of forward planning for people living with family carers, leading to crisis admissions following the carer’s illness or death.

As GOLD projects’ work with family carers found, it is possible to engage them with starting to think about the future (Chapters 4 and 5) and planned transitions should become more commonplace. However, it is important that appropriate residential options are available and families can feel confident that their relatives’ futures are secure. Learning disability services will need to be able to offer a range of options.

Because people currently living in residential or nursing homes are frequently isolated, this also highlights the important advocacy role which family and friends can play (Bigby, 2000) in safeguarding people against possible abuse and ensuring that their needs are met and their rights upheld.

6.5 Security in the family home

For many people with learning disabilities living in the family home, the increasing frailty or death of a carer results in a move from the family home. Staying at home is still too rarely an option even though it has several advantages for the person with learning disabilities who can:

- continue living in a familiar environment with familiar possessions which can help to provide a sense of security and provide more certainty about the future;
- avoid the trauma of moving (which is generally the advice given to any recently bereaved person);
- continue to use any informal supports in the immediate locality from neighbours and other acquaintances;
- maintain existing skills, where appropriate, such as shopping, cooking and housework in an environment they already know;
- continue to use any existing day services and social/leisure activities such as special clubs, and remain in touch with peers;
- use any aids and adaptations which may already be in place;
- reduce the costs to the local authority of providing alternative accommodation.
A GOLD project, undertaken by Housing Options (King, 2001), explored how the family home, whether rented or owned, could be used to provide secure accommodation for the future, enabling the person with learning disabilities to continue living there and maximising the advantages outlined above.

Home ownership

Consideration needs to be given to how maintenance and major repairs will be arranged and paid for. There are three main options:

- passing the property to the person with learning disabilities;
- managing the property by putting the family home in a discretionary trust;
- 'gifting' the property to a charity, who may be a social landlord, in return for a guarantee that the person with a learning disability can continue living there.

If the family home is unsuitable, it may be sold and the proceeds used to purchase something more suited to the needs of the person with learning disabilities.

These options, which need to be matched to individual family circumstances, differ in terms of how they may affect people’s benefit entitlements, who provides the ongoing control of the arrangements and flexibility to cater for changing needs.

Rented accommodation

Whether a person can remain in a rented family property will depend on the type of tenancy:

- Secure tenancies are only available for local authority accommodation and the person with a learning disability has a right to take over the tenancy provided it had not already passed from one parent to another on death.
- Assured tenancies are generally provided by housing associations. Although there are no rights to succession, the tenancy should be granted to any family member who has been living with the previous tenant for a year before that tenant’s death.
- Short-term assured tenancies are usually offered by private landlords and there is no security beyond the term of the tenancy which is usually six months.

Supported living would enable older people with learning disabilities to be supported in their own homes, rather than having to enter residential homes when parents or other family carers are no longer able to support them. Two government circulars (Department of Health, 2001a Annex B in both HSC200/016 and LAC 2001/23) confirm that capital and revenue can be used for this purpose. This would also be consistent with government policy on supporting older people in general to be supported within their own homes wherever possible.

Staying on in the family home may be desirable for some people with learning disabilities but making this happen depends on ensuring long-term security of accommodation and obtaining social services’ agreement to provide the necessary support. This can be complex, whether the property is owned or rented and families are advised to plan early if this is to be an option. Local authorities can also work proactively, talking to housing associations, for example, and offering people with learning disabilities tenancy rights in council accommodation (King, 2001).
6.6 Concluding comments

The work of the GOLD programme points to a number of ways forward which need to be recognised if the housing and support needs of people with learning disabilities are to be satisfactorily addressed as they grow older. The reality is that some people will face a number of moves in later life, even where plans have been made in advance.

Advocacy can be an important safeguard against unnecessary or inappropriate changes. Family dynamics are complex and often changing but family members and friends will also want to ensure the well-being of their relative.

Christine Bigby’s research provides a unique insight into what happened to a group of older people with learning disabilities who had left parental care in middle age and the key role which other relatives and family friends can continue to play. (See Appendix 4)

Service planning and development in relation to housing needs to enable people with learning disabilities and their families to have greater choice and control over where and how they live.

Policies and services should be developed in such a way that they can maximise people’s security regarding their living arrangements and minimise disruption in their lives.

Existing learning disability residential services will need to develop their capacity to meet people’s changing age-related needs so that they do not have to move into older people’s residential or nursing homes which may not cater for their needs, particularly if it means they no longer have access to specialist learning disability services.
Chapter 7

Supporting People with Down’s Syndrome and Dementia
Dr Karen Dodd and Dr Vicky Turk

7.1 Background

The GOLD programme’s Advisory Group identified the needs of people who develop dementia as a major area requiring attention, particularly in relation to adults with Down’s syndrome. This chapter is based on the work of one of the three GOLD projects which focused on aspects of dementia and developed a resource pack for supporting adults with Down’s syndrome and Alzheimer’s disease. The resource pack covers:

- the link between Down’s syndrome and dementia;
- diagnosis and assessment issues;
- supporting people with Down’s syndrome and dementia, their peers, and family carers;
- issues for services.

The other two projects focused on developing and evaluating psycho-social interventions, including reality orientation and reminiscence work, for people with Down’s syndrome who develop dementia; and evaluating the use of Dementia Care Mapping (DCM) as a tool for improving the support provided to people with Down’s syndrome who develop dementia, using a person-centred approach. Information about these projects can be found on the Foundation’s website (www.learningdisabilities.org.uk).

7.2 Introduction

Services are now seeing more people with Down’s syndrome who develop dementia as a direct consequence of their greatly increased life expectancy. This increased incidence not only profoundly affects individuals with Down’s syndrome who develop dementia, but also creates challenges for their families and peers, as well as service providers and commissioners.

Margaret Fray describes an occasion when her sister Kathleen was getting into a car to go shopping: She had her feet on the ground and was sitting sideways in the car, but by the way she looked at me I knew that she did not know what to do next. I ran out and spoke to her gently, easing her legs into the front of the car. She became alert again and was perfectly alright, but I felt such a cold fear (BILD 1999).

Down’s syndrome is a developmental disability and the most common genetic cause of learning disability. Approximately 15% of people within learning disability services have Down’s syndrome. Average life expectancy has increased significantly, from nine years in 1929, to the present average of over 50 years, with some people living into their seventies.

Dementia is a global term describing a group of diseases that affect the brain. In all cases there is progressive loss of brain tissue so that symptoms worsen over time. Currently this process is irreversible. However, researchers are investigating possible protective treatments and medication...
to slow the process. Current thinking in the general population suggests that HRT (specifically oestrogen), non-steroid anti-inflammatory medication, Vitamin E and low dose aspirin may all have protective properties. It is also suggested that being more mentally active is protective.

A group of 'cognitive enhancer' drugs, termed 'cholinesterase inhibitors' (Aricept, Exelon and Reminyl) has been developed and are being used with the general population. However, their use with people with Down's syndrome is still in the early stages and advice should be sought from local specialist medical practitioners.

The resource pack

The resource pack (Dodd and Turk, 2002) is designed to help family carers, staff and other professionals support people with Down's syndrome and dementia through providing comprehensive information and guidance. It aims to help them to care more effectively for people with Down's syndrome and dementia by focusing on practical day-to-day issues. These include how to:

- Maintain skills.
- Treat treatable conditions.
- Understand and respond appropriately to changes in behaviour and function.
- Provide emotional reassurance for carers.
- Improve the confidence of carers to look after individuals.
- Identify local supports and resources.
- Be open to the problems that may arise, and help with tips and solutions to cope.

7.3 What is the link between Down's syndrome and dementia?

Researchers have found that people with Down's syndrome are more likely to develop Alzheimer's disease (Emerson et al, 2001). People with Down's syndrome usually have an extra chromosome 21, and it is now known that some of the genes that are important in Alzheimer's disease are found on this chromosome.

Other major risk factors for developing dementia in the general population are thought to be: being female; history of head injury; and vascular risks. There may also be additional risk factors for people with learning disabilities and especially those with Down's syndrome. It is well documented that people with Down's syndrome have additional vascular problems. Head injury may also be caused by repeated self-injury or falls associated with physical disability and/or epilepsy.
7.4 How do we know that it is dementia?

Almost all people with Down’s syndrome over the age of 30 have been found to develop the brain changes associated with Alzheimer’s disease, although not all will develop the clinical signs. Research indicates that people with Down’s syndrome are most likely to show clinical signs over the age of 50 years, although these can be found in younger people. Many people with Down’s syndrome seem to show accelerated ageing with or without dementia e.g. hair loss and increased frailty (Oliver and Holland, 1986).

It is important that an accurate diagnosis of dementia is made because the early symptoms of dementia are easily missed or misinterpreted. Onset may be very gradual and carers may not notice these early signs. Sometimes these can be attributed to other causes e.g. challenging behaviour, effects of life events, sensory disability or environmental changes. Family carers may not understand why these changes are happening particularly if this is the first time that their son or daughter is having problems. Good and regular documentation of a person’s skills and abilities will help to identify these early changes. Information from people who have had a long-term relationship with the person can make a particularly valuable contribution to an assessment.

Many of the early symptoms of dementia are common to other conditions which are often treatable. Differential diagnosis is therefore essential to identify and treat any existing conditions. The most common of these in people with Down’s syndrome are:

- depression;
- thyroid problems;
- sensory difficulties i.e. vision and hearing;
- physical problems e.g. infections, diabetes;
- other psychological and psychiatric problems e.g. obsessional slowness, effect of stress and life events, bereavement and loss.

Thorough assessment is the key to accurate diagnosis. Assessment should contain the following elements:

- a detailed medical, family and developmental history;
- details of previous psychological assessments and assessments of adaptive functioning;
- current physical status including tests for thyroid, liver function, infection, other physical illnesses, sensory loss in vision and hearing; MRI scan where necessary;
- assessment of current cognitive abilities;
- assessment of current functional and adaptive skills.

All adults with Down’s syndrome should have a baseline assessment of their skills and abilities, preferably between the ages of 30 and 35. Each service is likely to be using their own assessment tools as there is no standardised assessment as yet. The assessment batteries commonly used are rarely
helpful with people with Down’s syndrome due to their pre-existing level of cognitive impairment. Specific assessments (Oliver et al., 1998) are currently being developed and piloted, and should include assessment of memory, orientation, other cognitive functions and adaptive living skills.

7.5 Prevalence and progress

The prevalence of dementia in people with Down’s syndrome increases significantly with age, and is far more common than in the general population (5% for people aged 65 and older).

One study (Prasher, 1995) showed the following rates of dementia for people with Down’s syndrome:

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 – 39 years</td>
<td>2.0%</td>
</tr>
<tr>
<td>40 – 49 years</td>
<td>9.4%</td>
</tr>
<tr>
<td>50 – 59 years</td>
<td>36.1%</td>
</tr>
<tr>
<td>60 – 69 years</td>
<td>54.5%</td>
</tr>
</tbody>
</table>

The average age of onset is 54 years and the average interval from diagnosis to death is less than five years. In practice this can range from 12 months to over 10 years. Onset of epilepsy is usually an indicator of severity of dementia. Family carers and support staff can find it difficult to cope with the rapid change in people with Down’s syndrome who develop dementia.

Many family carers, professionals and other workers in specialist learning disability services and generic health and social care are still unaware of the vastly increased risk of Alzheimer’s in people with Down’s syndrome. Increasing awareness about this amongst all these groups will be important.

The high prevalence of Down’s syndrome and dementia will mean that all specialist learning disability providers and most GPs will encounter individuals with dementia and will therefore require the appropriate knowledge and skills.

Staff in specialist community learning disability teams will need to develop the specialist skills required and will subsequently need to train other professionals and frontline staff/carers. Other agencies may also be able to offer help and expertise. These may include local services for older people, the Alzheimer’s Society and other dementia groups, carers organisations e.g. Mencap, Crossroads, the Down’s Syndrome Association and independent advocacy groups.
### 7.6 Stages in dementia

In general, people with Down’s syndrome display similar symptoms to those experienced by those in the general population. The changes that occur over time can usefully be grouped into three main stages: early, middle and late.

The symptoms listed below are those seen most frequently. However, it is important to remember that all individuals are different and each person may show a unique pattern within a common framework. Progression of the dementia also varies across individuals. It is particularly difficult to identify the stages of dementia in people who have more profound levels of learning disability.

<table>
<thead>
<tr>
<th>Early stage</th>
<th>Middle stage</th>
<th>Late stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of short term memory.</td>
<td>Symptoms become more obvious, particularly loss of language skills – naming objects/maintaining a logical conversation/understanding instructions.</td>
<td>Loss of eating/drinking skills.</td>
</tr>
<tr>
<td>Language problems (finding the right words).</td>
<td>Disorientation (time, place and person).</td>
<td>Problems with mobility.</td>
</tr>
<tr>
<td>Disorientation.</td>
<td>Long periods of inactivity or apathy.</td>
<td>Often requiring 24-hour care.</td>
</tr>
<tr>
<td></td>
<td>More severe changes in personality and social behaviour.</td>
<td>Increase in health problems e.g. pressure sores and infections.</td>
</tr>
</tbody>
</table>
7.7 Common difficulties

A number of difficulties can emerge. They are described here, either because they are the most frequently misunderstood or because they cause the most concern to those supporting individual service users.

Mobility and perceptual problems

Often one of the earliest signs of difficulty is when the person has problems with stairs, steps, kerbs and uneven surfaces. This can also be seen in bathing and swimming. Mobility as such, is often not the problem, but the person has difficulties in understanding depth perception and so becomes anxious and/or phobic.

"...nothing would persuade her to go even near the stairs again, and to get her to go to the bathroom I had to hang a sheet across the top of the stairs so that she could not even see them." (BILD 1999)

This can cause major problems with transport and upstairs environments. This can be misinterpreted as a behavioural problem e.g. the person does not want to get on the bus because they don't want to go to the day centre. Aids and adaptations are important but need constant assessment to ensure that they are still appropriate to the person's needs.

Memory

Short-term memory problems are common from the earliest stages. This affects all other aspects of the person's life, particularly in relation to understanding instructions and questions. The impact can be most significant for people who live in independent or semi-independent settings. Appropriate interventions can assist in the early stages e.g. use of pictorial shopping lists. If a cognitive enhancer is to be prescribed, then this is the stage at which it should be considered.

As information in the person's long term memory remains for longer, this can cause problems when the person wishes to continue with activities that are now no longer safe e.g. crossing the road. This can cause behavioural difficulties when carers need to intervene. There are a number of techniques available to help people retain their memories including reminiscence work, life books, appropriate use of music, symbols and pictures, environmental prompts.

Communication skills

Maintaining communication is fundamental in supporting the person with dementia. Carers and staff will need either to understand the person and/or to modify their communication style to meet the current needs of the person. As the dementia progresses it is important for carers to increasingly provide simpler choices and clearer instructions.
Behaviour

A whole range of difficult behaviours can emerge but these are often short-lived and require little intervention. Sometimes these can be a re-occurrence of previous behaviours (e.g. hoarding) or an exacerbation of existing personality/behaviour traits (e.g. slowness). It is important not to see behaviours as attention seeking or due to stubbornness, but to understand why they might be occurring. The most common reasons are:

- due to changes in the brain (e.g. change of taste causing eating difficulties), disinhibition, misuse of objects (e.g. urinating in the bin), confusion;
- difficulties in communication and interaction (e.g. aggressive behaviour caused by not being able to make needs known), extreme distress;
- behaviours caused by issues other than the dementia (e.g. depression, life events, abuse);
- increased withdrawal into the self leading to preoccupation with sensory experiences and parts of their own bodies.

Changes to the person’s sleeping and day/night routine are very common and give rise to significant problems regarding both safety and carers’ welfare. Problems associated with dusk are common (known as sundowning) and can often be helped by increasing levels of light at this time of day.

It is important to remember that once the person begins to show signs of dementia, the focus of care should be on this in the context of their learning disability. It is also essential that all other factors which could cause similar symptoms are ruled out first before a diagnosis of dementia is given.

Although caring for a person with dementia can be physically and emotionally demanding, it can bring rewards. Carers are often able to be creative with the care that they can provide, adapting to a slower, less hectic pace of life.

7.8 Supporting people with Down’s syndrome and dementia

Knowledge of best practice is increasing with experience and the guidance outlined below will help staff to provide the best quality of support. Again, these are divided into the three stages, although it is recognised that the progression of dementia does not fit neatly into these stages; each person experiences dementia in a unique way.

Within all the stages there are many areas which are critical to address in understanding and supporting people with Down’s syndrome and dementia. The Resource Pack for professionals and carers provides practical advice in coping with all the major implications of supporting and caring for people with Down’s syndrome with dementia.
<table>
<thead>
<tr>
<th>Early stage practices</th>
<th>Middle stage practices</th>
<th>Late stage practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closely monitor and document change.</td>
<td>Keep the person appropriately mentally and physically active.</td>
<td>The emphasis in the later stages moves towards the provision of high quality 24-hour care. This will include particular attention to:</td>
</tr>
<tr>
<td>Treat any medical conditions.</td>
<td>Maintain physical health.</td>
<td>- Maintaining mobility and movement.</td>
</tr>
<tr>
<td>Help the person, the family and support staff understand the probable diagnosis as appropriate.</td>
<td>Ensure adequate nutrition and fluids.</td>
<td>- Lifting and handling.</td>
</tr>
<tr>
<td>Focus on maintaining skills; keep independence by increasing staff supervision and prompting.</td>
<td>Protect and maintain safety with regular risk assessments.</td>
<td>- Maintaining nutrition and fluids.</td>
</tr>
<tr>
<td>Keep changes in the environment and daily routine to a minimum; provide structure and supports to daily routines and to help orientation.</td>
<td>Give appropriate help with self-care.</td>
<td>- Skin care and prevention of pressure sores.</td>
</tr>
<tr>
<td>Simplify routines and reduce choices.</td>
<td>Intervene to reduce agitation and distress.</td>
<td>- Prevention of infection and other physical health matters, e.g. constipation.</td>
</tr>
<tr>
<td>Keep verbal requests simple and clear.</td>
<td>Adapt to significant differences in ability on a day-to-day basis; this can affect all aspects of their functioning e.g. mood, memory, and self-care skills.</td>
<td>- Ongoing attention to safety issues.</td>
</tr>
<tr>
<td>Help the person to maintain self-awareness.</td>
<td>Work with families, carers and peers to understand the changes.</td>
<td>- Work with families, carers and peers regarding terminal care and death.</td>
</tr>
<tr>
<td>Reassure the person daily.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7.9 Issues for services

The main issues arising in providing services for people with Down’s syndrome and dementia are set out below. (A fuller document aimed at commissioners is available from www.learningdisabilities.org.uk)

Residential provision

A range of residential provision is needed, including ‘ageing in place’ wherever possible and appropriate. Clearly it is best practice to try and keep the person with Down’s syndrome and dementia in their own familiar environment. However a move is sometimes inevitable due to issues in the environment or in the care provided. An interdependent relationship between the individual and an older family carer may be an additional difficulty. Experience has shown that where this has led to very restricted opportunities then a change in environment can sometimes be of benefit to the person with Down’s syndrome and dementia, at least in the short term.

When a future move is considered unavoidable, then debates arise about the timing of the move and the best environment for the person. Moving people in the early or middle stage of dementia can raise ethical issues, and may exacerbate the rate of deterioration. However, late moves can lead to an increased risk of early death. Careful thought needs to be given about the ability of the new service to cope with the person throughout the stages of dementia. The new service should be able to cope with the person’s current level of need and their future needs until death. Multiple moves should always be avoided.

The effect on other residents if the person with dementia is moved elsewhere must also be considered, as there are issues of loss involved. At the same time, it is important to consider the impact of moving someone with dementia into an existing home where the other people will have to cope with the inevitable death of a person previously unknown to them.

Current thinking would indicate that people with Down’s syndrome and dementia are best cared for in services with specific learning disability expertise. The strategy for residential provision should consider the need for increasing specialist health care and eventually terminal care for individuals as their dementia progresses. It must ensure that there is a range of suitable accommodation with appropriate staffing i.e. ground floor bedroom and bathroom facilities, safe gardens for wandering, and physical aids/adaptations for physical disability and/or terminal care. This also applies to respite services.

Because depth perception problems can make it difficult for people with dementia to use stairs, Surrey Oaklands NHS Trust decided that all people with Down’s syndrome would be moved into ground floor accommodation as part of their resettlement programme. This was in order to reduce the risk of individuals having to move in the future.
The range of residential provision should include:

- Packages of care being put into place in situ in existing family homes or social care housing; registration issues may need to be resolved.
- Registered nursing homes or other 24-hour staffed facilities. This is likely to be either for people with learning disabilities or for another client group e.g., older person’s dementia services. Where people access services for older people they are often more than 20 years younger than the other residents, and for this reason amongst others they are rarely appropriate (see Chapter 6).
- Use of general hospitals/hospices for terminal care (see Chapter 8).

**Day/leisure service provision**

Day opportunities are often provided in large day centres which are typically poorly equipped for the needs of frail, confused individuals. Maintaining a person's placement, however, is very important in terms of helping to provide consistency and stability in routines, independence and social networks. It can be the critical factor in maintaining a family or residential placement.

Planning for the day care needs of the person with Down’s syndrome and dementia will need to ensure increased availability of services with the following features:

- smaller, quieter groups and smaller rooms (e.g., for lunchtime);
- focus on memory aids/reminiscence;
- a predictable, simplified timetable;
- a suitable number of skilled, experienced staff.

**The COPE (Caring for Older People) project** in Edinburgh was developed within a large day centre. Planning for a more client-focused service identified the need to make specific provision for a small group of older people with Down’s syndrome who were becoming frail and developing dementia. Space was set aside to develop a physical environment which could meet their particular needs, paying attention to the decoration, the layout of the area and clear signposting. This group of older people is also being supported by staff, some of whom they already know. COPE enables people to continue using a familiar centre which they have been attending for many years and the project can help to minimise their disorientation and maintain their skills.

**Environmental considerations in residential and day services**

Environmental issues are critical in the care of people with Down’s syndrome and dementia. Sensitive planning and adaptation can help staff and family carers to minimise some of the impact of the dementia for the person. Environments may need to be altered so that they are: calm; predictable; familiar; suitably stimulating and safe.
Some specific environmental modifications have been found to have a positive effect in helping support people with dementia. Specifically, thought needs to be given to:

- **Flooring:** no uneven surfaces; no steps; avoid shiny slippery surfaces; ensure continuation of colour from room to room; avoid patterns;
- **Lighting:** avoid shadows which can look like pools of water, or frighten people; sufficient lighting in the evening can reduce sundowning (described earlier);
- **Furnishings and fittings:** should be traditional to reflect the person’s long term memory and hence make sense to them; care needs to be taken with fittings (e.g. taps, cookers, radiators) both from an understanding of their use (especially if very modern) and from a safety perspective;
- **Gardens and access points:** these are critical to allow safe wandering. If the person can gain direct access to the road from either the house or garden, then this must be regularly reviewed to ensure the person’s safety;
- **Mirrors:** reflections can cause major problems if the person can no longer recognise themselves; this can cause fear of intruders especially at night and disrupt sleeping patterns, three-way dressing table mirrors and mirrored wardrobe doors can cause difficulties for some people.

**Staffing qualities**

Listed below are the ideal qualities that staff should have to support and care most effectively for people with Down’s syndrome and dementia.

- Flexible – able to react to day-to-day service user’s needs.
- Able to cope with change especially the rate of change.
- Able to move from support to care.
- Able to make life fun for the person with every activity.
- Able to implement care programmes to maintain independence for as long as is realistically possible.
- Able to adapt communication style to service user need.
- Aware of additional health needs (e.g. epilepsy, liver problems, medication, thyroid, sensory impairments).
- Able to observe and document service users’ current functioning.
- Willing to support the person in terminal care.

**Supporting family carers**

Families often find it difficult to come to terms with the diagnosis of dementia. Having adapted to having a son or daughter with Down’s syndrome, they now have to face the additional complication of dementia. It is important to identify the specific needs of family carers (see Chapters 4 and 5).
Access to respite care, sitter services, home help and carer support groups may be helpful. Some older family carers find it difficult to accept support and help for the first time and this needs to be handled very sensitively. Where the person with Down’s syndrome and dementia lives with an older carer with their own health needs, services need to be particularly sensitive and co-ordinated to respond to the individual and joint needs. Separate advocacy should be available to both the person and their relative. Issues of other family members developing dementia may cause additional concern for carers.

**Working with peers**

The effect on other people with learning disabilities of seeing a friend deteriorate is rarely considered. Helping peers to understand can reduce their distress and enable them to be more considerate and understanding of their friend’s changing needs. In some cases it can also prevent placements breaking down. To help people with learning disabilities understand and talk about life cycle and dementia, three accessible booklets have been published (BILD in press).

**Care management**

Good care management is the cornerstone of effective dementia care and the following principles should apply:

- accurate assessment of individual need in order to develop an effective care plan; carers and advocates (where relevant) must be involved as well as the person with dementia and relevant professionals;
- understanding of risk and consent issues in dementia;
- excellent planning and liaison between specialist learning disability services, primary health care services, social services, secondary health care services and the private and voluntary sector;
- co-ordination of resources identified in the care plan without unnecessary delays or duplication;
- regular review and monitoring of needs to adapt environment, staffing and care to meet current levels of functioning;
- active ongoing care management i.e. cases must not be closed;
- speedy decision making and finance availability, with financial packages that taper upwards;
- flexibility in co-ordination and/or pooling of budgets where there is interdependency.
7.10 Concluding comments

The growing numbers of people with Down's syndrome who develop dementia places additional demands on services. Commissioners and service providers will require greater knowledge and understanding of these demands and need to ensure that they have the resources required to plan and deliver effective and high quality services. This will involve effective care management systems, adaptation of existing services, development of new services and the creation of new, more appropriate and flexible packages of care and support. This will enable people with Down's syndrome and dementia, their families and their peers to receive the high quality support that they require.
Chapter 8

Supporting People through Terminal Illness and Death

Hilary Brown, Sophie Burns and Margaret Flynn*  

8.1 Introduction

This chapter presents the lessons from a study of services that have cared for a person with learning disabilities during a terminal illness. It reflects on how the service learned of the person's illness, how they mobilized services and made decisions, and how they worked together to provide support in the person's last months and weeks. It also documents the way staff, as individuals and as teams, made sense of their experiences, how they evaluated the input of other professionals and what barriers they had faced as they tried to make it possible for the person they were caring for to have a 'good death'.

Todd (in press) notes the pervasiveness of death imagery in the old large-scale institutions and hypothesises that because of this legacy community services have found it hard to accommodate death in realistic and respectful ways. The GOLD project was framed in terms of how services could make possible an 'ordinary' death for people with learning disabilities and uses the generic literature on death and dying as a reference point. Two important issues when people are dying are where they hope to die and secondly whether they expect their doctors and carers to be open with them about their condition. We found that most services did all that they could to keep the people they were caring for at home but that they were not prepared around issues of disclosure.

The experiences of people with learning disabilities and their carers described here provide signposts for how best services can both prepare for and respond to people with terminal illness. These are drawn together at the end of this chapter as guidance for good practice.

8.2 The project: services and individuals

The project was based on a series of case studies in which the service network was viewed as the 'unit' for the study, as well as the individual client who had died. Twenty-one individual case studies were included from 12 services. In all, 31 interviews were conducted with care staff, 16 with service managers, 18 with health care/learning disability professionals, three with service users, six with family members, eight with local community representatives and one with an external representative. Five staff/team meetings and one meeting with a group of older people with learning disabilities were convened and documented. All names have been changed.

The initial parameters for inclusion were that the person who had died should have been living in residential care at the time their illness was identified. Although the main focus was on people who were older, a rigid age limit was not set and we included some younger adults and people who had been living with a life-limiting illness for all of their lives. Most of the case studies involved an individual who had died between six months and five years previously unless there were special issues we were trying to explore, for example where the person with a learning disability was being cared for in a hospice, living in a secure unit or using respite services. We also wished to explore the experiences of people with learning disabilities from minority ethnic groups.

*The authors would also like to acknowledge the input of the Palliative Care Network convened by Nola Blackman and Lynda McEwen, and thank Sarah Burchill, Pete Stevens, Stuart Todd and all the staff and families who so generously shared their time and experience.
Some services had cared for a number of people in the final stages of their lives and had developed internal guidelines for their staff and/or protocols for working with other agencies. For other services this was their first or only experience. The bias was towards services which were stable and which felt they had delivered a good quality of care.

We were also told about other cases in these services which had gone badly. From these 'shadow' cases, we were able to draw out the aspects of death and dying that staff found most distressing and, conversely, build a picture of what staff believed to be a good death. On the whole staff had found it more difficult to deal with sudden and unexpected deaths and, in line with the mainstream literature, they had found symptoms such as haemorrhaging distressing and had found it hard to respond to open grief on the part of relatives (Low and Payne, 1996).

A specific protocol was drawn up to protect the person's confidentiality and that of key professionals involved in their case. We approached each interview as a source of information but also as an interesting process through which participants were helped to reflect on the death and the demands it had made on them. We were alert to the fact that the accounts were likely to be actively 'edited' (Seale, 1991) and that they might be emotional for both interviewer and interviewee.

**Audit of deaths at Community Team level**

To put these individuals into context we drew on figures collated within one health district by a community learning disability team that had monitored all deaths in its catchment area. The authority has an estimated population of 200,000 with approximately 585 people on the learning disabilities register. However they identify that number many people, particularly those with mild learning disabilities, may not be registered. Thirteen clients of the community team died in the year 2000-01, seven men and six women, and the cause of death was recorded in all cases. The deaths could be quite clearly categorised into younger clients who were mainly suffering from cerebral palsy and died from some kind of respiratory failure; and older clients for whom the causes of death were more varied but included cancers and heart disease.

**8.3 Features of a good death**

In the literature and these interviews a good death tends to have been defined in relation to the following features:

- Diagnosis is prompt and followed up by curative treatment for as long as this is practicable and feasible.
- Treatment decisions are made on the basis of the evidence, the patient's informed choices and/or their best interests.
- The transition from curative to palliative treatment and nursing is then managed appropriately so that intrusive interventions are not still being tried when the person is approaching death, adding to physical burdens of pain or tiredness.
It takes place at home or in a setting which is as homely as possible and where the person's previous social bonds can be maintained and acknowledged right up until the time of, and after, the death.

Physical symptoms are well managed and pain is avoided; there is no inappropriate prolonging of life or resuscitation when death is inevitable.

Psychological symptoms are well managed and unnecessary distress is avoided usually by disclosing the prognosis and helping the person to prepare themselves, so that the person is not left isolated.

Death is 'timely': there is a sense that it is the right time for the person to die and there is some degree of readiness as each stage gives way to the next.

Different professionals and different agencies work together seamlessly.

Relatives, carers and other loved ones are helped to prepare for the person's death and supported afterwards.

These are the criteria against which we analysed the case studies gathered during the project, to see how the organisation of services for people with learning disabilities facilitated or hindered such a good death occurring.

**Diagnosis and treatment**

There were issues of late diagnosis in several of these case studies. In some cases there were extenuating circumstances, which meant that symptoms or changes were put down to other causes, as in Maria's story:

**Maria was an Austrian woman with Down’s syndrome who was smuggled into Britain by her mother during the war. She had moved into a residential service for people with learning disabilities in her late forties, when her mother was killed in a fire in their home. Her English was fair, although not her first language. She was in her late fifties when she suffered the onset of dementia. The onset of her dementia was not diagnosed for a long time because the first noticeable signs appeared at the same time that her best friend, with whom she had shared a room, moved out of the house to a nursing home. Her withdrawal and low mood were taken to be signs of depression, and she saw a counsellor for two years. When her health and abilities deteriorated further, care staff raised their concerns with the GP and at this stage Maria was referred to a psychiatrist, who diagnosed Alzheimer's. A decision was made that Maria would be cared for at home and not move to a nursing home as her friend had done. Eventually, her health deteriorated to such an extent that she had to be admitted to the general hospital. She died after two weeks of being nursed there.**
The problem of diagnostic overshadowing, where symptoms are understood by health care professionals as part of the learning disability, rather than part of the person’s illness, is highlighted in the following account from a learning disability service manager:

…when Mary was in hospital, it wasn’t when she was really ill; she was actually in the rehab ward and on her care plan, under her basic physical needs, her problem need was that she had a learning disability and epilepsy and I had to run through the whole of the care plan with the sister to point out that that wasn’t what her problem need was; that wasn’t the cause of why she couldn’t mobilise any more or why she couldn’t feed herself any more because she’d done all that before regardless of the difficulties she had with her learning disability.

Nor was diagnosis carried out using orthodox tests in some cases: the GP diagnosed bowel cancer in Daniel without instituting tests and Christina’s breast cancer was not picked up until it had reached a very advanced stage.

Coherent decision-making

We found in our study that there was no agreed format for making decisions in terms of who should be involved, nor were decisions being made against a background of clear principles about consent or best interests. This is not to imply that decisions were not being made with good intentions; but that they were made on an ad hoc basis, with very varying involvement of parents or relatives. Daniel’s brother was approached to make a hasty judgement about whether blood could be taken in the absence of his consent even though he had explicitly handed over responsibility for day-to-day decision making to the staff team who knew his brother best. On the other hand Ben’s mother, who had not been directly involved in his care since childhood, decided with the consultant oncologist that Ben would not receive any further curative treatment although his cancer was one that could have responded positively to active treatment. Staff who knew him noted that there was no provision for them to challenge this decision. Judicial review was not used in any of the cases in our sample to address these potentially fraught judgements but one formal case conference was convened to address the issue of whether to insert a PEG feeding tube to ease the last months of Thomas’s life.

A smooth transition from curative to palliative treatment

These decision-making issues are most acute at the point where a shift of treatment goals is most explicit. If the shift takes place too late as it did for Mark, potentially intrusive interventions may still be tried at a very late stage and relatives and staff left unsure that the end stage has been reached. When the shift happens too early however, as it had for Ben, there is a real risk that people with learning disabilities do not receive potentially life-saving treatment.

This shift also determines the mood of the service as well as the clinical decisions as the death may come to dominate the service’s other activities and relationships with other residents. Ally’s service found it very helpful to be told clearly that they could stop trying to be active and involve her in outings and suchlike and allow her to gradually withdraw as she approached the end of her life. The usual ‘sentimental order’ (Glaser and Strauss, 1964) of the service, perhaps one of busy or cheerful activity,
may be compromised, with staff not knowing how to handle the new mood and tasks, especially if the dying period is prolonged and/or if the person’s care needs change dramatically as for example the two individuals in the case studies who died as a result of Alzheimer’s.

Place of death

Grande, Addington-Hall and Todd (1998) found four factors affecting the likelihood of a home death:

- the presence of a primary carer at home;
- the person’s age, with older people more likely to die in hospital;
- gender, with women more likely to die in hospital than men;
- socio-economic status with more well off people likely to die at home.

The key variable is whether the staff can ‘stay the course’ and in this a cohesive staff group may act to keep people with learning disabilities out of hospital and compensate for other disadvantages they experience. However, there is evidence that some services (especially those which had previous experiences of poor care and communication in hospital) adopted a kind of siege mentality and perhaps did not consider hospice or nursing care even when it was indicated for proper symptom management and pain control.

In the course of our study, Barry was the only person we came across who had access to a hospice during the time that he was ill.

**Barry had secondary metastases in his brain,** which caused significant changes in his behaviour, leading to the manager of his residential home looking for alternative placement options (he was trying to jump out of windows and they did not have a ground floor room that he could use). Barry was admitted to a hospice on a respite-care basis, and although staff at the hospice were keen to remain involved in his care, they felt that he should be able to go home with an outreach palliative care service. However, after a difficult period back at his original placement, he eventually moved into a nursing home because the care staff in the residential learning disability service were unable to cope with his additional needs. Staff from the hospice were left feeling disappointed that Barry did not have the support he needed to be able to die at home in a familiar environment.

**Physical symptoms and pain control**

It was in the area of pain control that collaborative working appeared most important. Where the person was not able to make their needs known, the staff who knew them best felt most able to interpret facial expressions and body language. For example, one staff team came to see Daniel’s ‘lemon face’ as a possible signal of pain. A speech and language therapist was brought in to help the team to read these signals and one of the community learning disability team observed that:
... they were terrified of him going into a hospice...[because of his]
communication that was so subtle, it was all about eye movements and lip
movements and everything, and they just thought, we would rather he didn't
have to move and he could stay with people who knew him.

The decision of Fiona's service that she would stay was partly informed by previous experience of
clients going into the local district general hospital and receiving a poor quality of care there. Given
her fear of needles, they managed her pain with the use of Fentanyl patches, an opiate drug similar to
morphine that could be administered by the social care staff who knew her.

But there may be times when hospice care could deliver a better service and it is important that
people with learning disabilities are helped to access the most appropriate support at different stages
of the illness. One team were not experienced enough to realise that the syringe pump which had been
set up to deliver morphine failed, and it was not until their client asked if they could ‘get a knife to cut the
pain out’ that they were alerted to the need to call in expert help.

There are two approaches to the assessment of pain relief. One relies on sensitivity. The other is
advocated in a recent document on palliative care for people with mental health needs (National
Council for Hospice and Palliative Care Services and Scottish Partnership Agency for Palliative and
Cancer Care, 2000) which suggests that clinicians use a normative model and do not wait to be asked
but use their clinical experience to prescribe a level of pain relief which they would consider
appropriate for other patients. The best care will involve a combination of these approaches, or a shift
as the illness progresses and the person becomes less able to make their own decisions or articulate
their needs. Hence it is important that social care professionals do not insulate themselves from clinical
expertise.

Psychological symptoms and disclosure

Relieving distress hinges on communication (Glaser and Strauss, 1964). Seale's study of over 600
random deaths in England in 1987 confirmed the impression that a move had taken place towards
openness in communication about dying, especially in relation to cancer (Seale, 1991). 81% of general
practitioners, hospital doctors and community nurses involved in caring for people who were dying
favoured awareness, with hospital doctors doing most of the 'telling' with back-up from GPs. The view
from palliative care professionals consulted in this study was that disclosure is important, but that
sensitivity towards the individual's readiness for disclosure is vital.
Social care staff in this study often felt caught between doctors and relatives in terms of deciding if they could be open, as in Daniel’s case.

Daniel was a man in his 50's who was dying of bowel cancer. When they knew he was entering the final stages of his illness, the team in his residential service asked the GP to be open with him because, although he had no verbal communication, they sensed that he knew how serious the situation was. The GP never sat down and told Daniel that he was dying and the care staff did not feel they had sufficient authority to initiate a conversation with him directly. When she sensed that he did not have long to go, Daniel’s keyworker told him it would be ‘okay to let go’ and reported that he seemed visibly relieved. He died the next day.

Nevertheless, even where people had not been told ‘officially’ we heard of some conversations when the person made it clear that they suspected they were dying and also displayed a certain readiness for disclosure. Fiona and Anna both initiated the comments that revealed to their carers the level of their awareness of death approaching. Only Anthony’s case proceeded on the basis of open acknowledgement.

Fiona was in the very advanced stages of cancer. Her family, with the support of her residential service, had decided not to tell her that she was dying, although they agreed that if she ever asked questions they should be honest with her. A short time before she died, she said to a member of staff who was close to her that she was ‘going to see Mummy in heaven’.

Anna had lived for many years with a life-threatening respiratory condition, and although she understood that she was ill, it was not clear if she knew the seriousness of her condition. She told her mother a couple of weeks before she died that a member of staff was leaving and that she would also be ‘leaving soon’. In hindsight, Anna’s mother understood this to be Anna’s acknowledgement that the end of her life was approaching.

Anthony was 80 and had been diagnosed with an inoperable gastric cancer. He knew explicitly that he was dying and drew on his religion to prepare himself for the end of his life. Staff joined him in singing hymns the evening before he died; this helped the staff afterwards both in terms of their own grieving but also because they felt that Anthony had been prepared and seemed at peace.
Responsibility for making decisions about disclosure tended to fall on the care staff in our case studies, and they often felt unprepared or unqualified to make those decisions. Social care staff do not have the same status as other professional staff, nor do they have the same legitimacy as family members to seek and/or pass on information on behalf of the person. They had the additional task of deciding what and when to tell other residents so that they could also be prepared for the person’s death. Sudden shifts in acknowledgement were more likely to have happened where a planned approach had not been taken or where there had been no consensus about the merits of openness. Absence of mutual professional respect led to disagreement as to who is best placed and/or has the moral mandate to reflect the gravity of the situation back to the dying person.

Death is timely

The organisation of this work over time (see Strauss and Glaser, 1970, who describe in detail the temporal ordering of dying work), involves how transitions are managed; the changing needs of caring for the person as their illness worsens, interacts with organisational issues, such as the need to change shift patterns, introduce waking night staff, and shift from social to nursing care.

This need for flexibility was managed best in those services that operated a number of services from a central hub as opposed to small isolated services that had to find the flexibility from additional personal inputs or by buying in temporary staff to provide extra duties. This was also the case where individuals went into hospital for periods of treatment and needed to be accompanied by staff from the residential service. Two services decided that they could not manage these shifting demands and the person was moved into a nursing home. Several services referred back to care managers for additional resources and these were made available without undue delay.

The different case studies illustrated different trajectories, including sudden death, several which had been expected since childhood and were overdue, a lingering death, one which demanded entry and readmission to different services, and a ‘suspended sentence’ scenario when the person remained on a plateau awaiting a dramatic decline.

Working across professional and agency boundaries

The different professional and social groupings of people who should be involved when an individual has palliative care needs have been outlined in the medical literature (O’Neill and Rodway, 1998). Learning disability services were well supported by primary care teams and by oncology services but less so by specialist dementia services or by secondary health care. Social care staff tended to take on some of the roles that would usually be restricted to qualified nursing staff. Often links had to be established from scratch, without formal networks or arrangements being in place previously. For example in Mark’s service:

Mark left a very good legacy, because, okay, yes, it was difficult in the hospital while he was there, and okay, it was difficult when he came back here, but it was unique, the situation was unique to the Trust, unique to us as a staff team but also to the palliative care team, you know, so Mark actually brought an awful lot of people together and in a way that hadn’t happened before or since, but we have still got that contact and it has been established.
Relatives and care staff are supported

The staff team who cared for Ally still have a photo of her on the noticeboard in the kitchen and talk about her love of dancing and of how she used to greet them when they came on shift. Their shared account of how they rose to the challenge of caring for her is one that enhances their current sense of team solidarity. On the other hand, the staff team who were working in Anna’s service dissolved when she died suddenly after a difficult shift in which a staff member had been angry with her for not doing her share of the washing up. The staff member who found her left and never returned to the service and clearly found the incident shocking and undermining. Young staff in particular need extra support to see that they are not responsible for such events and to come to terms with the unfinished business in situations where the manner of a person’s death leaves difficult issues unresolved.

Staff also understandably expressed ambiguity. In Fiona’s team one worker said:

"I think everybody, all the staff were hoping that you know that they would be near Fiona at the time and so we felt quite privileged … that we were there with Fiona, holding her hand and talking to her at the time."

while another younger worker said

"Every day I felt 'Please don’t let it happen on my shift!'"

Because social care staff to some extent replace as well as augment the family they may find it difficult to manage the boundary with families and know when to withdraw. There may be dilemmas about whether the funeral should be held near the service which the person had used or near relatives’ homes. There are also real issues about whether the service should have an ongoing role in the lives of relatives who want to maintain social links with staff or residents. One service did keep ongoing contact with a mother who had been closely involved with the service over a 20-year period whereas another home manager had gradually withdrawn from a very intense friendship with the mother of a client she had supported; another manager felt caught because he could not see a way to withdraw.
8.4 Guidance for good practice

Drawing together the experiences of the people with learning disabilities and their carers in the study provides the following lessons for services:

- In order to inform improvements in commissioning and practice, the community learning disability team should monitor deaths in their catchment area, including an audit of the care offered, a review of inter-agency arrangements and of the involvement of specialist palliative care or dementia services.

- Services should ensure that people with learning disabilities participate in all available screening programmes (e.g., cervical, testicular, breast, prostate) and that diagnostic checks are carried out wherever unexplained symptoms or physical changes are present.

- Where significant decisions are to be made which depart from normal clinical pathways, such as ceasing treatment, not for resuscitation or other end of life decisions, these should be made in a formal case conference with recourse to independent advocacy or judicial review where there is controversy. Decisions about day-to-day care should be made by those carers most involved and documented on the care plan.

- Clinicians should do all they can to inform workers in the residential setting, and other carers, of the likely trajectory of the illness so that carers can gauge their input over time and make the necessary material and emotional adjustments.

- People with learning disabilities should be helped to die at home unless their needs are too complex or their dying too protracted for this to be managed. The criteria for receipt of specialist services should be the same as those for people who don't have learning disabilities. Hospice-at-home teams should be involved to facilitate this. If the person's needs are too great, they should be helped to access mainstream hospice services (rather than die in ordinary hospital wards).

- People who are not able to ask for pain relieving medication or sedation should be given medication according to the clinician's normal expectations of the needs of other patients with a similar illness. Where there are no realistic options for further curative treatment, or where a person with a learning disability has made an informed decision to refuse treatment this should not bar them from receiving equivalent pain relief and sedation.

- Disclosure needs to be on the agenda of every multi-disciplinary meeting so that those closest to the dying person are clear that they have the authority to decide for themselves when and if the person's questions should be answered openly.

- Care managers should be authorised to vary resources to allow a person to stay in their current placement during a final illness. Health Trusts should negotiate and establish standard protocols (proactively not reactively), with social services to govern who should pay for staff to augment care when people are being treated in hospital.

- Commissioners and the new Partnership Boards in England should ensure that palliative care needs are featured in local plans and joint investment plans so that formal networks are in place and accessing palliative care when it is needed is a straightforward process.
8.5 Concluding comments

The case studies in this project confirm and illustrate the problems with access to healthcare highlighted in *Valuing People* (Department of Health, 2001a). Where clients with learning disabilities were suffering from cancers these tended to have been diagnosed late and idiosyncratically. Difficult decisions were often taken outside formal case conferences and sometimes in ignorance of best practice in terms of consent to treatment and the physician's responsibility to act in the person's best interests.

Periods in hospital placed additional demands on care staff whose role in that system as informants and/or informal carers was variably supported: some care was excellent and in other cases communication broke down or was severely strained. Because links with mainstream oncology and hospice services were tenuous the desired outcome for many services was to keep the person at home and to manage by extending their own roles and stretching their resources. For many people featured in the case studies this worked well, but for others this emotive decision might have led to the person receiving less than adequate pain relief in the terminal stages of their illness.

Supporting someone who is dying can be a very positive experience for staff if they are helped to access services and to deal with their feelings both personally and professionally. Social care staff find themselves stretched: at one end of the spectrum they move into a space which families and close relatives might otherwise occupy while at the other end they have to take on nursing tasks which are outside of their usual professional role. These boundaries do need to be respected and new limits set. With support for this enhanced role many staff, as individuals and teams, came out of their experience stronger and more unified: some were considering new career choices and formal qualifications in the palliative care field. It seemed from our interviews that caring for the dying occupies a relatively high status position in relation to more ordinary care tasks.

Where the care had worked well it led to very positive feelings and seemed to have enhanced the status of individual key workers and the unity of staff teams. Where the death had proved more difficult, for example when Anna died suddenly after a difficult shift, it led to an implosion of the team and very possibly to long-term distress. Managers need to support people in response to difficult deaths (for example one team had been helped to go through a coroner's inquest after an accidental death in their service). Death is a messy business and care staff cannot control all the contingencies: realistic expectations may help to protect staff from inflated levels of stress and distress and leave them knowing that, even if less than perfect, an ordinary death was as important as any ordinary life.
A Charter of Rights for Older People with Learning Disabilities and for Older Family Carers

Throughout the UK there is greater awareness on the part of the governments of the needs of older people with learning disabilities and older family carers. They are however minority and often neglected, groups and it is important that their interests remain high on the agenda.

The Foundation for People with Learning Disabilities calls for older people with learning disabilities to have the right to be supported to:

- develop person-centred plans to meet their current and future needs.
- develop and maintain new friendships.
- maintain links with their families when they have left home.
- lead full lives with activities of their choice both during the day and also at evenings and weekends.
- have choices about where they live and with whom.
- have access to services which can adapt to their predictable age-related needs, both with respect to staffing and to their environment.
- have access to independent advocacy.
- have their physical and mental health needs met. They should have access to regular health check-ups, screening (including screening for the early onset of dementia if they have Down's syndrome) and prompt treatment if they become ill.
- have their religious, cultural and ethnic needs respected.
- be cared for in terminal illness as far as possible in a familiar environment, in a way that respects their wishes.

The Foundation for People with Learning Disabilities calls for older family carers, whose lives have been defined by their caring role, to have the right to:

- receive the practical and emotional support they require to continue to care for as long as they and their family member who has a learning disability wish. Support should include the provision of information, short-term breaks and access to support groups.
- be given the peace of mind that the needs of their family member who has a learning disability will be met when they are no longer able to care full-time or after their death. This means that planning needs to take place over a period of time and at the pace that the family wants, when a family carer reaches the age of 60.
- have support in their caring role. Their family member with a learning disability should have access to a range of activities outside the family home or additional support within the home according to individual preference.
- have access to an independent advocate.
- have their religious, cultural and ethnic backgrounds respected.
The Foundation believes that it is important that the following recommendations, based on the findings of the Growing Older with Learning Disabilities (GOLD) programme, are acted upon.

**For policy makers, planners and commissioners**

- A register of people with learning disabilities known to services needs to be developed and maintained so that authorities can plan and develop services for people with learning disabilities as they get older.
- Joint working is crucial. Learning disability services should take the lead in promoting partnerships between agencies.
- Planning ahead in the development of services is essential if the predictable age-related needs of older with learning disabilities are to be met without unnecessary disruption to their lives.
- Through the person-centred planning process, older people with learning disabilities should have choice about where they live and with whom if appropriate, this should include considering the possibility of remaining in the family home.
- Older people with learning disabilities should not be inappropriately placed in residential or nursing homes for older people.
- In any reconfiguration of day services it is important that the needs of older people with learning disabilities are met. Older people with learning disabilities should have access to a wide range of social opportunities and leisure activities of their choice, both during the day and at other times.
- Independent advocacy services should be available for older people with learning disabilities.
- It is important that services work together to provide the necessary expertise and support if people with learning disabilities develop dementia or are terminally ill. Wherever possible this should be in their own home.
- Older family carers need to be identified to ensure that they have access to a full range of support.
- It is crucial that processes are in place whereby families can begin to plan for the future at their own pace, when a family carer reaches the age of 60, with the added assurance that in an emergency the needs of their family member who has a learning disability will be met.
For service providers

- Older people with learning disabilities should have regular access to the full range of health care services in the community. They should have regular check-ups and participate in screening programmes. (If they have Down’s syndrome it is important that they are screened for the early onset of dementia.) They should then receive any treatments they require.

- It is important to give priority to supporting the relationships and social networks of older people with learning disabilities.

- Residential services need to recognise the value and importance of ensuring good relationships with family carers.

- Day services need to be responsive to the individual needs and wishes of people with learning disabilities as they grow older.

- The capacity to meet the predictable age-related needs of people with learning disabilities, to listen to their wishes and choices and to implement them as far as possible should be a priority for services.

- Staff need to receive appropriate training. (The units in the Learning Disability Awards Framework for older people and the training materials covering the menopause, dementia and terminal care will be valuable here.)

- Older people with learning disabilities should have access to an independent advocacy service, particularly if they have no links with their family.

- Services should meet the specific religious and cultural needs of older people with learning disabilities from minority ethnic communities.

The Foundation for People with Learning Disabilities will continue to seek to promote, in partnership with others, the interests of older people with learning disabilities and older family carers.

The Foundation is leading a three year project (2002-5), the Older Family Carers Initiative, funded by a Department of Health Section 64 grant. The Initiative aims to support local authorities in meeting the needs of older carers and their families.

(For details, contact the Foundation for People with Learning Disabilities or visit www.learningdisabilities.org.uk)
Bibliography


Howells, G. (1986) *Are the medical needs of mentally handicapped adults being met?*. *Journal of the Royal College of General Practitioners* 36: 449-53


McCarthy, M. (2001) 'Responses to women with learning disabilities as they go through the menopause', Tizard Learning Disability Review 7(1):4-12


Penrose, L.S. (1949) 'The incidence of mongolism in the general population', Journal of Mental Science 95:685-8


Appendix 1

Summary of the GOLD projects

GOLD externally funded projects

The Sharing Caring project, Sheffield Mencap in partnership with Sheffield Citizen Advocacy

The Sharing Caring Project was established in 1996 to identify the needs of people over the age of 67 who are still caring at home for a person with learning disabilities and to support adults with learning disabilities who live with an older family carer. The GOLD project aimed to identify the best ways to help families prepare for the future. Funding for this project was also provided by the Community Health Sheffield NHS Trust.

The Pakistani Carers project, the Sharing Caring project, Sheffield Mencap, in partnership with the Asian Disability project.

This project was set up to target older family carers from the Pakistani community and support them.

Contact: The Sharing Caring Project c/o Sheffield Mencap, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF.

Support for Older Carers project, The British Institute of Learning Disabilities (BILD)

In partnership with six local authorities across England, BILD supported the development of support groups for older family carers. The aim was to help families prepare for the future by providing information on service opportunities and benefits. The areas involved were: South Gloucestershire, Sunderland, Stoke on Trent, Lambeth, Gateshead and Sandwell. The lessons from running the groups are included in Appendix 3.

Contact: BILD, Campion House, Green Street, Kidderminster, Wolverhampton, DY10 1JL.

Adult placement scheme, United Response Northern Ireland with the University of Ulster

Older families had traditionally had a low uptake rate of adult placement services. Research was undertaken to identify why this was and it fed into the development of a service specifically targeted at their needs.

Contact: United Response Northern Ireland, 28 Park Drive, Bangor, Co Down, Northern Ireland, BT20 4JZ.

The Looking Forward project, Wandsworth Rathbone

This project sought to identify the aspirations of people with mild learning disabilities living with family carers over the age of 55. The family carers were also involved in this action research project which lead to the development of personal plans for each participant.

Contact: Generate (formerly Wandsworth Rathbone), 73 Summerstown, Tooting, London SW17 0BQ.
Living in the family home, The Housing and Support Partnership

Ageing parents and other relatives supporting a person with learning disabilities in the family home face huge difficulties securing future accommodation. Because of the shortage and uncertainty about statutory provision many families seek to make their own arrangements. The family home is a possibility, provided the necessary support can be arranged. This project explored how families could achieve this solution whether the home was owned or rented.

Contact: The Housing and Support Partnership, 78a High Streeet, Witney, Oxon OX8 6HL.

Dementia care mapping, Parkside Health

Dementia Care Mapping was developed as a person-centred approach to understanding and responding to the needs of people with dementia. This project examined whether this tool was useful for looking at and improving the support provided to people with Down’s syndrome who have dementia.

Contact: Parkside Health, Hammersmith and Fulham Learning Disabilities Team, 179-183 Fulham Palace Road, London SW6 8QX.

Evaluating psychosocial interventions, University of Birmingham

A range of non-pharmacological interventions is recommended for people who develop dementia, including reality orientation and reminiscence work. This project developed a protocol for evaluating the effectiveness of these methods specifically with people with Down’s syndrome who developed dementia. An important component of this was obtaining reliable measures of people’s abilities so that any change could be accurately demonstrated.

Contact: The School of Psychology, University of Birmingham, Edgbaston, B15 2TT.

A resource pack for supporting adults with Down’s syndrome and dementia, Surrey Oaklands NHS Trust

Many carers of people with Down’s syndrome are still surprised to hear about the prevalence of Alzheimer’s disease amongst this group, and have little information about how best to go about supporting a person with learning disabilities who develops dementia. This project aimed to fill the gap in the currently available resources by first investigating what information carers of people with both Down’s syndrome and dementia either found to be useful or would have liked in retrospect. The outcome is a comprehensive resource pack for commissioners, clinicians, paid and unpaid carers and people with learning disabilities themselves.

Contact: The Psychology Department, West Park Hospital, Horton Lane, Epsom, DE8 3E.
The inclusion of older people with learning disabilities as active members of their communities, East Lothian Care and Accommodation Project (ELCAP)

ELCAP is a charity that provides accommodation and services for people with learning disabilities in the East Lothian area of Scotland. This project aimed to develop new ways of assisting older people with learning disabilities to take their place alongside other older citizens in community activities. It explored two approaches. The first was to develop new leisure activities/associations which would bring together non-disabled and disabled older people from the outset. To this end weekly tea dances and an indoor bowls club were set up. The second was to support and promote the inclusion of people with learning disabilities into existing community leisure activities for older people. The project was externally evaluated by Scottish Human Services.

Contact: ELCAP, Woodbine Cottage, West Loon, Prestonpans, EH32 9N.

Community allotment club, Enable Scotland

This scheme sought to develop a self-sustaining integrated allotment club. The ideas evolved from considering the future opportunities for four older men with learning disabilities who were coming to the end of their involvement in a horticultural project. It was hoped that it would provide valued activity for the men as well as facilitating long-term relationships. It provided an inexpensive model which other services may wish to duplicate.

Contact: Enable Services, 46 Old Dalkeith Road, Edinburgh EH16 4T.

The menopause and women with learning disabilities, The Tizard Centre

Despite it being an experience common to all women, very little attention has traditionally been paid to menopause as it affects women with learning disabilities. This project explored what women with learning disabilities understand about the menopause, how they experienced it and what support they receive from services. Attitudes and practices of staff and carers were also explored. This research was used to develop a range of materials to support women with learning disabilities and those who may have a role supporting them, including family carers, workers and GPs.

Contact: The Tizard Centre, University of Kent, Canterbury Kent CT2 7LZ.

Support for people who are dying, Salomons Centre

This project had two main components. The first used case studies to understand the experiences of people with learning disabilities who have a terminal illness. The second produced training materials based on the lessons learned from the research, which will be of value to both learning disability and palliative care services. These materials are in preparation.

Contact: The Salomons Centre, Broomhill Road, Tunbridge Wells, Kent TN3 0TG.
GOLD In-house projects

GOLD Saturday Over 50 Group
Throughout the duration of the GOLD programme a group of nine older people with learning disabilities were supported to meet at least monthly. The intention was to ensure that the real life concerns of older people were being addressed and also to explore ways of actively involving older people in the programme.

GOLD stories research
To inform the priorities of the GOLD programme, questionnaires were sent to both older people with learning disabilities and their carers asking them to identify what was good and what was difficult about growing older with learning disabilities.

Misplaced and forgotten
In response to some of the case studies in the GOLD stories’ research and the experiences of one of the members of the GOLD Saturday group, attention was turned to the situation of people with learning disabilities living in residential services for older people. After a pilot study, a large quantitative investigation was undertaken. This involved sending questionnaires to over 2500 residential and nursing homes across the UK asking whether there were currently any people with learning living there and what their lives were like.

For further information about any of these projects or information about publications please contact the Foundation for People with Learning Disabilities or visit: www.learningdisabilities.org.uk.
Appendix 2

Publications from the GOLD programme

- Dementia Resource Pack and booklets on dementia for people with learning disabilities, (in preparation), Kidderminster: British Institute of Learning Disabilities
- GOLD video (2002). London: The Mental Health Foundation
- Training materials for staff supporting people with learning disabilities who have a terminal illness are in preparation
- Updates - Research & Policy Briefings, London: The Mental Health Foundation

Older People with Learning Disabilities — A Review of the Literature, 1:4
‘Having a Go’— User involvement in the GOLD Programme, 1:9
People with Learning Disabilities Using Residential Services for Older People, 2:6
Meeting the Needs of Family Carers of Adults with Learning Disabilities, 2:10
Giving People with Learning Disabilities the Chance to Continue Living in the Family Home, 2:17
Waking Older People with Learning Disabilities in England, 2:18
Misplaced and Forgotten?, 3:5
Support Groups for Older Family Carers of People with Learning Disabilities, 3:10
Preparing for the Future, 3:13
The Menopause and Women with Learning Disabilities, 3:14
Supporting Older Family Carers of People with Learning Disabilities from the Pakistani Community, 3:21
Psychosocial Interventions for People with Down’s Syndrome and Dementia 4:1
Appendix 3

Practical Guidelines for Setting Up and Running Groups for Older Carers

John Harris

This appendix provides practical advice for local authorities and other organisations intending to set up support groups for older family carers of adults with a learning disability. These practical guidelines are based on work undertaken by the British Institute of Learning Disabilities (BILD) and funded under the GOLD programme. Seven groups for older family carers were set up in different parts of England under partnership arrangements with local authorities.

The suggestions here are primarily intended for staff in local authorities with responsibility for adults with a learning disability and for joint commissioning managers.

Why set up older family carers' groups?

The BILD Support for Older Carers project funded through the GOLD programme demonstrated that support groups are an effective way to help some older families understand and access services. They can also help some families increase their preparations for the future. Support groups can also be vital reference points for local authorities keen to ensure that the voice of older family carers are included in the planning and monitoring of services.

How groups can help

Working in groups has a range of potential advantages:

- Group members can share experiences and provide mutual emotional support.
- Groups can be used for problem solving and passing on practical advice.
- Groups bring together people with common interests and needs who can be offered information or asked for their views and opinions.
- Local authorities can work with group members to plan future services. This should be done before the increasing age of the family carers results in a breakdown in care, high levels of distress among service users and expensive short term solutions by service providers.

However, the realisation of these potential benefits depends upon clear goals and good organisation. Lessons learned from the project are summarised below in the form of practical recommendations:

- Explain clearly and simply why family carers are being invited to a series of meetings and what benefits might arise for them and their relatives with a learning disability.
- Explain the recent White Paper, Valuing People, and the new emphasis it places on working in partnership with family carers and particularly older family carers.
- Provide information about local arrangements for support and any plans for re-developing existing services or introducing new services.
- Make arrangements for group co-ordination and facilitation. In the project Support for Older Carers projects the groups were coordinated by local authority staff or workers in voluntary sector organisations. Most committed between two and four days a month to this role.
The role of group co-ordinators

- Knowledge about learning disability issues.
- Sensitivity to and understanding of the role of family carers.
- Experience of facilitating groups.
- Organisational skills.

It is also worth considering:

- A 'job share' where two co-ordinators provide support for each other; cover in the event of other commitments and together can draw on a broader range of personal and professional skills.
- The benefits of co-ordinators employed by the local authority having easy access to the 'system' compared with the greater independence and freedom from conflicts of interest offered by staff from voluntary sector organisations.
- The extent to which co-ordinators represent the communities in which family carers live; for example, black family carers groups should be co-ordinated by staff from the black community and groups for male family carers should be co-ordinated by men.

Practical considerations in setting up groups

- Sufficient funding to cover room hire, transport where needed, refreshments, materials etc.
- An appropriate venue which is easily accessible, comfortable and not intimidating.
- Clear advance warning of any changes to the time or place of the meeting.
- Reliable and comfortable transport with trusted drivers/support staff.
- Appropriate care for family members with a learning disability of other dependent relatives.
- Consultation with family carers agreeing dates for two or three meetings well in advance.
- Identifying group members who need to be reminded of forthcoming meetings (e.g., with a telephone call the day before and possibly with a follow up on the morning before transport arrives).
- Avoiding dates that will clash with other commitments of groups members such as centre/school holidays.
Number of group members and frequency of meetings

- Groups for older family carers work best with between eight and 15 members.
- Groups operating over a lengthy period of time worked best on a monthly basis. (More intensive work was undertaken by groups set up for a limited period and these met as often as once a week. If the group is set up to work over a fixed period of time, make this clear and plan with group members how the sequence of meetings will finish.)
- Weekly groups proved to be intensive and best run for a limited period. This creates a style of its own that can have its benefits in terms of continuity.
- Meetings of up to about two hours worked well, with the most productive time being from mid-morning until lunchtime.
- Where lunch can be provided it creates opportunities for informal conversation and adds an important social dimension.

Recruitment of group members

Older family carers may not be easy to locate. Some may have had very little contact with services, while others may have become cynical about how much difference services can make to their lives. Sometimes energy and imagination may be needed first to make contact with family carers and secondly to gain their trust. Here are some practical suggestions which worked for groups:

- Use any organisational networks such as generic carers’ networks.
- Contact the family carers of anyone with a learning disability already known to your service.
- Use local community networks. Lots of family carers have informal contact with other family carers. This is particularly important in reaching family carers from minority ethnic groups.
- Provide basic information leaflets which explain in plain language who the groups are for and what they will do.
- Personal contact by phone or a visit is the most powerful way of getting older family carers involved.

Working in groups

To work effectively groups will need some active facilitation or chairing. In general, older family carers do not want to do this themselves, although they should be given the opportunity to discuss how the group is supported and by whom.
Groups work on the basis of shared 'ground rules'. It is helpful if these are made explicit, ideally as part of a group discussion. Some basic ground rules are:

- Respect one another.
- Value everyone's point of view.
- Let everyone have their say.
- Don't interrupt when someone is speaking.
- Keep to the point or relevant subject.
- Respect confidentiality.
- Keep to time schedule.
- Be kind to one another.

First meetings provide an opportunity for family carers to get to know each other by talking about their relatives and sharing their experiences of caring. This can lead on to the identification of common areas of concern or inconsistencies in service provision. These might form the basis of more structured meetings at a later stage.

Older family carers may need plenty of time to explain how their lives have been affected by their caring role. It is important that co-ordinators are prepared to listen and to take on board some of the views and ongoing concerns of older family carers. The pace of the meetings will be determined by the group members.

Co-ordinators need to support the sharing of experiences, both good and bad, without reacting negatively, feeling threatened or attacked.

It is likely that groups will request more information as time goes on. Sometimes this will point to gaps in an authority's provision. When this happens it is extremely helpful if the authority can be open and honest about current limitations and future plans.

Co-ordinators are expected to 'put everything right' but they will need to develop skills in managing feelings of frustration and resentment which may have been building up over many years.

Effective groups provide mutual support and develop problem solving strategies. An important activity for the co-ordinator is to foster 'self help' by the group.

Sometimes co-ordinators will be told about potentially sensitive issues affecting one family which have implications for the wider group. The co-ordinator should discuss with the carer on what terms this might be shared with the wider group.

Carefully selected videos can be useful in promoting discussion or helping family carers consider alternative ways of supporting their family members with a learning disability.

It is important to make a record of what the group members have talked about and what they would like to do in the future. Co-ordinators can help by preparing notes of each meeting in plain language and circulating these to all the group members. A regular newsletter that includes the notes from meetings together with a wider range of information of interest to family carers is particularly effective.
What to include in meetings?

The Support for Older Carers project indicated a number of topics which family carers found useful as subjects for group activities. These included:

- Group discussions based upon both positive and negative experiences of group members in their roles as family carers. This is likely to involve present arrangements for supporting the family as well as concerns about the future.

- Benefits available to people with a learning disability and their family carers under current welfare legislation. It is helpful if a local person with expertise on this topic is available to talk to the group.

- Information about current local provision for people with a learning disability and particularly any developments which focus on the needs of those who are experiencing the effects of age. It is helpful if a local commissioner or senior manager with responsibility for learning disability services is available to introduce the topic and answer questions.

- Planning for the future. While some families will have adopted a proactive approach, others will have avoided dealing with issues that appear both sensitive and insoluble. Those who have not previously discussed planning for the future are likely to require quite a lot of time between group sessions to take on board what this might mean for them and their relative with learning disability.

- The new arrangements for making Direct Payments to a person with a learning disability or their representative. Direct Payments make it possible for the person to make their own arrangements for residential provision (i.e., supported living), and can pay for their own support to undertake daytime activities. Updated guidance was recently issued by the Department of Health together with a version of the guidance designed to be accessible to people with a learning disability.

- The law as it relates to people with a learning disability and their families, for example, what is meant by ‘competence’ and informed consent, how the law affects peoples’ personal and sexual relationships and issues around inheritance and making wills. Again, it will be extremely helpful to have a local expert available to introduce these topics and to answer questions.

- The health needs of people with a learning disability and particularly the effects of increasing age on health. This may be best presented by a general practitioner, or a community or learning disability nurse with a special interest in this topic.

- The development of local and regional partnerships (for example, between health and social services) insofar as they affect the care available to people with a learning disability.
Appendix 4
Planning Ahead: Continuing Family and Other Caring Relationships in Later Life
Christine Bigby

Introduction

This Australian research (Bigby, 2000) tracks the subsequent life changes of a group of older people with learning disabilities who had left parental care in middle age. It examines the changing roles of family members and friends who take on the various caring roles that parents have hitherto fulfilled, but which parents are no longer able to perform because of their own frailty or because they have died.

The research suggested that, contrary to commonly expressed fears in this post-parental phase, other family members and friends do become more involved with the person with a learning disability, and do take on some parental roles. These informal networks are often more robust than expected, but because they can be vulnerable to disruption and shrinkage, this makes it all the more important that steps are taken to support and sustain them.

The caring roles of family and friends

The research focused on the provision of informal support, which she defines as: support which is provided on the basis of a personal rather than a paid relationship and may comprise [support from] family, friends, acquaintances and neighbours but excludes paid care or others paid to provide a service to that person.

One of the most common ways of thinking about informal support is in terms of 'caring for' and 'caring about' (Dalley, 1988).

Caring for involves the provision of hands-on care (e.g. assistance with washing and dressing, lifting), and skills development.

Caring about can include: decision-making; financial management; adoption of formal or legal roles; monitoring service quality; supervision of medical needs; co-ordinating support from other network members; back up or short-term replacement of other network members' support; emotional support; listening; advising; visiting and companionship.

While their son or daughter is living at home, parents fulfil both of these tasks; but in the post-parental phase, these are often split among different people. In terms of 'caring for' the study (Bigby, 1997a) found that:

- initially another family member or friend provided hands-on care for just over 50% of the adults;
- this had decreased to less than 20% by the time the person with a learning disability was about 65, and the majority were living in formal residential services;
• competing demands from other family members often meant that the family member had to relinquish their care of the relative with a learning disability.

However, this decline in hands-on caring from informal sources is compensated for by the fact that, following parental death, family and friends – and particularly the key person (see below) – assume important tasks of ‘caring about’.

Joe lived on a farm with his parents until his father died when Joe and his mother went to live with his sister, Freda, and her husband. When Joe was 53, his mother died, but Freda and her husband then began to have health problems. Eventually Freda found that she was unable to care for both Joe and her husband and arranged for Joe to move to a local older persons’ home. Freda is still very involved in Joe’s life and she visits him nearly every day, as does one of her daughters.

Siblings often became the main hands-on carers, though other relatives or even friends can fulfil this role. In a UK study of 121 people with learning disabilities over the age of 50, 17 were living with a relative; seven were still with a parent; six people lived with their sister, one with a niece, one with a nephew, one with a cousin, and one with a son (Moss et al., 1989).

Size and characteristics of informal networks

Earlier life experiences

These appear to influence the strength of relationships in later life and people who have stayed at home with their parents until middle age are likely to have stronger relationships with family members than those who left home when they were younger (Bigby, 1997a; Skeie, 1989).

Network composition and size

The informal networks of these middle aged and older people with learning disabilities were quite similar to younger peers who were still living with parents, although with the former, some members’ roles had often changed and intensified. The networks were dense (i.e. people knew each other) and mainly consisted of people from the same generation as the person with a learning disability or an older generation. For the majority of older people, family members comprised more than half of all network members. Networks were small with an average of six people in touch with the person at least twice a year.

Support from network members

The most common support older people received from their network fell into the ‘caring about’ category and involved visits and outings. However, more than three-quarters also received more concrete ‘caring about’ support such as mediation and negotiation with formal services or monitoring service quality, tasks usually undertaken by one network member – the key person.
The key person

The existence of a key person, who proactively oversaw the older person’s well-being by managing their affairs and negotiating service provision, was the most striking feature of these informal networks. As well as having frequent contact involving shared social activities, the key person took on a strong advocacy role.

The key person was usually a more distant relative or a friend. They had a strong attachment to, and a close long-term relationship with, the person with a learning disability and were very committed to their well-being.

This key person was often foreshadowed in parental plans for the future on the basis of their long-term relationship with and a negotiated commitment to the person with a learning disability.

Siblings would not necessarily be described as ‘distant’ relatives but, in the case of non-disabled older people, this role is more often assumed by children rather than siblings. The relationship between Jean and her brother Harry is typical of the key person role.

When Jean’s parents died she wanted to remain in the area where she had spent all her life rather than moving nearer to her brother, Harry, who lives on the other side of Melbourne. Harry arranged for her to move into a private residential service and visited her regularly but when the home changed hands and the standards were deteriorating he lodged a series of complaints about his sister’s care. Things did not improve so Harry then helped Jean to find and move into an older person’s home.

On his weekly visits, Harry and Jean walk round the shops and have a coffee together. He also helps Jean manage her financial affairs and when she developed problems with her eyesight, Harry organised and accompanied her to medical appointments. Jean does have another brother who she sees on special occasions, but Harry said he always had a much closer relationship with Jean and had agreed with his parents that he would ‘look after’ Jean when the time came.

The importance of informal networks

Formal services and informal networks perform different roles and formal organisations cannot replicate or replace all the caring tasks of the latter. However, as people with learning disabilities reach middle age and beyond, formal services increasingly replace and provide the hands-on care (i.e. the ‘caring for’) previously provided by parents.

As this research demonstrated, networks of informal relationships can continue to provide ‘caring about’ tasks, providing emotional support, managing and negotiating relationships with service providers and providing significant advocacy. These are crucial to people’s quality of life, particularly when they are living in residential services. Long-term commitment, advocacy and emotional support cannot easily be replicated by formal service providers.
The potential vulnerability of informal networks

Informal network members are often the same age or older than the person with a learning disability. As that person grows older, they are vulnerable to loss of contact with family and friends (Bigby, 1997b). For some of the older people in this study, the key person had died, to be replaced in some cases by a person from a younger generation such as a niece or nephew. Over time, though, the availability of 'successors' with sufficient commitment can sometimes peter out. Godfrey's experiences are typical of the loss of network members and the eventual absence of someone who can act as a key person. Ensuring the continuing presence of a key person is critical.

Godfrey had three brothers and a sister. When his parents died he went to live with one of his brothers and really enjoyed helping on the farm. However, when this brother died five years later, Godfrey's sister-in-law sold the farm. Godfrey moved in with another brother and his family but that brother also died a few years later and his sister then arranged for Godfrey to move into an older person's home close to her own home. She visited him regularly and monitored the quality of his care, taking up issues with staff when necessary. When Godfrey was 70, however, his only sister died and although her daughter now visits him on special occasions, she doesn't know him well and has her own family to look after. Godfrey still has occasional contact with his remaining brother but has not seen him for several years.

Planning for and supporting robust informal networks

As the study clearly demonstrated, these informal networks are dynamic and determined by a combination of personal characteristics, social and economic factors and the pattern of opportunities available. Networks will change over time as the person with a learning disability ages, but families and service providers must focus on assisting them to develop and sustain these informal relationships.

Developing 'key person succession' plans

Planning by parents and workers for the post-parental phase can tend to focus on where the person will live and ensuring their personal safety and security, but attending to the key person role will be central in terms of ensuring flexibility and quality of support.

This research suggests that the parental planning can be a key mechanism for supporting the continuation of robust informal networks and the most successful are 'key person succession plans' (Bigby, 1996). These are not detailed, formal plans, but include the planned transfer of responsibility for overseeing the wellbeing of the person with a learning disability.

Choice of the key person is based on the strength of their prior relationship and a negotiated explicit long-term commitment. Succession plans are flexible and responsive, and less likely to go awry than detailed residential plans. Key people have the flexibility to respond to the changing needs and wishes of the person with a learning disability and to changes in policy and services.
The planning process

Family members, as well as parents, should be involved and people nominated as key persons will often find discussions less emotionally difficult and can facilitate the involvement of the person with a learning disability.

The role of services

Formal services can assist the key person by equipping them with knowledge of the service system; later life opportunities; and the developmental potential of adults with learning disabilities. Services must recognise and respect the involvement of network members even if they are more distant relatives or unrelated. Conflicting views may sometimes arise between a key person and the person with a learning disability and services need to be alert to such tensions and consider what is in the latter’s best interests.

Staff in learning disability services need relevant educational and training opportunities, not only about the ageing process and ageist attitudes. They can also learn about practical strategies for fostering relationship networks such as: PLAN (Etamnski, 2000), circles of support (Gold, 1994), citizen advocacy (Ramcharan, 1995), and community building (Kulzgen et al., 2000).

All these demonstrate successful processes for building networks and the intensive and lengthy work that is involved. Building and sustaining people’s informal networks is hard work, so planning, commitment, resources and positive attitudes towards older people are all required.
Overall estimates

There are no reliable official statistics concerning the number of people with learning disabilities in the UK. Studies that have screened entire populations tend to indicate slightly higher prevalence rates (approximately six people with severe learning disabilities per 1000) than studies that only include people who are known to services as having learning disabilities.

If these prevalence rates are combined with a 1995 estimate of the UK population (58.3 million) the results suggest that between 230,000 and 350,000 people in the UK have severe learning disabilities.

Studies that have looked at people with mild learning disabilities have reported much more diverse prevalence rates. Again studies that have screened entire populations have shown higher prevalence rates (25-39 people with mild learning disabilities per 1000 general population) than studies that only include people who are known to services as having learning disabilities (less than 10 per 1000).

Again, combining these prevalence rates with the 1995 estimate of the UK population the results suggest that between 580,000 and 1,750,000 have mild learning disabilities.

Throughout adulthood prevalence rates for severe and mild learning disabilities decline due to increased mortality among people with learning disabilities when compared with the general population (Emerson et al, 2001).

Prevalence and Incidence

The link between the numbers of older people with learning disabilities and increased life expectancy is complex. A large increase in the UK general birth rate between the 1950s and 1960s means that a relatively large group of people with learning disabilities are now approaching late middle age (Fryers, 1993). A number of other factors are associated with the changing age profile of people with learning disabilities.

Factors likely to lead to an increase in the numbers of people with learning disabilities:

- An increase in maternal age (associated with higher risk factors for some conditions associated with learning disabilities, such as Down’s syndrome).
- Improved survival of ‘at risk’ infants, such as low birth weight infants, due to improved health care.
- Increasing levels of HIV and AIDS in children.
- A higher birth rate amongst certain minority ethnic groups who also experience higher prevalence rates of learning disabilities. An increase in numbers here is linked to the rising proportion of people from minority ethnic communities in the UK.

Footnote:

Prevalence rates are the total number of cases of learning disabilities, old and new, existing in a population at a given point in time. The incidence of learning disabilities is the number of new cases of learning disabilities arising in a population in a stated period of time (Fryers, 1993, cited in Emerson, 2001).
Factors likely to lead to a decrease in the numbers of people with learning disabilities:

- **Increased availability of prenatal screening, e.g. for Down’s syndrome.**

- **Improving health care and support resulting in fewer ‘at risk’ infants developing learning disabilities.** (Emerson et al., 2001.)

*Valuing People* (Department of Health, 2001) predicts an annual increase of 1% over the next 15 years for people with severe learning disabilities because of:

- increased life expectancy, particularly among people with Down’s syndrome;

- growing numbers of children and young people with complex and multiple disabilities surviving into adulthood;

- a sharp rise in the reported number of school age children with autistic spectrum disorder some of whom will have learning disabilities;

- a greater prevalence of severe learning disability amongst some minority ethnic populations of South Asian origin.

Despite the fact that people with learning disabilities have benefited from an increased life expectancy, this is still significantly lower than that of the general population - 75 for men and 80 for women (Office of National Statistics, 2001). As the recent White Paper pointed out (Department of Health, 2001a):

**Evidence of avoidable illness and premature death among people with learning disabilities is a major cause of concern.**

Attention to this would further improve the life expectancy of more people with learning disabilities. Chapter 3 details the major health challenges for people with learning disabilities as they age.

**Life expectancy**

There have been significant improvements in the life expectancy for people with learning disabilities. In 1930, the mean life expectancy of people with learning disabilities was about 20 years (Carter and Janca, 1983). This contrasts with a recent California study which found the life expectancy of people with learning disabilities (excluding those with Down’s syndrome) to be 70-74 years (Strauss & Eyman, 1996). About half of all people with learning disabilities can now expect to live for as long as the general population (Hogg and Lambe, 1998).

Because of the difficulty in establishing whether the groups measured are similar enough to draw any reliable conclusions (Emerson et al., 2001), these comparisons should be treated with caution. When looking at increased life expectancy, it is necessary to focus on the following groups:

- people with Down’s syndrome;

- people with severe learning disabilities (excluding Down’s syndrome);

- people with mild learning disabilities.
People with Down’s syndrome

The most reliable evidence of increased life expectancy is for people with Down’s syndrome, an identifiable group who comprise about 15% of all people with learning disabilities. In the early 1900s, their mean life expectancy was less than 10 years (Penrose, 1949) but about half of them will now survive into their 50s with some reaching their 60s and 70s (Janicki, 1999). Recent studies of the life expectancy of people with Down’s syndrome have produced significant variations. These can be partly explained by diverse experiences of health care, particularly in the developed world through access to improved health care, including heart surgery and antibiotics. However, life expectancy for people with Down’s syndrome is still well below that of the general population because of their tendency to premature ageing, and increased vulnerability to dementia (see Chapter 7).

People with severe learning disabilities (excluding Down’s syndrome)

This group includes some people with medical conditions associated with their learning disability including physical disabilities, cerebral palsy and epilepsy; though biological factors cannot always be identified. Access to improved health care means that people with severe learning disabilities are living longer than previous generations. Many more ‘at risk’ infants with low birth weights are also surviving. However, life expectancy for this group still falls well short of that of the general population and survival beyond the age of 50 is rare (Janicki, 1999).

People with mild learning disabilities

This group includes those people whose learning disability is generally not associated with biological factors. Although their life expectancy is still slightly lower than the general population, many can expect a normal life span and amongst them there are centenarians (Janicki et al. 1999). It is reasonable to assume that this group will have shared in the significant increase in life expectancy for all people (in the developed world at least).

Because of variations in life expectancy across these three groups, the proportion of people with severe learning disabilities is typically less in groups of older people compared to younger people with learning disabilities (Moss, 1991).

The information set out above provides some general patterns. To predict the numbers of older people with learning disabilities in any area, together with their levels of disability, requires detailed information about the local population of people with learning disabilities.
Sheffield has maintained one of the most comprehensive registers of people with learning disabilities in the UK. Below are tables which profile the 2645 people with learning disabilities recorded on the register from a population of 538,000. They show where people live and also the specific age profile of people with Down’s syndrome.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>With Down’s Syndrome</td>
<td>25</td>
<td>47</td>
<td>40</td>
<td>68</td>
<td>71</td>
<td>31</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without Down’s Syndrome</td>
<td>310</td>
<td>385</td>
<td>302</td>
<td>413</td>
<td>372</td>
<td>272</td>
<td>178</td>
<td>86</td>
<td>33</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Home</td>
<td>332</td>
<td>418</td>
<td>297</td>
<td>347</td>
<td>267</td>
<td>153</td>
<td>72</td>
<td>32</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Residential Service</td>
<td>14</td>
<td>45</td>
<td>134</td>
<td>176</td>
<td>150</td>
<td>112</td>
<td>54</td>
<td>16</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

These tables show the specific age profile of people with Down’s syndrome and where people with learning disabilities live in Sheffield. Such registers need to be more widely developed and maintained to provide valuable information for authorities in planning services.

**Notes**

- The information does not include people living outside Sheffield.
- Family home includes people living with their families or independently of services.
The Foundation for People with Learning Disabilities works to improve the lives of people with learning disabilities through:

- Funding innovative research and service development projects and disseminating the findings.
- Listening to people with learning disabilities and involving them in its work.
- Seeking to influence policy.
- Providing specific and appropriate information to people with learning disabilities, family carers and professionals.

Launched in 1988, it is part of the Mental Health Foundation.

The Mental Health Foundation / Foundation for People with Learning Disabilities

UK Office
83 Victoria Street
London
SW1H OHW
Tel: 020 7802 0300
Fax: 020 7802 0301
Email:mhf@mhf.org.uk
Email:fpld@fpld.org.uk

Scotland Office
Merchants House
30 George Square
Glasgow G2 1EG
Tel: 0141 572 0125
Fax: 0141 572 0246

www.mentalhealth.org.uk
www.learningdisabilities.org.uk

ISBN: 1 903645 37 9
Price £27.50 professionals (£12.00 unwaged)

Published by The Mental Health Foundation October 2002